FOIA Number: 2018-0756-F

FOIA MARKER

This is not a textual record. This is used as an administrative marker by the William J. Clinton Presidential Library Staff.

Collection/Record Group: Clinton Presidential Records

Subgroup/Office of Origin: National AIDS Policy Office

Series/Staff Member: Kristine Gebbie

Subseries:

OA/ID Number: 3770

FolderID:

Folder Title:
June Chron Files 1994 [5]

Stack:	Row:	Section:	Shelf:	Position:
S	66	5	3	1

AIDS RESEARCH QUESTIONNAIRE

This questionnaire has fourteen sections. The first eight will be a base line for information on one's family organization, life attitudes, health, education and job history. The other six tables are designed to look at changes over a two year period of time in one's relationship system and health care. You will be asked these questions every four months for two years.
Thank you for your time and effort in completing the questionnaire and for any remarks you may have as feedback about the instrument. Andrea Maloney-Schara, LSWA

Please circle the appropriate answer and fill in any necessary blanks.
All information will be coded and therefore confidential.

SECTION 1

Date of Interview_____

Name _____SS_____

Phone number _____

1. What is your date of birth? __ __/__ __/__ __

2. What is your year of birth? _____

3. How old are you today? _____

4. How many years of education do you have? _____

5. Are you currently employed? **YES NO**

Please check the approximate salery range for the last year that you worked.
$10,000 - $20,000.00___ $20,000.00 - $40,000.00 ___ More ___

6. Are you in psychotherapy? **YES NO**

7. Is psychotherapy on going? **YES NO**

8. Does your spouse or significant other see the same therapist? **YES NO**

9. Note the number of months you have been in therapy._____

10. Are you HIV Positive? **YES NO**

11 What month and year were you diagnosed with HIV? _____

12. What month and year do you believe you contracted the virus? _____

13. How confident are you of your overall ability to manage your disease with a variety of strategies? (from alternative therapies and or only conventional medical practices)
1) not at all 2) very little 3) somewhat
4) most of the time 5) very confident

14. Have you thought about what it would be like living to be an older person?

YES NO

15. Do you have a special reason for wanting to live each day?
YES NO

16. Do you currently live with a partner? **YES NO**

17. Have you had more than one marriage or long term relationships. **YES NO**

18. Has the average relationship lasted two or more years? **YES NO**

19. Has the average relationship lasted more than ten years? **YES NO**

20. Do you have a tendency to continue relationships, even after people dissapoint you?
YES NO

21. Do you belive that you know how to make friends with difficult people? **YES NO**

22. Has your work life been as productive as you had imagined it would be? **YES NO**

23. Do you believe that it is possible for you to direct your life forward in a positive manner? **YES NO**

SECTION 2 Medical

SS _____

24. Are you overall satisfied with medical care? **YES NO**

25. Are you comfortable asking questions of your medical provider ?
1) not at all 2) very little 3) somewhat
4) most of the time 5) very confident

26. Have you been enrolled in a NIH or other sponsored drug protocol programs?
YES NO

27. Is this a continuing involvement? **YES NO**

28. Has this involvement with NIH been positive? **YES NO**

29. Please note on the separate schedule the number of the drugs that have been used during this time. Enter numbers 1-100 to signify which drugs are in use.

1-AZT 2-DDI 3-DDC 4-Interferon 5-Peptide T

6-Compound Q 7-Pneumonia drugs 8-Acyclover 9-other drugs.

30. Have there been side effects to the drugs that needed treatment by other drugs?
YES NO

31. Have there been side effects to the drugs that required hospitalization? **YES NO**

32. Have you been hospitalized for other problems? **YES NO**

33. Please note the major problems. _____

34. Have you used prescribed mood altering drugs? **YES NO**

35. Were they useful? **YES NO**

36. Have you used non prescribed mood altering drugs? **YES NO**

37. Were they useful? **YES NO**

38. If they are useful how long have you used them?_____

39. Have you used other drugs that have not been approved by the FDA as treatment for HIV infection? **YES NO**

Please note the name of the drug. _____

41. Do you believe that this drug has been useful? YES NO

SECTION 3 Alternative Treatments

SS_____

42. Has diet been an important part of treatment? **YES NO**

43. Have you been on a macrobiotic diet? **YES NO**

44. Have you used large doses of vitamins? **YES NO**

45. Does this include more than vitamins C and E? **YES NO**

46. Are there special foods or vitamins that you consider essential for health? **YES NO**

Please write the names in the blank space._____

47. Do you exercise three times a week for twenty minutes? **YES NO**

48. Do you practice meditation/relaxation at least three times a week ? **YES NO**

49. Has acupuncture been an important part of your treatment? **YES NO**

50. Has massage been an important part of your treatment? **YES NO**

51. Has the use of a chiropractor been a part of your treatment? **YES NO**

52. Has the use of group supportive therapy been a part of your treatment? **YES NO**

53. Have spiritual therapies been an important part of your treatment? **YES NO**

54. Has prayer been an important part of your treatment? **YES NO**

55. Is there a primary caretaker who is aware of all aspects of your health care?

YES NO

56. Do you have adequate health care coverage? **YES NO**

57. Do you believe that your medical or other service providers listen to you?
YES NO

58. Are you currently experiencing difficulties in any of the following areas;
1) insurance 2) job 3) friendships 4) with spouse
5) with family 6) other _____

59. Please note the level of difficulty: **(1) extremely difficult to.....**
(5) very little _____

60. Do you smoke cigarettes? **YES NO**

61. Have you smoked most of your adult life? **YES NO**

62. Have you had any addictions? **YES NO**

63 Have you recovered from any addictions? **YES NO**

64. Are there alternative treatments that you believe have been important in treating HIV infection? **YES NO**

Please write these treatments in the blank space. _____

SECTION 4 Family of Origin

SS _____

65. Are you the oldest in your family of origin? **YES NO**

66. Are you a middle sibling in the family of origin? **YES NO**

67. Are you an only child? **YES NO**

68. Do you have same sex siblings? **YES NO**

69. Do you have older sisters? **YES NO**

70. Do you have younger sisters? **YES NO**

71. Do you have younger brothers? **YES NO**

72. Do you have older brothers? **YES NO**

73. Do you have adopted or step siblings? **YES NO**

74. Are they younger siblings? **YES NO**

75. Were you raised with adopted or step siblings? **YES NO**

76. Did more than seven years separate you from your siblings? **YES NO**

77. Did anyone in your nuclear family die during your first ten years? YES NO

<u>If yes, please answer questions 78-88. If no please go to #89:</u>

78. Did your father die? **YES NO**

79. Did your mother die? **YES NO**

80. Did your brother die? **YES NO**

81. If yes, was he older? **YES NO**

82. Did your sister die? **YES NO**

83. If yes, was she older? **YES NO**

84. Did an adopted sibling die? **YES NO**

85. Did more than one sibling die? **YES NO**

86. Is there a stepsibling who died? **YES NO**

87. Did a stepsibling die? **YES NO**

88. If yes did you live with this sibling more than two years? **YES NO**

89. Did anyone in the nuclear family die between the time you were ten to twenty years old? YES NO

<u>If yes, please answer questions 90- 102. If not go to #103</u>

90. Did your father die? **YES NO**

91. Did your mother die? **YES NO**

94. Did your brother die? **YES NO**

95. If yes, was he older? **YES NO**

96. Did your sister die? **YES NO**

97. If yes, was she older? **YES NO**

98. Did an adopted sibling die? **YES NO**

99. Did more than one sibling die? **YES NO**

100. Is there a stepsibling who died? **YES NO**

101. Did a stepsibling die? **YES NO**

102. If yes, did you live with this sibling more than two years? **YES NO**

SECTION 5 Symptom Development in Family

SS_____

103. Were there major symptoms, physical, emotional and social in the nuclear family?
Physical would include hospitalizations or chronic illness, diabetes etc. that do not require hospitalization.
Emotional would include psychological or other mental conditions that limit functioning in job etc.
Social would includes drinking problems, arrests and or parents who separated or divorced, in this case both parents would be considered to have a symptom.
YES NO

If yes please answer questions 104-112 if not go to #113

MOTHER
104. Was mother symptomatic before you were ten? **YES NO**

105. Was mother symptomatic before you were twenty? **YES NO**

106. Was mother symptomatic in the year before or after you became HIV Positive?
YES NO

FATHER
107. Was father symptomatic before you were ten? **YES NO**

108. Was father symptomatic before you were twenty? **YES NO**

109. Was father symptomatic in the year before or after you became HIV Positive?
YES NO

SIBLINGS
110. Were there symptoms in siblings before you were ten? **YES NO**

111. Were there symptoms in siblings before you were twenty? **YES NO**

112. Were there symptoms in siblings in the year before or after you became HIV Positive? **YES NO**

SECTION 6 Family Contact

SS _____

Subjective scale of family contact and functioning before the age of ten:

113. Would you describe as generally positive your emotional contact with siblings?
YES NO

114. Would you describe as generally positive your emotional contact with your mother?
YES NO

115. Would you describe as generally positive your emotional contact with your father?
YES NO

116. Would you describe as generally positive your emotional contact with your maternal grandparents? **YES NO**

Please write the first names of the your maternal grandmother and grandfather.

_____

_____

117. Would you describe as generally positive your emotional contact with your paternal grandparents? **YES NO**

Please write the first names of the your paternal grandparents.

_____

_____

Subjective scale of family contact and functioning before the age of twenty:

118. Would you describe as generally positive your emotional contact with siblings?
YES NO

119. Would you describe as generally positive your emotional contact with your mother?
YES NO

120. Would you describe as generally positive your emotional contact with your father?
YES NO

121. Would you describe as generally positive your emotional contact with the maternal extended family? **YES NO**

122. Would you describe as generally positive your emotional contact with the paternal extended family? **YES NO**

Subjective scale of family contact and functioning from twenty to today:

123. Would you describe as generally positive your emotional contact with siblings?
YES NO

124. Would you describe as generally positive your emotional contact with your mother?
YES NO

125. Would you describe as generally positive your emotional contact with your father?
YES NO

126. Would you describe as generally positive emotional contact with the maternal extended family? **YES NO**

127. Would you describe as generally positive your emotional contact with the paternal extended family? **YES NO**

128. Would you describe yourself as physically healthy in the two years before HIV infection? **YES NO**

129. Would you describe your self as the overall highest functioning one of your siblings, in regards to jobs? **YES NO**

130. Would you describe your self as the overall highest functioning one of your siblings, in regards to education? **YES NO**

131. Would you describe your self as the overall highest functioning one of your siblings, in regards to creativity? **YES NO**

132. Was there distance from anyone in the nuclear family after you became HIV Positive? YES NO
This question is looking at changes in family relationships due to the family members reactions to HIV. These changes may have been temporary.
If yes, please answer questions 133-138, If not go to #139

133. Was there distance from anyone in the maternal extended family after you became HIV Positive? **YES NO**

134. Was there distance from anyone in the paternal extended family after you became HIV Positive? **YES NO**

135. Have you had more contact with those in the nuclear family ? **YES NO**

136. Have you had more contact with the maternal extended? **YES NO**

137. Have you had more contact with the paternal extended family? **YES NO**

138. Was the change due to an effort on your part? **YES NO**

SECTION 7 History with Partner

SS _____

Have you had a significant relationship that ended with a death or divorce? If the answer is yes or if you have a current partner, please answer the questions in terms of the history of this or your most significant relationship, rather than current changes. Social symptoms refer to drinking, affairs, job problems, etc. Emotional symptoms refer to such

periods of time when one has experienced (depression, poor judgment, recklessness etc.)

Please go to # 158 if you do not have a current partner or have not had a significant partner.

139. Are you currently living with your partner? **YES NO**

140. Does your partner try to solve your problems? **YES NO**

141. Would you describe your partner as too distant? **YES NO**

142. Is your relationship conflictual? **YES NO**

143. Does your partner make most of the decisions? **YES NO**

144. Are you comfortable with the relationship? **YES NO**

145. Has the relationship changed to be more supportive since you were diagnosed as HIV Positive? **YES NO**

146. Did your partner have physical symptoms before you were HIV Positive? **YES NO**

147. Did your partner have emotional symptoms before you were HIV Positive? **YES NO**

148. Did your partner have social symptoms before you were HIV Positive? **YES NO**

149. Did your partner have physical symptoms after you were HIV Positive? **YES NO**

150. If so did any of these problems require hospitalization? **YES NO**

151. Is your partner HIV Positive? **YES NO**

152. Have physical symptoms interfered with your partners life goals? **YES NO**

153. Has your partner had emotional symptoms after you were HIV Positive? **YES NO**

154. If so was your partner hospitalized? **YES NO**

155. Have emotional symptoms interfered with his/her life goals? **YES NO**

156. Has your partner had social symptoms after you were HIV Positive? **YES NO**

157. Have social symptoms interfered with his/her life goals? **YES NO**

SECTION 8 Self Scale

SS _____

SELF SCALE: BEFORE DIAGNOSED

PHYSICAL

158. Did you have physical symptoms before you were diagnosed HIV Positive?
YES NO

159. If so, were you hospitalized? **YES NO**

160. If so, more than five times? **YES NO**

161. Have physical symptoms interfered with your life goals? **YES NO**

EMOTIONAL (mood swings, depression, poor judgment, recklessness etc.)

162. Have you had emotional symptoms before you were diagnosed HIV Positive?
YES NO

163. If so, were you hospitalized? **YES NO**

164. Have emotional symptoms interfered with your life goals? **YES NO**

SOCIAL (drinking, affairs, job problems, etc.)

165. Have you had social symptoms before you were diagnosed HIV Positive?
YES NO

166. Have social symptoms interfered with your life goals? **YES NO**

AFTER DIAGNOSED Self evaluation:

PHYSICAL

167. Have you had physical symptoms since you were diagnosed HIV Positive?
YES NO

168. If so, were you hospitalized? **YES NO**

169. If so, more than five times? **YES NO**

170. Have physical symptoms interfered with your life goals? **YES NO**

EMOTIONAL

171. Have you had emotional symptoms after you were diagnosed HIV Positive?
YES NO

172. If so, were you hospitalized? **YES NO**

173. Have emotional symptoms interfered with your life goals? **YES NO**

SOCIAL

174. Have you had social symptoms after you were diagnosed HIV Positive?
YES NO

175. If so, were you arrested, lost a job, or had other consequences? **YES NO**

MEDICAL INFORMATION

176. Last T cell count. _____ Date taken _____

177. Did the T cell count fluctuate more than 200 points during the last four months?
YES NO

178. Did the T cells move higher? **YES NO**

180. After being diagnosed as HIV Positive have you been able to communicated medical information to others in the family? **YES NO**

181. Did you consider this a positive action? **YES NO**

182. If not, are you willing to keep trying to talk to people in the family? **YES NO**

183. Have you been able to communicate your medical information to important friends without having negative reactions? **YES NO**

184. Have you had to change your physicians one or more times because you were not satisfied with treatments? **YES NO**

PART 2 WILL BE USED TO NOTE CHANGES OVER TWO YEARS.
This information will be gathered every four months.
TODAYS DATE_____

Please answer these questions about your life during the last four months.

SECTION 9 SELF SYMPTOMS

185. Have you had physical symptoms? **YES NO**

186. Have you had emotional symptoms? **YES NO**

187. Have you had social symptoms? **YES NO**

188. Have you had more than one symptom? **YES NO**

189. Have you used illegal drugs? **YES NO**

190. Have you had unprotected sex? **YES NO**

191. Have you been hospitalized for more than a week? **YES NO**

SECTION 10 FAMILY SYMPTOMS

192. Has anyone in the family had physical symptoms? YES NO

If yes, please answer the questions 193-209 or go to #210.

193. Was person the mother? **YES NO**

194. Was person the father? **YES NO**

195. Was person the significant other? **YES NO**

196. Was person the older sister? **YES NO**

197. Was person the younger sister? **YES NO**

198. Was person the older brother? **YES NO**

199. Was person the younger brother? **YES NO**

200. Was person the maternal grandmother? **YES NO**

201. Was person the paternal grandmother? **YES NO**

202. Was person the paternal grandfather? **YES NO**

203. Was person the maternal grandfather? **YES NO**

204. Was person a maternal Aunt? **YES NO**

205. Was person the maternal Uncle? **YES NO**

206. Was person the paternal Aunt? **YES NO**

207. Was person the paternal uncle? **YES NO**

208. Was person a child in the maternal extended family? **YES NO**

209. Was person a child in the paternal extended family? **YES NO**

SECTION 11 PARTNER SYMPTOMS

210. Was there a symptomatic person in the significant other's family? YES NO

If yes, please answer questions 211- 227 or go to #228

211. Was person the mother-in-law? **YES NO**

212. Was person the father-in-law? **YES NO**

213. Was person the significant other? **YES NO**

214. Was person the older sister-in-law? **YES NO**

215. Was person the younger sister-in-law? **YES NO**

216. Was person the older brother-in-law? **YES NO**

217. Was person the younger brother-in-law? **YES NO**

218. Was person the maternal grandmother-in-law? **YES NO**

219. Was person the paternal grandmother-in-law? **YES NO**

220. Was person the paternal grandfather-in-law? **YES NO**

221. Was person the maternal grandfather-in-law? **YES NO**

222. Was person a maternal Aunt-in-law? **YES NO**

223. Was person the maternal Uncle-in-law? **YES NO**

224. Was person the paternal Aunt-in-law? **YES NO**

225. Was person the paternal Uncle-in-law? **YES NO**

226. Was person a child in the maternal extended family-in-law? **YES NO**

227. Was person a child in the paternal extended family-in-law? **YES NO**

SECTION 12 RELATIONSHIP CHANGES

PLANS TO CHANGE SELF:

228. Have there been planned changes to alter the time that you spend with people (the frequency) or the way that you feel about others (the intensity) within the family or with your significant others? YES NO
If yes, please answer questions 229-282 If no, go to 283

229. If you decided to change, did you anticipate any reaction to these changes in your significant relationships? **YES NO**

RELATIONSHIP CHANGE IN SIGNIFICANT OTHER FAMILY

If you have had a partner during this time and these questions apply please answer 230-257 or go to #258

230. Did a change take place in the frequency of contact with the significant other? **YES NO**

If the frequency changed but not the feeling about the other please leave the following two questions blank. If your feeling state changed please note so. A negative change will be scored by two circling both questions as (NO).

231. Was the intensity of the interactions positive? **YES NO**

232. Was the intensity of the interactions neutral? **YES NO**

These questions apply to relationships with your
MOTHER
234. Did a change take place in the frequency of contact with mother? **YES NO**

235. Was the intensity of the interactions positive? **YES NO**

236. Was the intensity of the interactions neutral? **YES NO**

FATHER
237. Did a change take place in the frequency of contact with father? **YES NO**

238. Was the intensity of the interaction positive? **YES NO**

239. Was the intensity of the interaction neutral? **YES NO**

SIBLINGS
240. Did a change take place in the frequency of contact with sibling? **YES NO**

241. Was the intensity of the interaction positive? **YES NO**

242. Was the intensity of the interaction neutral? **YES NO**

MATERNAL GRANDPARENTS

243. Did a change take place in the frequency of contact with maternal grandparents? **YES NO**

244. Was the intensity of the interaction positive? **YES NO**

245. Was the intensity of the interaction neutral? **YES NO**

PATERNAL GRANDPARENTS

246. Did a change take place in the frequency of contact with paternal grandparents? **YES NO**

247. Was the intensity of the interaction positive? **YES NO**

248. Was the intensity of the interaction neutral? **YES NO**

AUNTS

249. Did a change take place in the frequency of contact with aunts? **YES NO**

250. Was the intensity of the interaction positive? **YES NO**

251. Was the intensity of the interaction neutral? **YES NO**

UNCLES

252. Did a change take place in the frequency of contact with uncles? **YES NO**

253. Was the intensity of the interaction positive? **YES NO**

254. Was the intensity of the interaction neutral? **YES NO**

CHILDREN

255. Did a change take place in the frequency of contact with your or your spouses children? **YES NO**

256. Was the intensity of the interaction positive? **YES NO**

257. Was the intensity of the interaction neutral? **YES NO**

OWN FAMILY

258. Were there changes in your own family during this time. If yes, please answer question 259-282 or go to #283.

MOTHER

259. Did a change take place in the frequency of contact with mother? **YES NO**

260. Was it positive? **YES NO**

261. Was it neutral? **YES NO**

FATHER

262. Did a change take place in the frequency of contact with father? **YES NO**

263. Was it positive? **YES NO**

264. Was it neutral? **YES NO**

SIBLINGS

265. Did a change take place in the frequency of contact with sibling? **YES NO**

266. Was it positive? **YES NO**

267. Was it neutral? **YES NO**

MATERNAL GRANDPARENTS

268. Did a change take place in either the frequency or intensity of the relationships with the maternal grandparents? **YES NO**

269. Was it positive? **YES NO**

270. Was it neutral? **YES NO**

PATERNAL GRANDPARENTS

271. Did a change take place in the frequency of contact with the paternal grandparents? **YES NO**

272. Was it positive? **YES NO**

273. Was it neutral? **YES NO**

AUNTS

274. Did a change take place in the frequency of contact with aunts? **YES NO**

275. Was it positive? **YES NO**

276. Was it neutral? **YES NO**

UNCLES

277. Did a change take place in the frequency of contact with uncles? **YES NO**

278. Was it positive? **YES NO**

279. Was it neutral? **YES NO**

CHILDREN

280. Did a change take place in the frequency of contact with children? **YES NO**

281. Was it positive? **YES NO**

282. Was it neutral? **YES NO**

SECTION 13 ATTITUDES AND RELATIONSHIP

283. Do you have a special reason for wanting to live each day? **YES NO**

284. Do you currently live with a partner? **YES NO**

285. Have you begun any new love relationships? **YES NO**

286. Is your current major relationship stable? **YES NO**

287. Does your partner help you out financially? **YES NO**

288. Are you currently experiencing difficulty financially?
1) not at all 2) very little 3) somewhat
4) most of the time 5) very confident

289. Are you currently experiencing difficulty with insurance?
1) not at all 2) very little 3) somewhat
4) most of the time 5) very confident

290. Are you currently experiencing difficulty with your job?
1) not at all 2) very little 3) somewhat
4) most of the time 5) very confident

291. Are you currently experiencing difficulty with friendships?
1) not at all 2) very little 3) somewhat
4) most of the time 5) very confident

292. Have you invest more than 50% of your energy into important relationships?
YES NO

293. Do you invest more than 50% of your life energy into important projects?
YES NO

294. Has your life been productive during this time?
1) not at all 2) very little 3) somewhat
4) most of the time 5) very confident

295. Have you been able to accept any physical constraints due to being HIV Positive?
1) not at all 2) very little 3) somewhat
4) most of the time 5) very confident

296. Have you been able to direct your life forward in a positive manner despite problems?
1) not at all 2) very little 3) somewhat
4) most of the time 5) very confident

297. Have you been healthy during this time?
1) not at all 2) very little 3) somewhat
4) most of the time 5) very

SECTION 14 Health Care

SS _____

298. Are you satisfied with the medical care?
1) not at all 2) very little 3) somewhat

4) most of the time 5) very confident

299. Can you ask always ask questions of your medical provider ?
1) not at all 2) very little 3) somewhat
4) most of the time 5) very confident

300. Have you used any new drugs that have been used during this time?

Please write the names down. _____

301. Have there been side effects to the drugs that needed treatment by other drugs?
YES NO

302. Have there been side effects to the drugs that required hospitalization? **YES NO**

303. Have you been hospitalized for other problems? **YES NO**

304. Please note the major problems. _____

305. Have you used prescribed mood altering drugs? **YES NO**

306. Were they useful? **YES NO**

307. Have you used non prescribed mood altering drugs? **YES NO**

308. Were they useful? **YES NO**

309. If they are useful how long have you used them?_____

310. Have you used other drugs that have not been approved by the FDA as treatment for HIV infection? **YES NO**

Please note the name of the drug. _____

311. Do you believe that this drug has been useful? **YES NO**

312. Has diet been an important part of treatment? **YES NO**

313. Have you been on a macrobiotic diet? **YES NO**

314. Have you used large doses of vitamins? **YES NO**

315. Does this include more than vitamins C and E? **YES NO**

316. Are there special foods or vitamins that you consider essential for health?
YES NO

Please write the names in the blank space._____

317. Have you exercised three times a week? **YES NO**

318. Do you practice meditation/relaxation at least three times a week ?

YES NO

319. Has acupuncture been an important part of your treatment? YES NO

320. Has massage been an important part of your treatment? YES NO

321. Has the use of a chiropractor been a part of your treatment? YES NO

322. Has the use of group supportive therapy been a part of your treatment? YES NO

323. Have spiritual therapies been an important part of your treatment? YES NO

324. Has prayer been an important part of your treatment? YES NO

325. Have you had contact with a primary caretaker who is aware of all aspects of your health care? YES NO

326. Do you have adequate health care coverage? YES NO

327. Do you believe that your medical provider can listen to you? YES NO

328. Have friends died from AIDS during this time? YES NO

329. Have you had unprotected sex? YES NO

330. Have you had calm relationships with friends? YES NO

331. Have you recovered from any addictions? YES NO

332. Are there alternative treatments that you believe have been important in treating HIV infection? YES NO

Please write these treatments in the blank space. _____

333. Highest T cell count for the period. _____

334. Did the T cell count fluctuate more than 200 points during this time period? YES NO

335. Did the T cells move higher? YES NO

336. What is your P 24 Antigen Level _____

337. What is your CD4 to CD 8 ratio? _____

338. Have you communicated medical information to others in the family? YES NO

339. Was this successful? YES NO

340. If not are you willing to keep trying to talk to people in the family? YES NO

341. Have you been able to communicate your medical information to

important friends? **YES NO**

342. Have you had to change your physicians because you were not satisfied with treatments? **YES NO**

343. Are you qualified for and reciving Medicare **YES NO**

344. Do you have private insurance and is it adequate? **YES NO**

345. Do you belong to an HMO and is it adequate? **YES NO**

346. Are there other topics that you think should be included in this questionnaire?

Please write suggestions _____

THE WHITE HOUSE

WASHINGTON

June 16, 1994

MEMORANDUM TO KATHRYN CLEMENT, BUILDING MANAGER FOR 750 17th STREET, NW

FROM: Andrew E. Barrer, Ph.D.
Office of the National AIDS Policy Coordinator

SUBJECT: Suite 1060 access

The following office staff from our other office should be allowed access to our suite Monday through Friday:

SALLY JONES

LISA LEWIS

KATHRYN (KITTY) LLOYD

SANDY MASSENBURG

DEBORAH SPEIGHT

KAREN WILLIAMSON

GRETCHEN WIRTH

If you have any questions, please contact me at 632-1090. Please forward this list to the building security desk.

Thank you.

THE WHITE HOUSE

WASHINGTON

June 16, 1994

Daniel M. Pernell, III
3845 South Capitol Street, S.E.
Washington, D.C. 20032

Dear Mr. Pernell:

Thank you for volunteering your services and ideas to the Office of National AIDS Policy. In the battle against AIDS, having the assistance of experienced professionals is a great asset and widens our spectrum of community involvement.

I look forward to working with you in the future. Please don't hesitate to contact me if I can be of service. I can be reached at 202/632-1090.

Sincerely,

John Paul Gurrola
Director of Communications
Office of National AIDS Policy

MAX ROBINSON CENTER
OF WHITMAN-WALKER CLINIC INC
3920 S. CAPTIOL STREET, SE • WASHINGTON, DC 20032
202-562-1160 • TTY 202-562-1178 • FAX 202-562-1240

Communication Adviory Board

May 27, 1994

Office of National AIDS Policy
Executive Office of the President
Director of Communications
Mr. John Paul Gurrola
Washington, D.C 20503

Dear Mr. Gurrola:

I enjoyed meeting with you on Thursday night at he Gertrude Stein Dinner, and I am willing to learn more about the channels of networking with your office.

I was particularyly excited by the possibility of knowing and working as part of a planning team, or volunteering with your office. I feel confident that my postion as Chairman of Max Robinson Community Adviory Board and Founder of Contact and Communtiy OutReach (NewsLetter)--both in networking and public relations--would allow me to fill your needs effectively.

Please call me if I can provide you with further information. I Look forward to hearing from you. Thank you again for the courtesy that you have extended to me.

Sincerely:

Daniel M Pernell (III)

Chairman
Daniel M. Pernell, III
Home: 202-547-5175
Work: 202-707-8239

707-1899 FAX

Enclosure:
Max Robinson (Biographical Summary)

P.S. We are tempararily located in (Covenant Baptist Church) at 3845 South Capitol Street., S.E. Washington, D.C. 20032.

Facts Sheet on the Max Robinson Center

Max Robinson Center is dedicated to providing HIV/AIDS-related services and education/prevention to people residing east of the Anacostia River in Washington, D.C.

A nurse practitioner provides medical evaluations, treatment and medications, and well as gynecological exams, for people with HIV/AIDS. Anonymous HIV antibody testing and counselling is offered to those who want to know their HIV status.

Case managers conduct an intake for each client with HIV/AIDS to help determine the client's physical, emotional and practical needs. case managers work with clients to ensure that they have a support network and access to medical care, public benefits, and concrete services such as housing and food.

Run by a full-time staff nutritionist, the food bank provides 50% of a person's dietary needs, offering mostly canned and nonperishable items at no cost to the client.

Outreach for AIDS Support and Intervention Services (Oasis) targets IV drug users and other substance abusers with HIV prevention information, counseling and referrals for treatment and rehabilitation programs.

Max Robinson Center clients also have access to all services provided at Whitman-Walker main facility at 1407 S. Street, N.W.

Biographical Summary

The Center is named after the nation's first African-American network news anchor, Max Robinson, who died in December 1988 of AIDS. Robinson won three Emmys for his work in broadcasting. One of the founders of the National Association of Black Journalists, Robinson fought racism and apartheid in the newsroom and the world at large. He was also a founding member of TransAfrica, an organization run by his brother Randall Robinson, that lobbies for a more progressive U.S. foreign policy approach toward nations in Africa and the Caribbean.

A spokesperson for Robinson at the time of his death said that Robinson wanted to emphasize the importance, particularly to the African-American community, of AIDS education and prevention. He also said Robinson pointed out the urgency for developing AIDS treatment, and that people with AIDS need to be treated humanely.

Robinson attended Oberlin College and Virginia Union University and began his career in broadcasting as a disc jockey in his native Richmond, Virginia. In 1965, he moved to Washington and joined WTOP-TV (now WUSA-TV) as a floor director trainee.

Hoping to get on-camera, Robinson joined WRC-TV as that station's first African-American reporter. There, his career took off when he produced a special called "The Other Washington", an Emmy-Award winning documentary on African-American life in Anacostia.

In 1969, Robinson returned to WTOP to become the city's first African-American news anchor. In 1978, Robinson moved to ABC-TV in Chicago to anchor its "WORLD News Tonight" broadcast as part of a three-person team, with Frank Reynolds in Washington and Peter Jennings in London.

CONTACT AND COMMUNITY OUTREACH

DANIEL M. PERNELL, III
FOUNDER

1132 4th STREET, N.E.
WASHINGTON, D.C. 20002
202 547-5175

GRASS ROOT
COMMUNITY NETWORKING
HEALTH CARE INFORMATION
NEWSLETTER

CCOR NEWSLETTER

March 15,1994 To April 15, 1994 VOLUME 14.

" Our Children ... are in dire need of Real Health Care Services."

This picture published by the New York Times won the features photography prize for freelancer Kevin Carter. A vulture watches a starving Sudanese girl die.

CONTACT AND COMMUNITY OUTREACH

FOUNDER DANIEL M. PERNELL, III

Newsletter Published Monthly by Contact and Community OutReach members
1132 4th Street, N.E.
Washington, D.C. 20002
(202) 547-5175
CCOR Publication Members
Writer/Editors
Layout of Issue
Distribution
Photographer
****

Daniel M. Pernell, III
Founder

Tony Montas
Spanish Consultant and Advisor

Kevin Jayson
Avery Jackson
Donald Burch, III
William Ampley
Bradley M. Lewis

Courtney Williams
Public Relationship (contact)

Tina Spencer
Gertrude Dennis
Mary Mitchell
Scotia McLean

Dr. Anne E. Pharr, Ph.D
Senior Technical Staff

Meg Bennett, RN, MA
Hiv Education Innovations

Mrs. Shola A. Idown, M.S.,
Nutrition and Dietary

Mr. Raymond A. Carter
Businessman

CONTACT AND COMMUNITY OUTREACH

DANIEL M. PERNELL, III
FOUNDER

1132 4th STREET, N.E.
WASHINGTON, D.C. 20002
202 547-5175

GRASS ROOT
COMMUNITY NETWORKING
HEALTH CARE INFORMATION
NEWSLETTER

SOME ARTICLES ARE EXCERPTS FROM NEWSPAPER, MAGAZINE, AIDS FORUM AND ONSITE INTERVIEWS.

District Child Abuse Reports

Child Abuse cases arriving in record numbers. If new child abuse and neglect cases filed in D.C. Superior Court continue to run at the same pace, the total number of cases for 1994 will reach 1,800, about 30 percent above last year's record-setting to total of 1,376, court officials said.

This year so far, 479 cases had been filed, compared to 367 cases filed last year. In a 15-day period last month, 100 cases were filed. Eleven new cases were brought into court, and nine more--each case involving one child--were filed on April 16, 1994.

The common denominator in many of these cases were drug abuse by one or both parents.

Rock Held By Child Was Crack

A Kindergarten student was sitting in her reading class in Northwest on April 18, 1994 a Monday afternoon when her substitute teacher noticed a small, white clump in the little girl's hand. The teacher took a closer look, and to her amaze saw that the little girl was holding a small amount of what look like crack cocaine.

Marilyn Riley, Chief of the child and family services division of the D.C. Human Service Department said. "It's a sign of the times in which we live. It's not something I'm really surprised about, that children's at their younger age would be exposed to drugs of the streets.

The discovery of the girl holding crack cocaine at the Marie Reed Learning Center, in the Adams-Morgan neighborhood, came less than a week after two 10-year-old boys were taken into custody by police in Prince George's County after crack allegedly was found in one pupil's book bag.

D.C. public school officials said it does not appear that the kindergartner knew what she had.

Gold Water's grandson talks about HIV status....

Phoenix -- A new national magazine for people infected with the virus that causes AIDS is presenting former U.S. Sen. Barry Goldwater's grandson as an HIV-positive sex symbol. Ty Ross, 31, of Scottsdale, was photographed nude and talked frankly about his HIV status. Interview, Mr. Ross who told his mother he was homosexual when he was 17. His grandmother then told Sen. Goldwater about his diagnosis.

The 1964 Republican presidential candidate, famous for his conservatism, publicly discussed having a gay grandson last year when he denounced the ban on homosexuals in the military as "just plain dumb."

Reported from LA

Michael Jackson remain under investigation by Los Angeles and Santa Barbara grand juries for alleged sexual molestation, despite word that the probe would conclude by month's end.

Tips For Parents

Parents should warn their children about the hazard of household products that can be abused as inhalants. The following warning signs may indicate use of inhalants:

- **Drunken appearance, slurred speech, loss of coordination and blood shot eyes but no smell of alcohol.**
- **Chemical smell on breath, skin and clothing.**
- **Rash or sores around the mouth or nose.**
- **Flu-like symptoms, including headache, nausea, runny nose, coughing.**
- **Lack of ability to concentrate.**
- **Keeping a stash of products that can be inhaled in bed or the bathroom, as well as gear such as plastic bags or rags.**

For more information, call the American Council for Drug Education at 301-294-0600 or 800-488-DRUG.

Going After Underage Drinkers

Alcohol-Buying Teens May Encounter Undercover 'COPS in Shop'.

The liquor industry and law enforcement agencies have joined force to combat underage drinking in the Washington area during high school prom season.

The program "COPS in Shops," would put police officers from the District and five surrounding counties behind the counters of liquor convenience stores where teenagers are know to try to buy alcohol.

Underground investigations involving liquor sales to minors are nothing new in the area, but this time the industry has set aside $60.000 to help pay for it.

Michele Woodward of the Century Council, a trade group of more than 800 vintners, distillers, brewers and wholesaler nationwide, said we want to get the message across to kids that there is a consequence to their behavior.

Officers who volunteer for the program would work four hour shifts and be paid our of the $60,000, as well as $15,000 set aside from safety funds fro the Virginia Department of Motor Vehicles, the Maryland State Highway Administration and the D.C. Department of Public Works.

" If you are to young to buy, don't even try," is the signature slogan of a poster to be distributed to 144 high schools and 20 colleges and universities throughout the area. Maryland law prohibits anyone under the age of 21 from possessing or drinking alcohol. Each offense carries a penalty of up to $1,000 in fines or two years in jail. Virginia's minors face up to $2,500 in fines or a year in jail. In the District, the penalty is $300 in fines and loss of a driver's license for up to a year.

Lt. Jacqueline Zovak of the D.C. police prostitution, gambling and liquor unit, said It the law is changed, and they are arrested for buying alcohol, it would have a larger impact."

FDA Approves Drug For Kids With HIV

The U.S. Food and Drug Administration has approved the use of Gaminune N, an immunizing agent made from blood plasma, to treat HIV-infected children and bone marrow transplant patients over age 20.

Data submitted to the FDA showed that HIV-infected children receiving gamimune N developed 41 percent fewer serious bacterial infections and 37 percent fewer hospitalizations than those getting a placebo. The study did not show any increase in life expectancy, but one researcher said the number of children in the sample (394) was too small to measure that. Another study found that bone marrow transplant patients receiving the drug had a lower risk of septicemia and other infections, interstitial pneumonia and acute graft-vs-host disease in the first 100 days after the transplant.

Gamminune N is a Mile Inc. brand name for immune globulin intravenous (IGIV), which is used to treat immune disorders such as the congenital inability to make antibodies, a cancer of white blood cells called B-Cell lymphocytic leukemia, and a disease that destroys blood-clotting cells.

As of last September, 4,906 American children under 13 had been diagnosed with AIDS, according to the Atlanta-based federal Center for Disease Control and Prevention.

Straight Talk for Teens

The Nation Clearinghouse for Alcohol and drug Information offers free pamphlets on alcohol, smoking, marijuana, crack and cocaine, and hallucinogens. Results of the 1993 "Monitoring the Future" survey indicate that tobacco, alcohol and drug use by teenagers continues to rise at alarming rates.

Illegal drug use is consistently up for teens in grades 8,10 and 12. Binge drinking remained around 28 percent among high-school seniors, but increased among 10th graders, rising from 21.1 percent in 1992 to 23 percent in 1993. The number of teens who use cigarettes and other tobacco products is also climbing. The order any of the five "Tips for Teens About... publication, **call 1-800-729-6686 or write NCADI, P.O. Box 2345, Rockville, Md. 20847-2345.**

High Blood Pressure Incidence Drops

The number of American with high blood pressure fell to 50 million from 63.6 million in the last 10 years, the American Heart Association said in its annual statistical report. The report also estimated that 2.2 million American children ages 12 to 17 smoke cigarettes, and 9 million children under age 5 live with a smoker, raising their risk of asthma and respiratory infections.

Heart disease and stokes killed 923,422 Americans in 1991 They will cost the health care system about $128 billion this year, the association estimated. That includes $102 million in payments to doctors, nurses, hospitals and nursing homes; $8 billion for drugs and $18 billion in lost productivity.

In 1990, accounting to the most recent available data, 478,179 women died of heart disease, compared with 447,900 men who died. Women first surpassed men in heart disease death in 1984. Ultimately children may join the ranks of 417,000 people who die each year of tobacco-related deaths. Mothers who smoke 10 or more cigarettes a day can cause as many as 26,000 of asthma among their children each year.

Half Of Children in Oregon Survey Have Tooth Decay.

Reported in Atlanta,Ga. On November 26,94. About half the children surveyed on Oregon have cavities, which shows states must provide more dental care for young people, health officials said.

Dolores Malvitz of the division of oral health at the federal Centers for Disease Control and Prevention."In spite of all medical progress, dental disease persists in children,". " Some groups of children still have large amounts of dental decay that remains untreated."

The 1991-92 statewide study of 2,872 Oregon children ages 3 to 12 also found that American Indians, Asians and Hispanics had a higher prevalence of dental disease than whites.

Children's Defense Fund Cites Gun Violence

The equivalent of a "classroomful" of children is killed every two days by firearms, the Children Defense Fund reported. Warning that homicide is now the nation's third leading cause of death for elementary and middle school children.

The children's advocacy group in, its annual State of America's Children report, called for "cease-fire" in "American's undeclared 20th Century civil war," citing a steep rise both in the number of children victimized by guns and those arrested for committing crimes with guns.

The National Association of Children's Hospital and Related Institutions calculates the average gun injury at $14,434. While 13 children die each day from gunfire, another 30 are injured. The report also quoted psychiatrists and other experts on the effect on children in high-crime areas, many of whom have witnessed robberies, stabbings, and killings.

Firearm Death For Children 1979-91

	Age	
	1-14	15-19
White	6,580	25,623
Male	5,019	21,732
Female	1,561	3,891
Black	2,207	13,293
Male	1,590	11,782
Female	617	1,511
Other	240	961
All	9,027	39,877

Source: National Center for Health Statistics.

A Legacy Of AIDS Orphans

Study Cites Need For More Services

By the end of the decade, between 72,000 and 125,000 American children will be left motherless because of AIDS, according to estimates in a study released today.

The study, conducted by the Orphan Project in New York City, lists Washington as one of the cities likely to be hardest hit, estimating that between 1,100 and 2,200 children here will lose their mothers to HIV-related deaths by the 2000. The numbers are highest by far in New York City, where there will be 30,000 children and adolescents orphaned by the disease by the end of the decade, New York is followed by Newark; Miami; San Juan, Puerto Rico; Los Angeles and the District of Columbia.

Children Issue Safety Warning

Hill Panel Urged To Back Injury-Prevention Measures...

More than 100 children went to Capitol Hill to tell Senate Labor and Human Resources subcommittee on children stories about injuries that could have been prevented. The hearing was part of the National Safe Kids Campaign, aimed at publicizing measures such as bike helmets, drowning prevention, smoke detectors and safely seats.

Former surgeon general C. Everett Koop, chairman of the campaign, said more than 13 million children are treated each year for unintentional injury at a cost of $13.8 billion.

Nearly 8,000 children die each year from unintentional injury, claiming more lives than all other children diseases combined. Koop, said good preventive measures save families untold suffering.

Safe Kids wants Congress to provide subsidies to low-income families for child safety devices, grants to states that approve injury prevention laws and grants to train physicians in injury prevention counseling.

The number of children in poverty increased in 1992 to 14.6 million, or 21.9 percent of the total. the number of children reported as abused or neglected in 1992 rose to 2.9 million, three times the figure for 1980. The number of children living in foster care rose to 442,000 in 1992, nearly 70 percent more that the figure a decade earlier.

In comparing of 50 states, the District of Columbia ranks the poorest.

Simple Ways to Help Your Child Get Better Grades

You can help your C-average child or teenager boost his grades to Bs or even As by following a few simple tips, says a university psychologist.

"It doesn't take a lot of work to help your child get better grades," declared Dr. Gary Brown, author of "How to Improve Your Grades and Live Happily Ever After."

Here are his suggestions:

✓ Discuss your expectations with your child early in the school year. Tell him what kind of grades you feel he should get.

"Letting your child know what you're expecting will help motivate him to achieve the goal," said Dr. Brown, chairman of the department of psychology at the University of Tennessee-Martin.

✓ Go to your child's school and meet her teacher or counselor. Let them know you're willing and able to help your child do better.

When parents show this much interest, teachers will often notify them of upcoming tests and important assignments facing their child. It's a simple way of making sure your child will be prepared.

✓ While you're at the school, find out exactly how your child's final grade will be determined.

For example, in some classes the final grade is an average of all test scores throughout the year. But sometimes, especially in high school, the final grade may be heavily dependent on a term paper or written report. If that's the case, make sure your child spends more time and effort on that report.

✓ Create a "study hall" at home. It's too distracting for children to try to do homework while watching TV or listening to the radio, or while sprawled on a bed. Instead, set up a desk or table, facing a wall, with a good reading lamp, where he can study.

✓ Allow the child to have a 10-minute break after 50 minutes of study. Research shows a 50-10 cycle is most efficient for studying.

✓ Review the material verbally with your child, or have him read the material out loud. "This verbal input is important," Dr. Brown said. "Research shows that people learn better when they're listening to material as well as reading it."

✓ Reward good grades. The reward can be anything from letting your child watch more TV to taking him for an ice cream soda — whatever works for you and your child.

— *DAN McDONALD*

A T T E N T I O N ! !

20% DISCOUNT

Paint In Your Home or

Apartment Commercial
Business, Churches,
Realestate Property
Stripping & Waxing
Floors,

& Window Cleaning

Call YESS at 546-9623

Youth Entrpreneuers for
Self Sufficency

Office of
Educational Programs & Operations

Division of
Curriculum & Educational Technology

HIV/AIDS Education Program
Birney Elementary School
Martin Luther King Avenue & Bunker Road, S.E.
Washington, D.C. 20020

HELP ME TO BE ABLE TO SAY "NO" AND MEAN IT

When challenged to be a show off,
Please help me to say "NO" and mean it.

When offered a drink of alcohol,
Please help me to say "NO" and mean it.

When tempted to get into a heated argument,
Please help me to say "NO" and mean it.

When thinking of being disobedient to my parent(s),
Please help me to say "NO" and mean it.

When considering being disrespectful of my teacher(s),
Please help me to say "NO" and mean it.

When faced with the opportunity to steal from another,
Please help me to say "NO" and mean it.

When selfishness and selfcenteredness overcome me,
Please help me to say "NO" and mean it.

When being encouraged to have unsafe sex,
Please help me to say "NO" and mean it.

Written By: Jackie Walton Sadler, M.A., MPH, CHES
Healty People/Healthy Environment
The Secretary's National Conference On Alcohol-Related Injuries
Roundtable Discussion
Tuesday, March 24, 1992

Telephone: (202) 767-8837, 8839 or 8840 Fax Number: (202) 767-7162

BOYS TOWN

"He ain't heavy, Father ... he's m' brother"

FATHER FLANAGAN'S BOYS' TOWN OF WASHINGTON D.C.
4801 Sargent Road, N.E.
Washington, DC 20017

BOYS TOWN HAS COME TO WASHINGTON, DC

Boys Town has opened its Treatment Foster Family Services Program in Washington, DC. We are eager to care for the children of the Nation's Capitol and to change the way America cares for her children. We know that you are too!

Join our team as a treatment foster parent. Boys Town will give you training, consultation, and all the help you need to be successful.

Please give us a call:

(202) 832-7343

LEGAL SERVICES

for HIV/AIDS-related problems

available at

THE MAX ROBINSON CENTER

The Legal Services Department of the Whitman-Walker Clinic
can help with:

•Entitlements
Initial Social Security applications
Appeals from denials of Social Security claims

•Child Custody

•Wills
Powers of Attorney
Living Wills

•Discrimination

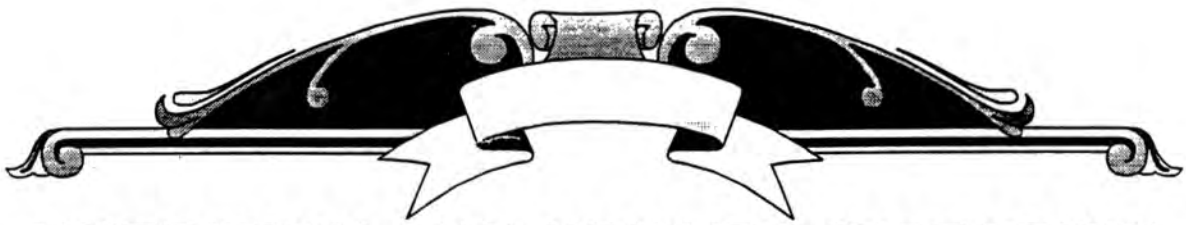
•Insurance

We can also provide **referrals** for:

Housing, Unemployment Compensation, Divorce and Consumer Matters

---

Please contact Sylvia Earl at 202/562-1160
to arrange an appointment
at the Max Robinson Center



NUTRITION AND HIV/AIDS INFECTION

Nutritional care is an essential component of treatment for all HIV/AIDS infected individuals at all stages of the disease.

Malnutrition, severe weight loss and gastrointestinal problems are common consequences of AIDS. Comprehensive and sustain nutritional care can promote optimal intake of food and weight gain during period of wellness as well as address malnutrition and gastrointestinal complications during period of illness. SSS Nutrition and Dietetic Care Services, Inc., have group of experts, Registered Dietitian/Nutritionist, to provide necessary nutrition consult. Most medical insurance accepted.

Call SSS Nutrition and Dietetic Care Services, Inc.
344 University Boulevard West, Suite 326, Silver Spring, MD 20901
(301) 871-5509

HIV-AIDS SUPPORT GROUP

(FOR LC EMPLOYEES ONLY!)

You are invited to attend an organizational meeting for a renewed HIV-AIDS Support Group. This group is being organized to provide emotional support for people living with AIDS or HIV infection, for caregivers of these people, and for anyone who has lost a friend or loved one to AIDS. Managers and staff who want to support fellow LC employees dealing with these issues are encouraged to come.

We need people to make this work. It's been tried before. Let's try again.

WHERE: COPYRIGHT CATALOGING DIVISION
CONFERENCE ROOM
LM 513 (YELLOW QUADRANT)

Contact: Kim Black
(preferably by e-Mail, otherwise ext. 78080)

CONTACT AND COMMUNITY OUTREACH
Founder and President
Daniel M. Pernell, III
1132 4th Street, N.E.
Washington, DC 20002

TO:

Office Of National AIDS Policy
Executive Office oF The President
Washington, D.C. 20503

Attn: Mr. John Paul Gurrola
Director of Communications

CONTACT AND COMMUNITY OUTREACH

DANIEL M. PERNELL, III
FOUNDER

1132 4th STREET, N.E.
WASHINGTON, D.C. 20002
202 547-5175

GRASS ROOT
COMMUNITY NETWORKING
HEALTH CARE INFORMATION
NEWSLETTER

CCOR NEWSLETTER

March 15,1994 To April 15, 1994 VOLUME 14.

" Our Children ... are in dire need of Real Health Care Services."

This picture published by the New York Times won the features photography prize for freelancer Kevin Carter. A vulture watches a starving Sudanese girl die.

CONTACT AND COMMUNITY OUTREACH

FOUNDER DANIEL M. PERNELL, III

Newsletter Published Monthly by Contact and Community OutReach members
1132 4th Street, N.E.
Washington, D.C. 20002
(202) 547-5175
CCOR Publication Members
Writer/Editors
Layout of Issue
Distribution
Photographer
****

Daniel M. Pernell, III
Founder

Tony Montas
Spanish Consultant and Advisor

Kevin Jayson
Avery Jackson
Donald Burch, III
William Ampley
Bradley M. Lewis

Courtney Williams
Public Relationship (contact)

Tina Spencer
Gertrude Dennis
Mary Mitchell
Scotia McLean

Dr. Anne E. Pharr, Ph.D
Senior Technical Staff

Meg Bennett, RN, MA
Hiv Education Innovations

Mrs. Shola A. Idown, M.S.,
Nutrition and Dietary

Mr. Raymond A. Carter
Businessman

CONTACT AND COMMUNITY OUTREACH

DANIEL M. PERNELL, III
FOUNDER

1132 4th STREET, N.E.
WASHINGTON, D.C. 20002
202 547-5175

GRASS ROOT
COMMUNITY NETWORKING
HEALTH CARE INFORMATION
NEWSLETTER

SOME ARTICLES ARE EXCERPTS FROM NEWSPAPER, MAGAZINE, AIDS FORUM AND ONSITE INTERVIEWS.

District Child Abuse Reports

Child Abuse cases arriving in record numbers. If new child abuse and neglect cases filed in D.C. Superior Court continue to run at the same pace, the total number of cases for 1994 will reach 1,800, about 30 percent above last year's record-setting to total of 1,376, court officials said.

This year so far, 479 cases had been filed, compared to 367 cases filed last year. In a 15-day period last month, 100 cases were filed. Eleven new cases were brought into court, and nine more--each case involving one child--were filed on April 16, 1994.

The common denominator in many of these cases were drug abuse by one or both parents.

Rock Held By Child Was Crack

A Kindergarten student was sitting in her reading class in Northwest on April 18, 1994 a Monday afternoon when her substitute teacher noticed a small, white clump in the little girl's hand. The teacher took a closer look, and to her amaze saw that the little girl was holding a small amount of what look like crack cocaine.

Marilyn Riley, Chief of the child and family services division of the D.C. Human Service Department said. "It's a sign of the times in which we live. It's not something I'm really surprised about, that children's at their younger age would be exposed to drugs of the streets.

The discovery of the girl holding crack cocaine at the Marie Reed Learning Center, in the Adams-Morgan neighborhood, came less than a week after two 10-year-old boys were taken into custody by police in Prince George's County after crack allegedly was found in one pupil's book bag.

D.C. public school officials said it does not appear that the kindergartner knew what she had.

Gold Water's grandson talks about HIV status....

Phoenix -- A new national magazine for people infected with the virus that causes AIDS is presenting former U.S. Sen. Barry Goldwater's grandson as an HIV-positive sex symbol. Ty Ross, 31, of Scottsdale, was photographed nude and talked frankly about his HIV status. Interview, Mr. Ross who told his mother he was homosexual when he was 17. His grandmother then told Sen. Goldwater about his diagnosis.

The 1964 Republican presidential candidate, famous for his conservatism, publicly discussed having a gay grandson last year when he denounced the ban on homosexuals in the military as "just plain dumb."

Reported from LA

Michael Jackson remain under investigation by Los Angeles and Santa Barbara grand juries for alleged sexual molestation, despite word that the probe would conclude by month's end.

Tips For Parents

Parents should warn their children about the hazard of household products that can be abused as inhalants. The following warning signs may indicate use of inhalants:

- **Drunken appearance, slurred speech, loss of coordination and blood shot eyes but no smell of alcohol.**
- **Chemical smell on breath, skin and clothing.**
- **Rash or sores around the mouth or nose.**
- **Flu-like symptoms, including headache, nausea, runny nose, coughing.**
- **Lack of ability to concentrate.**
- **Keeping a stash of products that can be inhaled in bed or the bathroom, as well as gear such as plastic bags or rags.**

For more information, call the American Council for Drug Education at 301-294-0600 or 800-488-DRUG.

Going After Underage Drinkers

Alcohol-Buying Teens May Encounter Undercover 'COPS in Shop'.

The liquor industry and law enforcement agencies have joined force to combat underage drinking in the Washington area during high school prom season.

The program "COPS in Shops," would put police officers from the District and five surrounding counties behind the counters of liquor convenience stores where teenagers are know to try to buy alcohol.

Underground investigations involving liquor sales to minors are nothing new in the area, but this time the industry has set aside $60.000 to help pay for it.

Michele Woodward of the Century Council, a trade group of more than 800 vintners, distillers, brewers and wholesaler nationwide, said we want to get the message across to kids that there is a consequence to their behavior.

Officers who volunteer for the program would work four hour shifts and be paid our of the $60,000, as well as $15,000 set aside from safety funds fro the Virginia Department of Motor Vehicles, the Maryland State Highway Administration and the D.C. Department of Public Works.

" If you are to young to buy, don't even try," is the signature slogan of a poster to be distributed to 144 high schools and 20 colleges and universities throughout the area. Maryland law prohibits anyone under the age of 21 from possessing or drinking alcohol. Each offense carries a penalty of up to $1,000 in fines or two years in jail. Virginia's minors face up to $2,500 in fines or a year in jail. In the District, the penalty is $300 in fines and loss of a driver's license for up to a year.

Lt. Jacqueline Zovak of the D.C. police prostitution, gambling and liquor unit, said It the law is changed, and they are arrested for buying alcohol, it would have a larger impact."

FDA Approves Drug For Kids With HIV

The U.S. Food and Drug Administration has approved the use of Gaminune N, an immunizing agent made from blood plasma, to treat HIV-infected children and bone marrow transplant patients over age 20.

Data submitted to the FDA showed that HIV-infected children receiving gamimune N developed 41 percent fewer serious bacterial infections and 37 percent fewer hospitalizations than those getting a placebo. The study did not show any increase in life expectancy, but one researcher said the number of children in the sample (394) was too small to measure that. Another study found that bone marrow transplant patients receiving the drug had a lower risk of septicemia and other infections, interstitial pneumonia and acute graft-vs-host disease in the first 100 days after the transplant.

Gamminune N is a Mile Inc. brand name for immune globulin intravenous (IGIV), which is used to treat immune disorders such as the congenital inability to make antibodies, a cancer of white blood cells called B-Cell lymphocytic leukemia, and a disease that destroys blood-clotting cells.

As of last September, 4,906 American children under 13 had been diagnosed with AIDS, according to the Atlanta-based federal Center for Disease Control and Prevention.

Straight Talk for Teens

The Nation Clearinghouse for Alcohol and drug Information offers free pamphlets on alcohol, smoking, marijuana, crack and cocaine, and hallucinogens. Results of the 1993 "Monitoring the Future" survey indicate that tobacco, alcohol and drug use by teenagers continues to rise at alarming rates.

Illegal drug use is consistently up for teens in grades 8,10 and 12. Binge drinking remained around 28 percent among high-school seniors, but increased among 10th graders, rising from 21.1 percent in 1992 to 23 percent in 1993. The number of teens who use cigarettes and other tobacco products is also climbing. The order any of the five "Tips for Teens About... publication, **call 1-800-729-6686 or write NCADI, P.O. Box 2345, Rockville, Md. 20847-2345.**

High Blood Pressure Incidence Drops

The number of American with high blood pressure fell to 50 million from 63.6 million in the last 10 years, the American Heart Association said in its annual statistical report. The report also estimated that 2.2 million American children ages 12 to 17 smoke cigarettes, and 9 million children under age 5 live with a smoker, raising their risk of asthma and respiratory infections.

Heart disease and stokes killed 923,422 Americans in 1991 They will cost the health care system about $128 billion this year, the association estimated. That includes $102 million in payments to doctors, nurses, hospitals and nursing homes; $8 billion for drugs and $18 billion in lost productivity.

In 1990, accounting to the most recent available data, 478,179 women died of heart disease, compared with 447,900 men who died. Women first surpassed men in heart disease death in 1984. Ultimately children may join the ranks of 417,000 people who die each year of tobacco-related deaths. Mothers who smoke 10 or more cigarettes a day can cause as many as 26,000 of asthma among their children each year.

Half Of Children in Oregon Survey Have Tooth Decay.

Reported in Atlanta,Ga. On November 26,94. About half the children surveyed on Oregon have cavities, which shows states must provide more dental care for young people, health officials said.

Dolores Malvitz of the division of oral health at the federal Centers for Disease Control and Prevention."In spite of all medical progress, dental disease persists in children,". " Some groups of children still have large amounts of dental decay that remains untreated."

The 1991-92 statewide study of 2,872 Oregon children ages 3 to 12 also found that American Indians, Asians and Hispanics had a higher prevalence of dental disease than whites.

Children's Defense Fund Cites Gun Violence

The equivalent of a "classroomful" of children is killed every two days by firearms, the Children Defense Fund reported. Warning that homicide is now the nation's third leading cause of death for elementary and middle school children.

The children's advocacy group in, its annual State of America's Children report, called for "cease-fire" in "American's undeclared 20th Century civil war," citing a steep rise both in the number of children victimized by guns and those arrested for committing crimes with guns.

The National Association of Children's Hospital and Related Institutions calculates the average gun injury at $14,434. While 13 children die each day from gunfire, another 30 are injured. The report also quoted psychiatrists and other experts on the effect on children in high-crime areas, many of whom have witnessed robberies, stabbings, and killings.

Firearm Death For Children 1979-91

	Age	
	1-14	15-19
White	6,580	25,623
Male	5,019	21,732
Female	1,561	3,891
Black	2,207	13,293
Male	1,590	11,782
Female	617	1,511
Other	240	961
All	9,027	39,877

Source: National Center for Health Statistics.

A Legacy Of AIDS Orphans

Study Cites Need For More Services

By the end of the decade, between 72,000 and 125,000 American children will be left motherless because of AIDS, according to estimates in a study released today.

The study, conducted by the Orphan Project in New York City, lists Washington as one of the cities likely to be hardest hit, estimating that between 1,100 and 2,200 children here will lose their mothers to HIV-related deaths by the 2000. The numbers are highest by far in New York City, where there will be 30,000 children and adolescents orphaned by the disease by the end of the decade, New York is followed by Newark; Miami; San Juan, Puerto Rico; Los Angeles and the District of Columbia.

Children Issue Safety Warning

Hill Panel Urged To Back Injury-Prevention Measures...

More than 100 children went to Capitol Hill to tell Senate Labor and Human Resources subcommittee on children stories about injuries that could have been prevented. The hearing was part of the National Safe Kids Campaign, aimed at publicizing measures such as bike helmets, drowning prevention, smoke detectors and safely seats.

Former surgeon general C. Everett Koop, chairman of the campaign, said more than 13 million children are treated each year for unintentional injury at a cost of $13.8 billion.

Nearly 8,000 children die each year from unintentional injury, claiming more lives than all other children diseases combined. Koop, said good preventive measures save families untold suffering.

Safe Kids wants Congress to provide subsidies to low-income families for child safety devices, grants to states that approve injury prevention laws and grants to train physicians in injury prevention counseling.

The number of children in poverty increased in 1992 to 14.6 million, or 21.9 percent of the total. the number of children reported as abused or neglected in 1992 rose to 2.9 million, three times the figure for 1980. The number of children living in foster care rose to 442,000 in 1992, nearly 70 percent more that the figure a decade earlier.

In comparing of 50 states, the District of Columbia ranks the poorest.

Simple Ways to Help Your Child Get Better Grades

You can help your C-average child or teenager boost his grades to Bs or even As by following a few simple tips, says a university psychologist.

"It doesn't take a lot of work to help your child get better grades," declared Dr. Gary Brown, author of "How to Improve Your Grades and Live Happily Ever After."

Here are his suggestions:

✓ Discuss your expectations with your child early in the school year. Tell him what kind of grades you feel he should get.

"Letting your child know what you're expecting will help motivate him to achieve the goal," said Dr. Brown, chairman of the department of psychology at the University of Tennessee-Martin.

✓ Go to your child's school and meet her teacher or counselor. Let them know you're willing and able to help your child do better.

When parents show this much interest, teachers will often notify them of upcoming tests and important assignments facing their child. It's a simple way of making sure your child will be prepared.

✓ While you're at the school, find out exactly how your child's final grade will be determined.

For example, in some classes the final grade is an average of all test scores throughout the year. But sometimes, especially in high school, the final grade may be heavily dependent on a term paper or written report. If that's the case, make sure your child spends more time and effort on that report.

✓ Create a "study hall" at home. It's too distracting for children to try to do homework while watching TV or listening to the radio, or while sprawled on a bed. Instead, set up a desk or table, facing a wall, with a good reading lamp, where he can study.

✓ Allow the child to have a 10-minute break after 50 minutes of study. Research shows a 50-10 cycle is most efficient for studying.

✓ Review the material verbally with your child, or have him read the material out loud. "This verbal input is important," Dr. Brown said. "Research shows that people learn better when they're listening to material as well as reading it."

✓ Reward good grades. The reward can be anything from letting your child watch more TV to taking him for an ice cream soda — whatever works for you and your child.

— *DAN McDONALD*

A T T E N T I O N ! !

20% DISCOUNT

Paint In Your Home or

Apartment Commercial
Business, Churches,
Realestate Property
Stripping & Waxing
Floors,

& Window Cleaning

Call YESS at 546-9623

Youth Entrpreneuers for
Self Sufficency

Office of
Educational Programs & Operations

Division of
Curriculum & Educational Technology

HIV/AIDS Education Program
Birney Elementary School
Martin Luther King Avenue & Sumner Road, S.E.
Washington, D.C. 20020

HELP ME TO BE ABLE TO SAY "NO" AND MEAN IT

When challenged to be a show off,
Please help me to say "NO" and mean it.

When offered a drink of alcohol,
Please help me to say "NO" and mean it.

When tempted to get into a heated argument,
Please help me to say "NO" and mean it.

When thinking of being disobedient to my parent(s),
Please help me to say "NO" and mean it.

When considering being disrespectful of my teacher(s),
Please help me to say "NO" and mean it.

When faced with the opportunity to steal from another,
Please help me to say "NO" and mean it.

When selfishness and selfcenteredness overcome me,
Please help me to say "NO" and mean it.

When being encouraged to have unsafe sex,
Please help me to say "NO" and mean it.

Written By: Jackie Walton Sadler, M.A., MPH, CHES
Healty People/Healthy Environment
The Secretary's National Conference On Alcohol-Related Injuries
Roundtable Discussion
Tuesday, March 24, 1992

Telephone: (202) 767-8837, 8839 or 8840 Fax Number: (202) 767-7162

FATHER FLANAGAN'S BOYS' TOWN OF WASHINGTON D.C.
4801 Sargent Road, N.E.
Washington, DC 20017

BOYS TOWN HAS COME TO WASHINGTON, DC

Boys Town has opened its Treatment Foster Family Services Program in Washington, DC. We are eager to care for the children of the Nation's Capitol and to change the way America cares for her children. We know that you are too!

Join our team as a treatment foster parent. Boys Town will give you training, consultation, and all the help you need to be successful.

Please give us a call:

(202) 832-7343

LEGAL SERVICES

for HIV/AIDS-related problems

available at

THE MAX ROBINSON CENTER

The Legal Services Department of the Whitman-Walker Clinic
can help with:

•Entitlements
Initial Social Security applications
Appeals from denials of Social Security claims

•Child Custody

•Wills
Powers of Attorney
Living Wills

•Discrimination

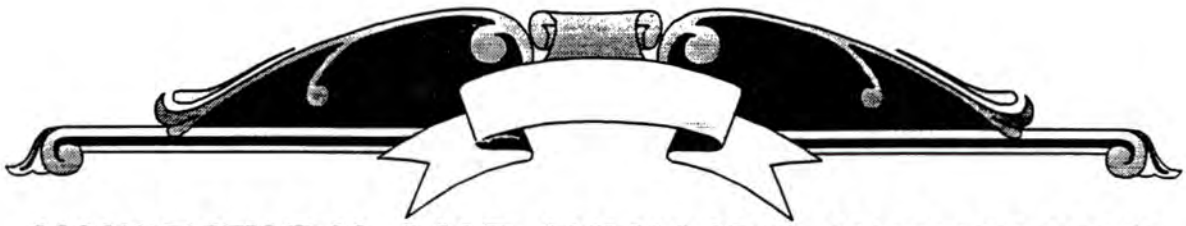
•Insurance

We can also provide **referrals** for:

Housing, Unemployment Compensation, Divorce and Consumer Matters

---

Please contact Sylvia Earl at 202/562-1160
to arrange an appointment
at the Max Robinson Center



NUTRITION AND HIV/AIDS INFECTION

Nutritional care is an essential component of treatment for all HIV/AIDS infected individuals at all stages of the disease.

Malnutrition, severe weight loss and gastrointestinal problems are common consequences of AIDS. Comprehensive and sustain nutritional care can promote optimal intake of food and weight gain during period of wellness as well as address malnutrition and gastrointestinal complications during period of illness. SSS Nutrition and Dietetic Care Services, Inc., have group of experts, Registered Dietitian/Nutritionist, to provide necessary nutrition consult. Most medical insurance accepted.

Call SSS Nutrition and Dietetic Care Services, Inc.
344 University Boulevard West, Suite 326, Silver Spring, MD 20901
(301) 871-5509

HIV-AIDS SUPPORT GROUP

(FOR LC EMPLOYEES ONLY!)

You are invited to attend an organizational meeting for a renewed HIV-AIDS Support Group. This group is being organized to provide emotional support for people living with AIDS or HIV infection, for caregivers of these people, and for anyone who has lost a friend or loved one to AIDS. Managers and staff who want to support fellow LC employees dealing with these issues are encouraged to come.

We need people to make this work. It's been tried before. Let's try again.

WHERE: COPYRIGHT CATALOGING DIVISION
CONFERENCE ROOM
LM 513 (YELLOW QUADRANT)

Contact: Kim Black
(preferably by e-Mail, otherwise ext. 78080)

THE WHITE HOUSE

WASHINGTON

June 20, 1994

Mr. Bob Nelson
Manager, Direct HIV Services
Catholic Charities
3180 18th Street
San Francisco, California 94110

Dear Mr. Nelson:

Thank you for writing and sharing your ideas and concerns about housing for people living with HIV. This is indeed a critical area of concern and continues to receive my attention.

Adequate, affordable housing is a prerequisite to many basic services frequently needed by people with HIV/AIDS. The health and medical aspects of the epidemic have tended to overshadow the need for safe shelter that provides not only protection and comfort, but also a base from which to receive services, care, and support.

My staff and I are currently working with HUD and members of the AIDS housing community to identify and address several issues related to housing for persons living with HIV/AIDS. Issues we are discussing involve the reauthorization of the AIDS Housing Opportunities Act, HUD's consolidation plan, and the proposal to eliminate McKinney Act programs that serve persons living with HIV/AIDS.

I have recently met with Assistant Secretary Cuomo and conveyed to him my deep concerns about proposed funding levels for HOPWA as well as the consolidation activities relevant to HIV/AIDS housing. Next week, members of the National HIV/AIDS Housing Coalition and I will meet with Secretary Cisneros and will discuss the issues you have raised.

A national meeting bringing housing and services communities together is an excellent suggestion and one I fully support. I will ask my staff to explore this idea with appropriate persons in HUD and HRSA.

Again, thank you for writing and best wishes.

Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

Catholic Charities
ARCHDIOCESE OF SAN FRANCISCO
3180 18TH STREET, SAN FRANCISCO, CALIFORNIA 94110 FAX: (415) 863-5430 (415) 863-7443

June 9, 1994

814 Mission
San Francisco, Ca. 94103
(415) 281-1204

Tim — draft reply

Kristine Gebbie
National AIDS Policy Coordinator
750 17th St., NW, Ste 1060
Washington, D.C.

Dear Ms. Gebbie,

It was a delight to have a chance to speak with you in San Mateo last Friday. Thank you for your continued advocacy for people with HIV.

As part of an agency that is the principle supplier of housing for people with HIV in Northern California, I would like to take this opportunity to remind you of two urgent needs that we discussed at that meeting.

Recipient agencies, and those groups who are interested in applying for funds from HUD's Housing Opportunities for People with AIDS (HOPWA) program need to be convened on a national level. Meetings similar to the ones that are currently called by the Health Resources and Services Administration (HRSA) for Ryan White Title I eligible metropolitan areas (ema's) would be excellent opportunities to network and share techniques and resources. Experience has shown that such meetings have proved most cost-effective and provide much needed technical assistance. Your office could provide much needed leadership in ensuring that such meetings occur.

can we make this happen?

Secondly, it is extremely important that the HOPWA program not be merged with a consolidated McKinney program effort at this time. Such consolidation will most likely result in the loss of the unique nature the HOPWA program has in creating community input and response to the needs of people with HIV. The oversight of local planning councils in collaboration with the (HRSA) Ryan White CARE program for support services would also be lost if HOPWA were to be consolidated with other, non-HIV-specific programs.

We have worked very hard over the past ten years to create an integrated network of services that are responsive and responsible to the community of the San Francisco EMA (Marin, San Mateo, and San Francisco Counties), please help us to retain, support, and build this network.

Please feel free to contact me for ways we can be of assistance. Thank you again for your generous time last week and your continued support of our work.

Sincerely,

Bob Nelson
Manager, Direct HIV Services

cc: Congresswoman Nancy Pelosi, Senators Dianne Feinstein and Barbara Boxer

THE WHITE HOUSE

WASHINGTON

June 21, 1994

Gerri Mason Hall, Counsel
Extragovernmental Affairs
Office of Personnel Management
Washington, D.C. 20418

Dear Ms. Hall:

I am writing to you in regards to AIDSWALK Washington DC which will be held in September, 1994. As you may be aware, President and Mrs. Clinton, as well as Vice President and Mrs. Gore are serving as Honorary Co-Chairs of this annual event to benefit Washington DC and suburban Virginia and Maryland AIDS programs.

In order to avoid a conflict with the Combined Federal Campaign which will begin October 1, I would like to request approval for all federal agencies for fund raising solicitations during the month of August only. I understand that fund raising must follow the approved mechanisms set up by each Department and Agency. I would expect that the same guidelines followed for the Race For The Cure will be followed for this event.

If you have any questions regarding this request, please contact Andrew Barrer at my office at (202) 632-1090. Thank you for your assistance with this request.

Sincerely,

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

JUN 21 1994

THE WHITE HOUSE

Dear Randall —

Thank you for the copy of Trust, DDS. & Your Dentist. We need all sorts of continuing efforts to inform both public & professionals - I appreciate your contributions

Hillary Clinton

Randall P. Westman, D.D.S.
12915 Jones Maltsberger, #102
San Antonio, TX 78247

THE WHITE HOUSE

WASHINGTON

June 22, 1994

NOTE TO: DIRECTOR, NATIONAL INSTITUTES OF HEALTH
Through: Assistant Secretary for Health_____

SUBJECT: AIDS Research Issues Affecting the Hearing Impaired

FROM: National AIDS Policy Coordinator

On June 7, the Office of National AIDS Policy sponsored a meeting for the hearing impaired at the White House to discuss HIV/AIDS related issues of particular concern to this group. For your information, I have attached a press release describing the event. Several issues were raised that fall under the purview of the Office of AIDS Research (OAR). They were:

- Funding for research for mental illness, especially depressive disorders, that affect the hearing impaired was perceived to be either inadequate or non-existent.
- Increased opportunity for the HIV-infected hearing impaired to participate in clinical trials.
- Access to funding for HIV-related research by the deaf community.

We would like an opportunity to discuss these issues with the appropriate staff at OAR and/or to arrange a meeting at which OAR staff could discuss these issues with representatives from the deaf community.

Please have the appropriate person from your staff call Johanne Messore at (202) 690-5414 to discuss how you would like to respond to this community's concerns and how we might be of assistance to you in following-up on these issues.

Kristine M. Gebbie, RN, MN

Attachment

THE WHITE HOUSE

Office of National AIDS Policy

FOR IMMEDIATE RELEASE June 9, 1994

COORDINATOR GEBBIE MEETS WITH REPRESENTATIVES OF THE DEAF COMMUNITY TO COMMUNICATE ON HIV AND AIDS ISSUES

WASHINGTON, D.C. – On June 7th, National AIDS Policy Coordinator, Kristine M. Gebbie, met with approximately 15 representatives of the Deaf Community to discuss HIV issues and their profound effect on the Deaf Community. This meeting was a starting point with the Deaf Community to hear their concerns, learn from their experiences and expertise, and form a mutual commitment to work together and move forward with an agenda that will better meet the needs of their Community.

In response to today's Roosevelt Room meeting, Michael Felts, Co-founder of Deaf AIDS Action and a person living with HIV commented, "After more than ten years of struggle and frustration and no one willing to listen, finally -- I feel the door was open and there was a welcome mat. I hope this is a beginning that leads to change." Several different groups including the Department of Education, Deaf AIDS Action, Alexander Graham Bell Assoc. for the Deaf, Inc., Deaf Pride, National Coalition on the Deaf and HIV Community, National Association of the Deaf, Deaf Names Project, Gallaudet University and the National Institutes of Health participated in the meeting.

Margaret Bibum, the Deputy Director of Deaf Pride, Inc., said "We are a diverse Community and yet, we were able to come together and articulate our issues and concerns. She continued "I am positive that with all of our efforts we can begin to ensure that Deaf people are involved with the decision making process in anything related to HIV/AIDS services." Susan Karchmer of the College for Continuing Education at Gallaudet University, noted that "Coordinator Gebbie's willingness to listen and consider solutions is heartening...this is a first step -- a critical first step" she said.

Coordinator Gebbie appreciated everyone's participation and said about the meeting "I realize that there is a lot of work to do in relation to this Community and HIV. The Office of National AIDS Policy will work with the Deaf Community on areas involving; getting better statistics, ensuring representation for the Deaf Community in prevention planning, prevention curriculum, the service planning process, identifying important research questions and trying to get more printed/video materials available for the Deaf Community. I look forward to working with this Community and making a difference for Deaf people affected by HIV across our nation."

Father Brien McCarthy, the Catholic Chaplin at the Northwest Gallaudet Campus summed up the meeting by saying "there was a common consensus that our society must take in to account that many American communicate in American Sign Language (ASL), and that services have to be provided for them, keeping in mind that Deaf culture and its language is part of American culture and that Deaf people cannot be treated as second class citizens."

30-30-30

JUN 22 1994

THE WHITE HOUSE

Dear Belinda —

I'm so glad I got to meet you while I was in Little Rock — and I look forward to seeing you in Yokohama! I hope all is going well —

Best wishes —

Christine Gebbie

Ms. Belinda Johnson
2600 West Pershiang
Apt. 20
NLR, AR 72114
(501) 753-8782

JUN 22 1994

THE WHITE HOUSE

Dear Trudy —

Please share my thanks with all the folks involved in the breakfast and care-partner visits when I was in Little Rock. I very much appreciated the opportunity to learn more of your work, & the answer questions. Please let me know if I can be of assistance — Christine

Ms. Trudi James
Regional AIDS Interfaith Network
2002 South Fillmore
Box 12
Little Rock, AR 72204
(501) 664-4346

THE WHITE HOUSE

WASHINGTON

June 22, 1994

Mr. Joseph S. Barker
500 Court Square, #606
Charlottesville, Virginia 22902

Dear Mr. Barker:

Thank you for sending me copies of the replies you received from Senator Kennedy, Congressman Payne and Congressman Waxman regarding the compassionate use of marijuana. I trust by now that your original letter to me on this topic, that I forwarded to Dr. Joseph Timpone at the National Institute of Allergy and Infectious Diseases, has been answered to your satisfaction.

I am sure that the debate over this issue will continue for some time. In the meantime, I will continue to support a public health policy that has a sound scientific basis and support the use of therapeutic agents that have been shown to be safe and effective. If my staff can be of any further help to you, please contact us. I am forwarding your package to the Office of AIDS Research at the National Institutes of Health for their information.

Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

cc: Dr. Paul

FAX

TRANSMITTAL

Paul or Terry
I'm not sure
what this question
is - - -

dup • lex inc.

High Speed Digital Duplication
Full Service Copiers
Plastic & Strip Binding
Legal Briefs
Architectural Specs.
Newsletters
Sales Manuals

Phase II
Desktop Publishing
Word Processing
Database Management

104 Fifth Street N.E.
Charlottesville, VA 22902
Phone: 804/979-1296
Fax: 804/979-1311

Deliver To: Kristine Debbie - FAX # 202-632-1096

From: Joseph Barker

Date: 5-31-94

Pages: 7 (including this page)

Regarding: Compassionate F.N.D. response

Special instructions: Return FAX # 804-979-1311
for - Joseph Barker
Home ph # 804-293-9593

THE WHITE HOUSE

WASHINGTON

August 9, 1993

Mr. Joseph Barker
500 Court Square #606
Charlottesville, Virginia 22902

Dear Mr. Barker:

I was recently contacted by Representative L.F. Payne about your inquiry regarding the therapeutic use of marijuana for symptoms related to HIV. It is my understanding that the Federal program permitting marijuana use as an experimental treatment for HIV-related symptoms was discontinued last year.

The active ingredient in marijuana is available by prescription, should you and your physician find it useful in managing your symptoms. Information regarding research and the subsequent decision to discontinue permitting marijuana use can be obtained by contacting:

Dr. Joseph Timpone
Division of AIDS
National Institute of Allergy and Infectious Diseases
(301) 496-0700

As the AIDS Policy Coordinator I will advocate public health policy that has a sound scientific basis. You can be assured that I will support the use of therapeutic agents that have been shown to be safe and effective.

Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

cc: Representative L.F. Payne

CANNABIS BUYERS' CLUB
P.O. Box 2851 • Charlottesville, VA 22902
804-961-7217

TRANSCRIPT OF SONYA LIVE ON CNN AT 1:00 P.M.(E.T.) ON FEBRUARY 18, 1994

TOPIC: AND THE BAND PLAYED ON. HAVE WE FORGOTTEN AIDS?

1st QUESTION.

Joe (Barker) from Virginia

Joe - When will the Compassionate Investigational New Drug Program be reopened for marijuana?

Ms. Gebbie - I don't have a specific date, I know that that issue is being looked at, as people have raised the question about the use of marijuana, rather than the synthetic chemical that is the active ingredient. There are some studies ongoing now or some evaluations of that possibility. If you want to write my office we could try to get you some more specific information.

Sonya Friedman - Yes Ms. Gebbie, do I hear you saying that even though that this is not a santioned drug for the general population that the administration (because you really speak for Mr. Clinton in many ways) opens up the fact that this may be an exception, this is something that we are willing to look at, truly.

Ms. Gebbie - I know that there have been conversations about that, and I don't whether there is a specific timetable. That's why I was as vague as I was with the caller. I understand the question. To be one that has been asked by lots of people, inside and outside of government. It is a difficult one. I go back to an earlier time when around cancer, people did advocate the medical use of marijuana and in some states it was available. The availability of the synthetic compound replaced that, people are not satisfied with the sensations they get from that synthetic product so the question has come up again.

L. F. PAYNE
...DISTRICT, VIRGINIA
...WORTH BUILDING
..., DC 20515-4605
(202) 225-4711
FAX: (202) 225-1147
...STATE ASSISTANT
M. JOHNSON
1-800-535-4008

WAYS AND MEANS COMMITTEE
SUBCOMMITTEES:
TRADE
SELECT REVENUE MEASURES

Congress of the United States
House of Representatives
Washington, DC 20515-4605

July 9, 1993

Mr. Joseph Barker
500 Court Square, #606
Charlottesville, Virginia 22902

Dear Mr. Barker:

Thank you for your recent letter.

As you may know, President Clinton has appointed Khristine Gebbie as the National AIDS Policy Coordinator. Ms. Gebbie is responsible for coordinating all current federal programs to assist AIDS patients and combat the spread of the disease, in addition to recommending future measures. I have taken the liberty of forwarding your letter to Ms. Gebbie and will notify you as soon as I receive a response.

I am aware of the many problems you and other people with AIDS face each day as you fight this deadly disease. Last spring, I brought these problems to the attention of the President's health care task force. I urged the task force to remember these problems and address them as they craft a reform proposal. When the President presents his plan, I will be sure to recall your situation.

In the meantime, please feel free to contact me if I can be of assistance. It is my privilege to serve you in Congress.

Sincerely,

L. F. Payne

LFPJr:jl

...SHEFIELD, CASEWORK SUPERVISOR
...P.O. BUILDING
... STREET, SUITE 301
...VA 24641-1827
(804) 797-1280
...-8942

☐ MARGARET WATKINS, OFFICE MANAGER
ABBITT FEDERAL BUILDING
103 SOUTH MAIN STREET
FARMVILLE, VA 23901-1701
TELEPHONE: (804) 392-8331
FAX: (804) 392-8448

☐ GREG KELLY, DISTRICT MANAGER
P.O. BOX 2017
103 EAST WATER STREET, SUITE 302
CHARLOTTESVILLE, VA 22902-2017
TELEPHONE: (804) 295-8372
FAX: (804) 295-8059

Sept. 2, 1993

Kristine M. Gebbie
National AIDS Policy Coordinator
The White House
Washington, D.C. 20500

Dear Ms. Gebbie,

Thank you so much for responding to a letter that I had written to Representative L. F. Payne (D VA.) about the use of marijuana for people with AIDS. I have tried the prescription drug Marinol and found it to be totally unacceptable because of many negative side-effects. I returned to using marijuana and am doing very well.
Ms. Gebbie, I am 37 years old, college educated, and have been living with HIV for almost 9 years. I am a long term survivor. I am healthy and have had no opportunistic infections. PLEASE listen to those of us who are healthy and include us (me) in your discussions about how to beat this terrible disease. Study me, listen to us who have been personally fighting this disease for almost a decade. We do have valuable information that you and your staff could use. PLEASE DON'T leave us out of the process. I am available at any time to share myself, my expertise, my medical records, ANYTHING that will give us any insight in how to fight HIV. I am begging for my life, let me contribute what I know about HIV. Please take this seriously, I promise to not let you down.

Sincerely,
Joseph Barker

Joseph Barker
500 Court Square
606
Charlottesville, VA 22902
(804) 293-9593

2328 Rayburn House Office Building
Washington, DC 20515-0529
(202) 225-3976

District Office:
8436 West 3rd Street
Suite 600
Los Angeles, CA 90048-4183
(213) 651-1040

Congress of the United States
House of Representatives
Washington, DC 20515-0529

HENRY A. WAXMAN
29TH DISTRICT, CALIFORNIA

COMMITTEES:
ENERGY AND COMMERCE
CHAIRMAN, SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT
GOVERNMENT OPERATIONS

PHILIP M. SCHILIRO
ADMINISTRATIVE ASSISTANT

July 26, 1993

Mr. Joseph S. Barker
500 Court Square, #606
Charlottesville, Virginia 22902

Dear Mr. Barker:

Thank you for writing and letting me know of your support for the medical use of marijuana. I appreciate your taking the time to share your thoughts with me.

I was shocked by the arbitrary nature of the Public Health Service's recent decision to withdraw marijuana from the individual Investigative New Drug (IND) Program. As chairman of the Subcommittee on Health and the Environment, I'm concerned that people who are in the advanced stages of terminal diseases such as AIDS receive compassionate pain relief. With the election of a new Administration, I sincerely hope that HHS's decision will be reversed. I plan to hold hearings on this matter in the 103rd Congress and will keep your strong support for the medical use of marijuana in mind at that time.

Again, thanks for writing. I hope you will continue to contact me on all issues of concern.

With kind regards, I am

Sincerely,

HENRY A. WAXMAN
Member of Congress

HAW:my

EDWARD M. KENNEDY
MASSACHUSETTS

United States Senate

WASHINGTON, D.C. 20510

June 30, 1993

Mr. Joseph S. Barker
500 Court Square, Apt. 606
Charlottesville, Virginia 22902

Dear Mr. Barker:

Thank you for your letter about the therapeutic use of marijuana.

I believe that physicians should be able to prescribe the treatment they feel is most appropriate for seriously ill patients.

As you know, the Drug Enforcement Administration continues to oppose any reclassification of marijuana that would permit it to be prescribed for this purpose. The agency's position has already been the subject of extensive litigation, and I understand that further legal challenges are planned.

In my view, the decision should be based on sound medical and public health principles. It seems anomalous that morphine and cocaine can be prescribed in appropriate medical cases under current law, but that marijuana cannot. I hope that the courts, the Public Health Service, and the National Institutes of Health will continue to review the available medical evidence so that a final decision can be reached that affords seriously ill patients the opportunity to receive marijuana if their doctors conclude it is the most effective medication under the circumstances.

Again, I am grateful to you for letting me know your views on this most important subject.

Sincerely,

Edward M. Kennedy

EMK/rjs

THE WHITE HOUSE

WASHINGTON

June 22, 1994

Ms. Carol Woods
62 Rolling Road
Mars, Pennsylvania 16046

Dear Ms. Woods:

Thank you for your letter requesting consideration of your research proposal. As the purpose of my office is to coordinate HIV/AIDS policy within the Federal Government, we are unable to endorse or promote any specific product or proposal. I am forwarding your letter for further consideration to the Public Health Service agency whose mission includes your area of interest. I hope they will be able to provide you with an adequate response to your inquiry. Your letter has been forwarded to:

Dr. Joseph Jacobs
Director
Office for the Study of Alternative
Medical Practices
National Institutes of Health
Building 31, Room 3B-13
9000 Rockville Pike
Bethesda, Maryland 20892

Please contact Johanne Messore of my staff at (202) 690-5560 if we can be of any further assistance.

Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

cc: Dr. Jacobs

June 13, 1994
Johanne G. Messore
C:\WP51\FILES\Woods.kg

Carol Woods
62 Rolling Rd. 412 735-2342
Mars, PA 16046 412 776-2845
April 22, 1994

Carol Woods
Kristine M. Gebbie
Director of AIDs Policies
750 17th St. N.W.
Washington DC 20050

Paul - please draft reply

Dear Ms. Gebbie:

I understand that you are involved with the fight against AIDs, and hope you will be interested in the research I am trying to promote at this time.

Enclosed is a packet of information along with a research proposal and an article I have written, "Light Sensitivity Research Needed." The research proposal consists of 2 pages of theory, 2 pages of objectives and methods, 6 pages of explanations, 2 page survey and 1 page worksheet. There is a page listing proposal needs also.

The enclosed responses to the pilot survey show that my ideas are being taken seriously. I am hoping to get this research with the help of the funding from the Office of Research for Women's Health.

I believe that AIDs has the symptoms of a light sensitive illness and therefore AID's patients would benefit from a better understanding of light sensitivity gained from the completion of this research.

Recently CNN reported that Canadian researchers are saying that the break-down in the ozone layer allows 8 % more ultra-violet light to reach earth in the summer and 15% more in the winter.

Of importance would be the paragraphs underlined in the article, Light Sensitivity Research Needed," which lists some triggers to light sensitive diseases and the fact that the use of ultrviolet-blocking sunglasses, along with window films protecting from ultra-violet light are helpful in controlling these illnesses. Using vasoline at night in my eyes may help control my illness also. I believe it might be interesting to look at AIDs from a seasonal aspect.

Most of this information was sent to Dr. Fauci twice and I received no reply. I have long felt that there is a connection to the occurance of AIDs at the same time my disease first occured and they are both related to light sensitivity.

The article, "Bright Light, Big Therapy," in the Modern Maturity magazine February 1994, which I have included in this mailing suggests that light's effects on chemicals in the body is becoming recognized by the scientific community.

Since I believe this research survey to be a good research foundation, and there must be a multidisciplinary approach to effective light research with seasonal aspects included, I would like you to assist me in getting this research.

Currently, I am trying to find collaborators to do one research project at the University of Pittsburgh. Representative Ron Klink is going to help me. I would like you to read over this information and if you would send letters supporting this research to the following people it would be helpful.

The President of the United States
President William Clinton
The White House
Washington DC 20501

Vivian Pinn, Director ORWH
National Institutes of Health
Bldg. 1 Rm. 1
Bethesda MD 20892

Hoping to gain her support and gain funding

Honorable Ronald Klink
District Representative
Municipal Building
2700 Rochester Road
Mars, PA 16046

Congressional Representative working to get collaborators to file for a joint grant at the University of Pittsburgh.

Lewis Kuller
University of Pittsburgh
Graduate School of Medicine
Dept. of Epidemiology
130 DeSoto st.
Pgh., PA 25261

Head of the ORWH Vangard at University of Pittsburgh.

Although I deeply appreciate the efforts and expertise of Thomas A. Medsger Jr, M.D. Chief of Rheumatology and Clinical Immunology at the University of Pittsburgh with the pilot survey, he is not connected with the further research I am proposing at this time. If I cannot find collaborators in this area, I am going to need to look for them elsewhere, so I may need help finding them.

If this survey were given to AID's patients in different areas of the country, specifing elevation of the area from sea level (high being closer to sunlight rays), it might also reveal part of light's connection to AIDs, and part of it's triggering mechanism for AID's symptoms. It would be useful also to be aware of eruptions in the sun at the time these tests are given. Pittsburgh has one of the higher elevations in the country.

In my writing I speak of light's effects on weight control. I believe there is a connection to light sensitivity and nutritional needs of the body. A nutritionist will be part of the multidiscipline medical group.

Specifically we need to know exactly which light waves we are dealing with and their effect's on our chemical makeup. NASA ran tests on a recent space trip to measure the amount of light-waves reaching earth. I believe specialists in measuring light waves must be included in the multidisciplinary approach I am proposing.

Special attention to the caffeine intake also needs to be taken because it affects sleep drastically, and light sensitive people may he hypersensitive to it.

I think it would be wise to separate the survey's use in AIDs from the use of the survey I am proposing to do at the University of Pittsburgh, although I would use AID's patients in that survey also. The survey could have two uses.

Recently Representative Ron Klink, Our State Representative, interviewed me and said he would try to interest University of Pittsburgh collaboratars to work with me in submitting a joint grant proposal.

The Director or Coordinator of this research must have above average communication skills, and good understanding of statistical information. I am firm on having all data collected by all scientific disciplines in this research available to all participants. I think all medical arts researcher participants should have their names written on the research results in alphabetical order. I am open to suggestions that would promote cooperation between participants, because I feel competition for research funds and "glory," would undermine this researches' results.

In my writing I have had responses from some researchers that I would like to use as consultants.

I believe this survey used by AID's patients in different areas across the country may offer insights into cause and effects of AID's symptoms also.

I sincerely believe that blocking ultra-violet light waves can help control diseases. I feel we need to research how other light-waves affect us NOW, and I feel responsible to give this information to those who can use it to make a difference.

For AID's patients from differing areas to use this survey seems to be able to be done reasonably and inexpensively. Patients could fill the survey out while awaiting their physicians in waiting rooms. The results could be examined along with the multidisciplinary Sunlight Sensitivity Survey results by the specialists who would use them for logistic data of importance.

On April 17, 1994 CBS presented a movie called, "Children of the Dark," which showed two little girls who could die from exposure to sunlight." I was surprised at how little information the movie had about the light problem. I have been trying to get this specific research for years, and I am positive of it's value. I have many prominent researchers agreeing on the need for this research, yet no one in authority uses this information responsibly to cause awareness, get this research and fight these symptoms. Please help. Thank you for your valuable time and consideration.

Sincerely yours,

Carol Woods

Light Sensitivity Research Needed

Carol Woods, a middle aged woman living in Cranberry Twp., North of Pittsburgh, PA, has a rare sensitivity to sunlight that presented itself with an unprecedented 1:3200 Rheumatoid Arthritis Factor soon after her auto-immune symptoms began. Usually a titer of 1:160 or greater is abnormal. This factor often circulates in the blood of Rheumatoid Arthritis patients, but can occur in other diseases also. At the time, her Sedimentation Rate (amount of blood that settles in a test tube for an hour) did not go over 21 mm per hour so it remained normal.

She contracted tendinitis in her right hand in June 1977, which turned into arthritis and affected her left hand also. At this time, she experienced painful eyes because of conjunctivitis. Her menstrual periods became extremely painful and were accompanied by unbearable headaches, nausea, dizziness, cramping and a need to physically lay perfectly flat. A virus contracted in Jan. 1978 caused arthritic involvement to escalate around menstrual periods to involve first: wrists, then wrists and elbows, then wrists, elbows, shoulders, until all joints including knees and hips were involved. Extreme fatigue was also present.

Dizziness, inability to concentrate, forgetfullness, number reversal confusion, repetition, (she calls mind-functioning problems), became extreme problems especially in months from January until July. Her heartrate increased progressively after Januarys and eventually she was diagnosed as having Mitral Valve Prolapse with Premature Ventricular Contractions and there is evidence of Restrictive lung disease.

After a hospitalization in Feb. 1981, where Carol experienced double vision, she developed extreme eye pain upon looking into sunlight. Carol has at times been labeled "neurotic," or as having "emotional problems," which she rejected because of the monthly and seasonal cycles of her symptoms. She has also had basal cell carcinoma removed from her face and neck, though she is very protective about exposing herself to sunlight.

Thomas A. Medsger, Jr., M.D., Professor of Medicine, Chief, Division of Rheumatology & Clinical Immunology at Pitt University, through referrals, finally had Margaretta B. Moller, M.D., Otolaryngologist at Eye and Ear Hospital in Pittsburgh, diagnosed the extreme dizziness as inner-ear dysfunction in Feb. 1983. Thomas L. Slamovits, M.D., Ophthalmologist at Eye and Ear Hospital diagnosed kerititis sicca (meaning extremely dry eyes and one of the manifestations of Sjogren's syndrome) in Sept. 1983. Because of the extremely severe dizziness and eye problems connected with the onset of the illness and their seasonal features, Carol considers these diagnosis' significant connections in the field of auto-immune illnesses. These diagnosis' enabled Carol to understand many of her problems.

Rheumatoid Arthritis, Sjogren's syndrome, Fibromyositis, Psychoneurotic fibromialgia, and Sero-negative Lupus Erythematosus are some of the diagnosis she has had. She was a secretary at North Hills MH/MR Center until her symptoms became so severe that she could no longer work. She was granted Social Security Disability in 1986, several years later.

Over the past ten years, Carol has lived with a progressive problem of increasing sunlight sensitivity and has some interesting theories and observations about light's effects on humans.

She believes that light is beamed by spasm through the eye to a place in the brain that acts as a solar collector. This collector helps process light into energy while we sleep. An inner-ear dysfunction may cause faulty collection of this light beam so that it misses it's target in the brain and causes auto-immune responses.

Either sunlight changes seasonally and/or our body chemistry changes, resulting in differences in light sensitivity according to the season. After tendinitis came changes in her menstrual cycle, and after two gynecological operations which caused eye infections, she feels specific changes in hormonal chemistry affect light sensitivity.

The collection of sunlight affects chemicals in the brain so that faulty collection can cause dizziness, vertigo, headaches, menstrual problems, irritability, anxiety, depression, concentration difficulties, insomnia, weight problems, immune, auto-immune symptoms, etc..

The main symptoms of depression: fatigue, altered sleeping pattern, lack of appetite and concentration are related more to light sensitivity than emotion.

Emotion uses energy, and the available light allows our body to collect light energy in varying degrees in differing environments and seasons. An emotional reaction at one time could not cause chronic symptoms unless it triggered changes in the immune system. If other negative factors were present: seasonal, excessive exposure to harmful sun rays, hormonal balance, fatigue, over-work of specific body function, nutrition deficits or over-abundance, lack of sleep, (sleep is necessary to process light 's energy), emotions may HELP trigger light sensitive illness. Medications, and failure to take medications on time is an important factor also.

Light sensitive illnesses may occur without emotional stress, or with excitement of any kind acting as a trigger. Carol hopes that with understanding of these triggers, remissions from light sensitive illness' may be brought about some day.

Our body's collection of sunlight governs our nutrition needs and understanding sunlight's effects on our chemistry would lead to weight control. Light is very significant to our body's processing of food and regulation of appetite.

An altered sleep pattern is our body's way of protecting us against harmful rays from the sun and interferring with it can cause or escalate auto-immune symptoms. Her own sleep pattern has been altered so that in the winter she is awake all night and sleeps all day.

Wearing eyeglasses with lenses that block ultra-violet light is very helpful as is the use of ultra-violet blocking film or use of tinted windows in the home. Use of Duratears Ointment, especially before bedtime, not only helps control eye pain and infection; but there is a strong indication that it helps control symptoms. Complete avoidance of caffeine is also helpful.

Carol believes that it will take medical specialties working together to research light's effects on humans.

In response to an article she sent to medical institutions, Kendric C. Smith, Ph.D., Professor of Radiology, Stanford University, wrote that he believes a multidisciplinary clinic or institute just to study light responses in man is necessary also. She feels it is time to contact Senators and government representatives and have them allocate funding for this research, especially since the ozone layer is not giving us the protection from sunlight it once did.

She specifically wishes to know the components making up light that we are dealing with hourly, daily, monthly and seasonally, and how these changes affect humans. She wants to know if these affects vary when geographic origin and race are considered, along with a persons current geographical location.

In 1986, Carol wrote a survey which she believes shows that there is a consistent and predictable pattern to light sensitive illnesses when seasons and other specific symptoms are considered.

Recently Dr. Medsger sponsored part of this survey at the Falk Ambulatory Care Center's Arthritis Clinic at the University of Pittsburgh School of Medicine.

The survey requested information on a variety of ocular and other symptoms, including rapid heartbeat, skin itching, skin rash, headaches, fatigue, depression, inability to concentrate, sleep difficulties, dizziness, vertigo, eye pain, visual blurring, twitching eyelids, sneezing, mouth ulcers, joint pain and swelling, muscle pain and weakness, poor appetite, weight gain and loss, etc.

In this pilot survey's results, Dr. Medsger states, "These preliminary data suggest that patients with Sjogren's syndrome and Systemic Lupus Erythematosus have symptoms which immediately follow sunlight exposure (2.0-3.0 more frequently than normal controls). Other rheumatic disease patients also have a disproportionately increased frequency of such symptoms (1.5-2.6 times controls)."

He said, "The important conclusion is that these symptoms interfere with daily activities of the patients involved, thus creating a degree of disability. This area is a very practical one for research and it is our hope that those with interest and investigative expertise pertinent to this topic will view these survey results as rationale for a major research effort."

The preliminary data also suggests that patients with SLE and Sjogren's syndrome exhibit a connection of eye problems and ear dysfunctions more frequently than normal persons, showing where one focus of research may prove to be valuable.

The complete "Sunlight Sensitivity Survey" with additional methods and objectives in 1994, could be of benefit to other medical specialty fields, as it teaches awareness of sunlight-sensitive symptoms and may establish a consistent and predictable pattern of illness. The relationships between differing diagnosis' may help promote understanding of cause and effect's of specific types of light which can lead to better medical treatment

Carol believes that some of the diseases affected by light sensitivity are: Cancers, Depression, Schizophrenia, Insomnia, Diabetes, Chronic Fatigue syndrome, Guillian Barr Syndrome, Systemic Lupus Erythematosus, Discoid Lupus, Rheumatoid Arthritis, Sjogren's Syndrome, Schleroderma, Osteoarthritis, Other Rheumatic diseases, Anorexia Nervosa, Obesity, Crohn's Bowel Disease, Pre-menstrual syndrome, Migrain Headaches, Multiple Sclerosis, Muscular Dystrophy,and other diseases showing light sensitive symptomatology. A.I.D.'s and Alzheimer's Diseases exhibit light sensitive symptoms also.

She now needs to find collaborators willing to work with her, as a consultant only, on the complete survey at an appropriate research institution. Funding for this project may be possible through a public health service grant from the Office of Women's Research (ORWH). Vivian Pinn, Director ORWH, National Institute of Health, Bldg.1 - Room 201 Bethesda MD 20892, is in charge of promotion of women's research. Women's research, without considering sunlight's effects, cannot give an accurate, effective perspective of cause and effect's of diseases.

Carol wishes to promote awareness of sunlight sensitivity's symptoms and the need for light sensitivity research by asking organizations dealing with these illnesses to distribute this article to their members. Asking members to write senators and government representatives to focus attention on the need for this research and it's funding would be very helpful.

Interested persons may also write: Carol Woods, 62 Rolling Rd., Mars, PA 16046.

Sunlight 1 / 2 / 3 / 4 / 5 / 6 / 7 ___ 8 / 9 / 10 / 11 / 12 / 13 / 14 / 15 / 16 / 17 / 18 ___ 19 / 20 / 21 ___

Instant Symptoms 1 / 2 / 3 / 4 / 5 / 6 / 7 / 8 / 9 ___ 10 / 11 / 12 ___ 13 ___ 14 / 15 ___

W	S	S	A
/	2	3	4

Dizziness 1 / 2 / 3 / 4 / 5 ___ 6 / 7 / 8 / 9 / 10 / 11 ___ 12 / 13 / 14 / 15 / 16 ___ 17 ___ 18 ___ 19 / 20 / 21 ___

		FAIR	MOD.	SEVERE	YES	NO	W	S	S	A
				/	/		/	2	3	4
Abnormal Sleeping Pattern	1.				/		/	2	3	4
	2.				/					
	3.				/					
	4.- 5.				/					
		RIGHT	LEFT	BOTH						
Stutter						/				
Adolescent Eye				/	/					
Adult Eye				/	/		/	2	3	4
Eye Twitch			/		/		/	2	3	4
Eye Spasm						/				
Ear		/			/					
Inner-ear dysfunction		/			/					
Body Temperature		LOW	MED.	HIGH						
		/								
Menstrual Involvement		BEFORE	DURING	AFTER						
		/	/		/					
Weight		SAME	LOSS	GAIN						
				/						
	Gain				/		/	2	3	4
	Loss				/		4	3	/	2
					/		/	2	3	4

Food Craving 1 / 2 ___ 3 ___ 4 ___ 5 ___ 6 / 7 ___ 8 / 9 / 10 ___ 11 ___ 12 ___

Connecting Factors 13 ___ 14 / 15 / 16 ___ 17 ___ 18 ___ 19 / 20 ___ 21 ___ 22 ___ 23 ___ 24 / 25 ___ 26 ___ 27 ___

Rest 1 / 2 / 3 / 4 / 5 / 6 ___ 7 / 8 ___ 9 ___

	YES	NO
Rest	/	
	/	
Swollen Ears		/

Escalate Symptoms 1 / 2 / 3 / 4 / 5 ___ 6 ___ 7 / 8 / 9 ___ 10 / 11 / 12 / 13 / 14 / 15 ___

Control Symptoms 1 / 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 / 8 / 9 ___ 10 ___ 11 ___ 12 / 13 / 14 ___ 15 ___ 16 ___ 17 ___ 18 / 19 / 20 ___ 21 / 22 / 23 / 24 ___

DIAGNOSIS ___

General Population

SUNLIGHT SENSITIVITY SURVEY —

Sunlight	1		4		7		10		13		16		19						
	2		5		8		11		14		17		20						
	3		6		9		12		15		18		21						
Instant Symptoms	1		4		7		10		13										
	2		5		8		11		14										
	3		6		9		12		15						W	S	S	A	
Dizziness	1		4		7		10		13		16		19						
	2		5		8		11		14		17		20						
	3		6		9		12		15		18		21						

	FAIR	MOD.	SEVERE	YES	NO	W	S	S	A
Abnormal Sleeping Pattern 1. 2. 3. 4. 5.									
Stutter	RIGHT	LEFT	BOTH						
Adolescent Eye									
Adult Eye									
Eye Twitch									
Eye Spasm									
Ear Inner-ear dysfunction									
Body Temperature	LOW	MED.	HIGH						
Menstrual Involvement	BEFORE	DURING	AFTER						
Weight	SAME	LOSS	GAIN						
Gain / Loss									

Food Craving	1		3		5		7		9		11	
	2		4		6		8		10		12	
Connecting Factors	13		16		19		22		25			
	14		17		20		23		26			
	15		18		21		24		27			
Rest	1		4		7					YES	NO	
	2		5		8							
	3		6		9							
Swollen Ears												
Escalate Symptoms	1		4		7		10		13			
	2		5		8		11		14			
	3		6		9		12		15			
Control Symptoms	1		5		9		13		17		21	
	2		6		10		14		18		22	
	3		7		11		15		19		23	
	4		8		12		16		20		24	

DIAGNOSIS

General Population

10. Have you ever had severe ear problems as a child and/or adult? YES NO.
Which ear was involved? RIGHT LEFT BOTH.
Have you ever been told by a doctor that you have an inner-ear dysfunction? YES NO. Which ear was involved? RIGHT LEFT BOTH.

11. Classify your regular body temperature? (98.6 degrees is normal).
LOW NORMAL HIGH.

12. WOMEN, Can the onset of illness be traced to your menstrual cycle? YES NO.
Do symptoms change around your menstrual cycle? BEFORE DURING AFTER.
MEN, NOT APPLICABLE.

13. Has your weight changed notably since the onset of an illness?
REMAINED SAME LOSS GAIN.
Do you gain weight seasonally? WINTER__ SPRING__ SUMMER__ AUTUMN__.
Do you lose weight seasonally? WINTER__ SPRING__ SUMMER__ AUTUMN__.

14. Do you ever have instant, unexplainable appetite urges that are abnormal; example, one hour after finishing a large meal? YES NO.
Are the appetite urges seasonal? WINTER__ SPRING__ SUMMER__ AUTUMN__.
Do you crave (more than a normal desire) any of the following food groups?

1. nuts	5. breads	9. citrus fruits
2. fish	6. sweets	10. fruit
3. vegetables	7. red meats	11. grains, cereals
4. poultry	8. milk-cheeses	12. other

Can you connect a food craving with any of the following factors?

13. morning	18. Autumn	23. Summer
14. menstrual cycle	19. diahrea	24. altered sleeping pattern
15. Winter	20. Spring	25. Noon
16. fatigue	21. dreams	26. activated emotions
17. Evening	22. constipation	27. other

15. Do you sleep more than eight hours per day? YES NO.
Do you require frequent rest periods during the day? YES NO.
Do you become excessively tired after completing any of the following?

1. eating a meal	4. reading	7. having a bowel movement
2. slight exertion	5. carrying objects	8. riding in a car after dark
3. walking up stairs	6. watching television	9. other

16. Do your ears turn red and swell? YES NO.

17. Which factors cause or escalate symptoms of illness?

1. menstrual cycle	6. foods	11. lack of sleep
2. sunlight	7. Spring	12. not taking medicine on time
3. Winter	8. over-work	13. using ultraviolet light
4. cafeine	9. Autumn	14. activated emotions
5. Summer	10. fatigue	15. other

18. What factors help you control your illness?

1. sleep	9. cold showers	17. physical therapy
2. sunlight	10. proper diet	18. protective sunglasses
3. exercise	11. gold treatments	19. emotional support
4. Spring	12. body temperature	20. air-conditioning
5. weather	13. Summer	21. ultraviolet blocking eyeglass
6. vitamins	14. hormone pills	22. awareness-menstrual cycle dat
7. medication	15. sun bathing	23. avoidance of sunlight
8. Autumn	16. humidity	24. other

19. If you have a health problem, please give a brief diagnosis.

20. If you do not have an illness, please underline GENERAL POPULATION.

SUNLIGHT SENSITIVITY SURVEY

PLEASE UNDERLINE CORRECT ANSWERS

Classify Seasons by severest symptoms first - #1,2,3,4.

1. When you are exposed to sunlight, do you often experience any of the following symptoms?

1. cold sores	8. dizziness	15. rapid heartbeat
2. headaches	9. painful eyes	16. shortness of breath
3. itching	10. rashes	17. aching muscles
4. fatigue	11. diahrea	18. loss of voice
5. constipation	12. joint pain	19. ulcers in mouth, throat
6. sneezing	13. sun-poisoning	20. nausea
7. alertness	14. leg weakness	21. other

2. Do you ever experience instant, unexplainable and uncontrollable symptoms of

1. exhaustion	5. nausea	9. sneezing	13. loss of voice
2. dizziness	6. diahrea	10. double vision	14. inability to concentrate
3. hunger	7. weakness	11. breathlessness	15. other
4. headaches	8. chills	12. swollen ears	

Are instant symptoms seasonal? WINTER__ SPRING__ SUMMER__ AUTUMN__.

3. Do you ever experience symptoms of dizziness and/or mental dullness that are not connected with medication or alcoholic beverages? YES NO.
Do any of the following symptoms of dizziness and/or mental dullness apply to you?

1. headaches	8. visual problems	15. inability to concentrate
2. nausea	9. weakness in legs	16. buzzing, ringing in ears
3. double vision	10. need to lay flat	17. end subjects abruptly, if speaking
4. breathlessness	11. swollen ears	18. repeat already answered questions
5. earache	12. loss of balance	19. confuse numbers, recall 987 as 789
6. vomiting	13. spinning sensation	20. close eyes to aid memory
7. irritability	14. alertness, (night)	21. other

Would you classify the dizziness and/or mental dullness problems as?
FAIR MODERATE SEVERE.
Is the dizziness seasonal? WINTER__ SPRING__ SUMMER__ AUTUMN__.

4. Do you have an abnormal sleeping pattern? YES NO.
Is added waking time after 11 P.M.? YES NO.
Is added sleeping time after 8 A.M.? YES NO.
Which season is it most prevelant in? WINTER__ SPRING__ SUMMER__ AUTUMN__.
Does interfering with any sleep pattern cause or excellerate symptoms of an illness? YES NO.

5. Do you stutter? YES NO.
Is the stuttering seasonal? WINTER__ SPRING__ SUMMER__ AUTUMN__.

6. Did you have eye problems as a child ages 7 yrs. through 12 yrs.? YES NO.
Which eye was involved? RIGHT LEFT BOTH.

7. Do you have eye pain or eye problems as an adult? YES NO.
Which eye is involved? RIGHT LEFT BOTH.
Is your eye problem seasonal? WINTER__ SPRING__ SUMMER__ AUTUMN__.

8. Do your eyes ever twitch uncontrollably? YES NO.
Which eye is involved? RIGHT LEFT BOTH.
Is the twitching problem seasonal? WINTER__ SPRING__ SUMMER__ AUTUMN__.

9. Has a doctor ever told you that you have eye spasms? YES NO.

18. Which factors help you control your illness?

1. sleep	9. cold showers	17. physical therapy
2. sunlight	10. proper diet	18. protective sunglasses
3. exercise	11. gold treatments	19. emotional support
4. Spring	12. body temperature	20. air-conditioning
5. weather	13. Summer	21. ultraviolet blocking eyeglasses
6. vitamins	14. hormone pills	22. awareness-menstrual cycle dates
7. medication	15. sun bathing	23. avoidance of sunlight
8. Autumn	16. humidity	24. other

E. Factors controlling illness fit over-all pattern - seasonal, sleep related, related to menstrual cycle, ultraviolet blocking glasses help, avoidance of sunlight, etc.

19. If you have a health problem. please give a brief diagnosis?

E. People with specific diagnosis should exhibit many more light-sensitive symptoms on this survey than are found in the general population. A pattern of illness should be recognized on the survey work sheet as all answers are viewed on one page. The answers should be put on a general survey work sheet to determine the differences between all the people surveyed with a specific diagnosis and those of the general population.

20. If you do not have an illness, please underline in this area as GENERAL POPULATION.

E. This question recognizes the answers to the survey given by the general population.

COMMENTS

I believe that people with Lupus will exhibit symptoms in the survey to a much greater degree than people of the general population, and that these symptoms are connected by a somewhat consistent and predictable pattern.

The substance connecting all of the factors involved is light energy and its effect on chemicals regulating our body's make-up. The effects are many and various and they leave a great deal of respect for their solar source. I hope that this survey will help bring about the research into light sensitivity that I feel is so desperately needed at this time.

It is possible that my light sensitivity is toward a specific type of light energy and that some people may have a sensitivity toward different forms of the light energy coming at us in sunlight. Perhaps we can learn about other patterns caused by sensitivity to these other light forms if the seasonal information shows this.

There is a work sheet with my specific symptoms marked. I believe it shows that the symptoms are connected by a consistent and predictable pattern.

Along with this survey is a THEORY presented about sunlight sensitivity which is necessary for the understanding of the survey.

relate could do much to promote weight control.

14. Do you ever have instant, unexplainable appetite urges that are abnormal; example, one hour after finishing a large meal? YES NO.

Are the appetite urges seasonal? WINTER__ SPRING__ SUMMER__ AUTUMN__.

Do you crave (more than a normal desire) any of the following food groups?

1. nuts
2. fish
3. vegetables
4. poultry
5. breads
6. sweets
7. red meats
8. milk-cheeses
9. citrus fruits
10. fruit
11. grains, cereals
12. other

Can you connect a food craving with any of the following factors?

13. morning
14. menstrual cycle
15. Winter
16. fatigue
17. Evening
18. Autumn
19. diahrea
20. Spring
21. dreams
22. constipation
23. Summer
24. altered sleeping pattern
25. Noon
26. activated emotions
27. other

E. Abnormal appetite or aversion to food is light related. Solar collector battery theory could explain. Abnormal desire for food may result from specific nutritional needs and may help us learn how the body processes food. Explanation of survey question 13, is related.

15. Do you sleep more than eight hours per day? YES NO.
Do you require frequent rest periods during the day? YES NO.
Do you become excessively tired after completing any of the following?

1. eating a meal
2. slight exertion
3. walking up stairs
4. reading
5. carrying objects
6. watching television
7. having a bowel movement
8. riding in a car after dark
9. other

Faulty light collection causes fatigue. The body must sleep more to process light collection. The solar collector battery gets run down when exerting the slightest amount of energy. I believe the solar collector battery is our body's main energy source, and we need sunlight and sleep as well as food and water to survive.

16. Do your ears turn red and swell? YES NO.

E. Bogus question.

17. Which factors cause or escalate symptoms of illness?

1. menstrual cycle
2. sunlight
3. Winter
4. cafeine
5. Summer
6. foods
7. Spring
8. over-work
9. Autumn
10. fatigue
11. lack of sleep
12. not taking medicine on time
13. using ultraviolet lighting
14. activated emotions
15. other

E. Factors causing illness fit over-all pattern - seasonal, sleep related, related to menstrual cycle, fatigue, sunlight, etc.

9E. Eyes would focus inward to read, but not release to focus outwardly to look at school blackboard. Her doctor said eye spasms are common in over-achievers. A change in sunlight's pathway to the brain could be involved.

10. Have you ever had severe ear problems as a child and/or adult? YES NO.
Which ear was involved? RIGHT LEFT BOTH.
Have you ever been told by a doctor that you have an inner-ear dysfunction? YES NO.
Which ear was involved? RIGHT LEFT BOTH.

E. Inner-ear damage could explain dysfunction of eye spasm collection somehow. My right ear was either injured as a pre-school age child or 15 years ago. I developed severe dizziness and eye pain after the tendinitis in my right hand 8 yrs. ago. Apparently the immune response was activated by a combination of fatigue, active menstrual hormones, June sunlight, excessive strain on the hand pulling weeds while eye coordination of this function was taking place. A sensitivity to sunlight which activates dizziness and eye problems and causes a progressive type illness resulted. Problems progressed around menstrual cycles. A Rheumatoid Arthritis Factor was activated. Check for problems in opposite eye of inner-ear dysfunction. Could specific eyes or ears or eye and ear groups show any consistent symptoms?

If the survey shows light sensitivity by symptoms having positive responses elsewhere in the survey, perhaps the person should be tested for an inner-ear dysfunction?

11. Classify your regular body temperature? (98.6 degrees is normal).
LOW NORMAL HIGH.

E. My body temperature is low. It gets much lower when laying down flat. Seasonal chills occur when laying flat. This seems to relate to the inner-ear dysfunction in some manner.

12. WOMEN, Can the onset of illness be traced to your menstrual cycle? YES NO.
Do symptoms change around your menstrual cycle? BEFORE DURING AFTER.
NOT APPLICABLE

E. Check questions 17-1 escalate symptoms of illness, check 18-22 control illness by awareness of menstrual cycles. Seasons menstrual cycles occur in should be considered. 17-2, 17-3, 17-5, 17-7, 17-9, are connected as are appetite urges and connections with cravings. There is an over-all pattern showing heightened sensitivity to light at menstrual cycles, I believe.

13. Has your weight changed notably since the onset of an illness?
REMAINED SAME LOSS GAIN.
Do you gain weight seasonally? WINTER__ SPRING__ SUMMER__ AUTUMN__.
Do you lose weight seasonally? WINTER__ SPRING__ SUMMER__ AUTUMN__.

E. Light affects my colon and the way my body processes food. Winter weight gain could relate to altered sleep pattern, hunger and alertness after dark with less of an appetite during daylight hours.

The body may have problems taking in light energy with food, or it's processing of light energy and food at the same time may be difficult, especially in the winter. This could explain extreme hunger after dark and abnormal appetite at times with aversion to food at other times. I believe that the body utilizes nutrients differently in conjunction with sunlight collection and knowledge of how the light and nutrients

4E. Sleep is the single most important factor in controlling my illness. I require longer periods of time sleeping. Extremely severe symptoms are caused by interfering with the altered sleeping pattern. The need for sleep when exposed to sunlight regulates symptoms to some degree. With six hours of sleep, one could type for 30 minutes with few mistakes, before fatigue sets in. With 10 hours of sleep, one could type 60 minutes before fatigue becomes a problem. With adequate sleep, sunlight can be tollerated for a little longer, before symptoms occur. The body is like a rechargeable battery and needs sleep to restore it's proper current. Exposure to sunlight and the need to distribute and store energy throughout the body regulates sleep needs and wakefullness.

Sleep cures muscular aches and pains, especially those of weight bearing joints when they are occasionally used excessively. Perhaps a certain amount of current is alloted for daily functioning and abnormal usage of muscles, joints, causes malfunctions.

5. Do you stutter? YES NO.
Is the stuttering seasonal? WINTER__ SPRING__ SUMMER__ AUTUMN__.

E. Bogus question.

6. Did you have eye problems as a child ages 7 yrs. through 12 yrs.?
YES NO.

Which eye was involved? RIGHT LEFT BOTH.

E. The rapid growth period of children may institute hormonal changes as well as the path through which the eyes receive sunlight. This may affect puberty and menstrual cycles.

Are people who show light sensitivity at this age more sensitive or prone to immune type illnesses?

Right or left eye involved may prove significant in establishing link with inner-ear dysfunction and type or area of symptoms caused.

My daughter had eye spasms ages 9 yrs. to 12 yrs.. I could not tollerate sunlight at age 9. My sister had rheumatic fever and triple vision at age 9.

7. Do you have eye pain or eye problems as an adult? YES NO.
Which eye is involved? RIGHT LEFT BOTH.
Is your eye problem seasonal? WINTER__ SPRING__ SUMMER__ AUTUMN__.

E. Establish adult eye problems, eyes involved, seasonal complaints. Is there a connection with inner-ear dysfunction.

8. Do your eyes ever twitch uncontrollably? YES NO.
Which eye is involved? RIGHT LEFT BOTH.
Is the twitching problem seasonal? WINTER__ SPRING__ SUMMER__ AUTUMN__.

E. Check eye twitch for inner-ear dysfunction of opposite ear. Is eye twitch seasonal?

9. Has a doctor ever told you that you have eye spasms? YES NO.

E. Ciliary eye spasms are recently discovered. Not likely many people would know about them. This question would cause awareness. My daughter had them age 9 through 12 yrs.. There is a focusing mechanism dysfunction.

2. Do you ever experience instant, unexplainable and uncontrollable symptoms of?

1. exhaustion	5. nausea	9. sneezing	13. loss of voice
2. dizziness	6. diahrea	10. double vision	14. inability to concentrate
3. hunger	7. weakness	11. breathlessness	15. other
4. headaches	8. chills	12. swollen ears	

Would you classify these symptoms as seasonal? WINTER_ SPRING_ SUMMER_ AUTUMN_.

E. Instant symptoms could be explained by malfunction of the timer mechanism of the solar collector battery. Is this problem frequent with specific diagnosis'? Is it seasonal?

3. Do you ever experience symptoms of dizziness and/or mental dullness that are not connected with medication or alcoholic beverages? YES NO.
Do any of the following symptoms of dizziness and/or mental dullness apply?

1. headaches	8. visual problems	15. inability to concentrate
2. nausea	9. weakness in legs	16. buzzing, ringing in ears
3. double vision	10. need to lay flat	17. end subjects abruptly, if speaking
4. breathlessness	11. swollen ears	18. repeat already answered questions
5. earache	12. loss of balance	19. confuse numbers, recall 987 as 789
6. vomiting	13. spinning sensation	20. close eyes to aid memory
7. irritability	14. alertness (night)	21. other

Would you classify the dizziness and/or mental dullness problems as?
FAIR MODERATE SEVERE.

Is the dizziness seasonal? WINTER__ SPRING__ SUMMER__ AUTUMN__.

E. Faulty light collection causes dizziness and mental dullness symptoms. How many and how severe are symptoms common to specific diagnosis? Do the symptoms show a seasonal tendency? Are the symptoms connected to inner-ear dysfunction and/or eye problems? How do the dizziness symptoms connect with other symptoms of the survey and how do they relate to each other?

4. Do you have an abnormal sleeping pattern? YES NO.
Is added waking time after 11 P.M.? YES NO.
Is added sleeping time after 8 A.M.? YES NO.
Which season is it most prevelant in? WINTER__ SPRING__ SUMMER__ AUTUMN__.
Does interfering with any sleep pattern cause or excellerate symptoms of an illness? YES NO.

E. Altered sleeping pattern is caused by sunlight sensitivity. I believe the body reacts to light by causing late-night alertness and keeping us asleep during daylight hours, away from harmful affects in sunlight. Possibly, morning sunlight contains more harmful light components of light energy or it sets or regulates the timer mechanism. I believe morning sunlight exposure has some control over bowel movements. An odd feature is that use of more energy in an active day causes extreme late-night alertness when you would expect to be overly tired, especially if you have been exposed to more daylight than usual.

In the altered sleeping-pattern, (definitely more pronounced from January until June), appetite is less during daylight period, with extreme appetite in late night. There is a tendency toward constipation and the body holds weight. Fatigue, lack of sleep during altered sleeping pattern, or morning light can cause colon spasms which can be instant symptoms that occur in the evening.

EXPLANATIONS SUNLIGHT SENSITIVITY SURVEY

Does a certain group of people often experience these symptoms, and not the General Population?
(Lupus, Rheumatoid Arthritis, Alzheimers, A.I.D.S. patients).

When symptoms on this survey are connected, do they form a consistent pattern?

Are seasonal changes in sunlight evident as factors causing symptoms? Possibly body changes in chemistry allow sunlight to affect us differently seasonally.

Could this pattern of symptoms be explained by eye spasms and/or a Solar Collector Battery theory with malfunctioning automatic timer mechanism?

EXPLANATION of Questions

WINTER, SPRING SUMMER, AUTUMN may establish a change in components making up light energy that is directed at us from the sun. It is possible that our body chemistry changes seasonally allowing light to affect us differently.

Duratears ointment, not liquid tears, are very helpful in controlling some seasonal symptoms. Eye glasses blocking ultraviolet light help control symptoms and colon problems.

Right eye, left eye, right ear, left ear, both. The specific eye involved may prove significant in establishing a link with the specific inner-ear dysfunction and type or area of symptoms caused. Example: right inner-ear dysfunction, left eye twitch especially active from January until June, presenting problem tendinitis right hand.

PLEASE UNDERLINE CORRECT ANSWERS
Please classify seasons by severest symptoms first #1,2,3,4.

1. When you are exposed to sunlight, do you often experience any of the following symptoms?

1. cold sores	8. dizziness	15. rapid heartbeat
2. headaches	9. painful eyes	16. shortness of breath
3. itching	10. rashes	17. aching muscles
4. fatigue	11. diahrea	18. loss of voice
5. constipation	12. joint pain	19. ulcers in mouth, throat
6. sneezing	13. sun-poisoning	20. nausea
7. alertness	14. leg weakness	21. other

E. Establish body's basic reaction to sunlight. Direct sunlight causes skin rash problems. Indirect skin problems, not related to direct sunlight include sores near body openings such as cold sores, vaginal sores, eye, nose, ear sores. Solar collector battery timer dysfunction could explain most other symptoms. It's malfunction can cause inner dryness, excessive liquid build-ups, blockages, muscles or nerve spasms, abnormal heartbeats are a few. Eye spasms misdirected by inner-ear dysfunction may cause headache, nausea, dizziness. The body's major reaction to sunlight sensitivity are the symptoms of fatigue and altered sleeping pattern.

People with specific diagnosis' may exhibit many of these symptoms, while the general population would exhibit few of these symptoms.

An inner-ear dysfunction can cause light to be focused incorrectly into the brain, missing it's solar collector battery target and causing symptoms of an illness and immune responses.

Dizziness and mental dullness symptoms demonstrate sensitivity to sunlight, especially when connected with other symptoms on this survey. These symptoms present a MAJOR, DISABLING problem that is seasonal to some degree and is connected strongly with sunlight itself.

A lower than normal body temperature and chills seem to affect the body when it is laying in a flat position. This may indicate that the inner-ear is connected with body temperature maintenance.

Abnormal appetite or aversion to food is light related. Seasons affect the way the body processes food. The body may have problems taking in light energy and food at the same time and processing it. This could explain extreme hunger after dark with aversion to food during daylight especially in the winter and spring. The body holds weight in the winter and spring and there is a tendency toward constipation which is related to how food is processed. The colon is very involved in the food processing also. I believe that the body utilizes food nutrients differently in conjunction with sunlight collection, and knowledge of how the light and nutrients relate could do much to promote weight control.

Nuts are a craving common on winter evenings for me. Milk and orange juice are desired before and during menstrual periods. Specific nutrients may be necessary according to the cycle of light taking place in the body considering season, time of day, menstrual cycle, sexual drives active, temperature, humidity, activated emotions, over-all energy level, etc.

The solar collector battery theory explains most of these symptoms as they are not caused by direct sunlight unless it is received through the eyes. People with specific diagnosis' such as Lupus, Rheumatoid Arthritis, Alzheimer's Disease, and A.I.D.S. may exhibit many of these symptoms, while the general population would exhibit few.

Duratears ointment, not liquid tears, are very helpful in controlling some seasonal symptoms. Eye glasses blocking ultraviolet light help control symptoms and colon problems.

There is a six page EXPLANATION that is included with the survey and worksheet for recording purposes. It states the goals that may be accomplished through the survey.

SUNLIGHT SENSITIVITY SURVEY THEORY

Our brain incorporates a rechargeable solar battery with a computerized control center. Sunlight, perhaps by eye spasms, is directed to a target in the brain that acts as a solar collector battery.

Either sunlight changes seasonally or our body chemistry changes resulting in differences in light sensitivity according to the season. Specific light of a specific amount activates hormones, or hormones may allow reception of light of a specific nature, to enter the brain and pass to the solar collector battery. Seasonal escalation of illness in winter and spring seem to be caused by changes in light sensitivity, or light itself, and menstrual involvement reflects additional sensitivity. A female, therefore, is more sensitive to light before and during her menstrual period.

At ages nine to twelve years, when children experience a rapid growth period, their eye receptor of light is changed somewhat and hormones are activated. Adolesent eye problems may demonstrate a change in reception of light to a solar collector target. Eye sensitivity at this age may show an inclination to develop immune type illness in later years. Adult eye problems may relate to light sensitivity and have significance when connected with inner-ear dysfunction, explaining type or area of symptoms caused.

If the brain's solar collector battery is sensitized to sunlight or receiving inadequate or an over-abundance of light of a specific type, it throws off the body's and brain's normal functioning.

Sleep processes and/or distributes solar energy from the solar collector battery which has a timer mechanism that regulates many bodily functions involving sleep requirements, energy levels, nutritional needs, appetite and weight control, digestion, bowel movements, etc.

A dysfunction of the timer, resulting from faulty light ene collection can cause many symptoms. Some are inner-dryness, excessive liquid build-ups, blockages, muscle or nerve spasms, abnormal heart-beats, etc. (Possibly Sudden Infant Death Syndrome).

Instant symptoms, which are uncontrollable and unexpected can be explained by timer dysfunction. A few are instant exhaustion, instant hunger, instant breathlessness, instant chills, instant diahrea, instant nausea, etc.

The body adapts to faulty sunlight collection by causing late-night alertness and keeping us asleep during daylight hours, away from harmful components in sunlight. Possibly, morning sunlight contains more harmful light components or it sets or regulates the timer mechanism.

This altered sleeping pattern, (definitely more pronounced from January until June), is an important factor in controlling illness. Severe symptoms are caused when the altered sleep pattern is interfered with. Exposure to sunlight and the need to distribute and store energy throughout the body regulates sleep needs and wakefulness. The body is like a rechargeable battery and needs sleep to restore it's proper current.

OBJECTIVE II SUNLIGHT SENSITIVITY SURVEY

Are the combined connections of eye and ear dysfunction evident in light sensitive respondents to a larger degree than in the general population?

If the eye and ear connection is found, could a detailed medical history be checked to see if a seasonal pattern exists? (Documented medical records if possible.)

If these participants have additional testing and it is compared with a control group, can we gain useful information about light's effects on people and ways to control it?

If respondents to the questionnaire were tested before and after exposure to different types of light, at differing angles, would they demonstrate more severe symptoms than a control group?

Are the diagnosis of inner-ear dysfunction and nystagmus and/or eye palsies common among light sensitive participants?

What changes in testing would occur if these participants were tested after looking into sunlight, Jan., April, July and Oct. for 1 hour?

METHOD

Attention would be given to respondents to the survey concerning eye and ear connections. This would include ALL diagnostic groups taking the survey.

They would have additional information taken in the form of a medical history, from medical records if possible, to see if a documented seasonal pattern exists?

Additional testing would be given respondents before and after exposure to different types of light beamed from several different angles to determine cause and effect.

nystagmus and/or eye palsies
inner-ear dysfunction
mind-functioning symptoms listed on the survey
sleep studies
hand-eye coordination tests
heart-rate tests
today's technology brain-wave, ear balance tests
melatonin levels

Some of these tests could be repeated after the participant gazed into normal sunlight for 1 hour in Jan., April, July, and Oct. to see if changes occur. This may give some idea if body chemistry changes, seasonally, or if the light itself changes. Time of day would also need consideration and be registered along with the dates for this testing.

A test for nystagmus and/or eye palsies and one for inner-ear dysfunction would be given to participants to establish if they are common symptoms. These tests would be considered important and given if at all possible, even if the participant would not wish further testing.

over

OBJECTIVES I Sunlight Sensitivity Survey

Does a certain group of people often experience these light sensitive symptoms and not the general population?

Cancers, Depression, Schizophrenia, Insomnia, Diabetes, Chronic Fatigue syndrome, Systemic Lupus Erythematosus, Rheumatoid Arthritis, Sjogren's syndrome, Schleroderma, Osteoarthritis, Discoid Lupus, Other Rheumatic diseases, Anorexia Nervosa, Obesity, Pre Menstrual syndrome, Migrain Headaches, Crohn's Disease, Ulcerative Crohn's Disease, Ulcerative Colitis, Inflammatory Bowel Disease, Insomnia, Multiple Sclerosis, Muscular Dystrophy,

A.I.D.'s and Alzheimer's Disease exhibit light sensitive symptoms also.

When symptoms on this survey are connected, do they form a consistent and predictable pattern?

Are seasonal changes in sunlight evident as factors causing symptoms?

Could this pattern of symptoms be explained by eye spasms and/or a solar collector battery theory with malfunctioning automatic timer mechanism?

If the questionnaires of all of these light sensitive illnesses were compared, could we draw conclusions regarding causes and effects of light which could lead to effective treatment? Medical specialty fields would be working together, using state-of-the-art information, to explore necessary inter-actions of light sensitvity's symptoms.

Can extreme sensitivity to sunlight be disabling?

METHOD

An agreed upon questionnaire will be given to ( ) patients having diagnosis listed above which exhibit the over-all light sensitive pattern and ( ) who do not have any of the diagnosis listed.
The questionnaire will be given by professional personnel until such time as there are ( ) completed questionnaires in each of the diagnostic categories.

By classifying similarities and differences of these diseases according to symptoms and seasons shown on the questionnaire, conclusions can be drawn about the mechanic causes and effects of these diseases that may help control them. The explanations of the survey may be of some use in accomplishing this.

Meetings of all representatives of medical groups involved would be needed to coordinate and standardise the survey, set it's agenda and review and analyze it's data and draw conclusions.

If many light sensitive symptoms are frequently active as shown by the questionnaire, a degree of disability would be shown to exist.

over

RESEARCH PROPOSAL SUNLIGHT SENSITIVITY SURVEY

As the writer and owner of the survey's copyright I propose:

to be a paid consultant of it's use in all medical fields.

to be reimbursed for all necessary travel expenses, phone calls, made in connection with this survey from my home, copy, postage and office expenses including secretarial or office work when it is required, and any other reasonable expenses connected with the survey.

to have a copy of all physician's opinions and conclusions drawn from the survey.

to have copies of, or access to all survey questionnaires for my own use and convenience.

to be free to have data gained from the survey analyzed by others and draw my own conclusions from the data.

to be free to diseminate or publish this information at my own discretion (newspaper articles, etc.) without prior approval.

my name to be used as author of this survey and my contributions to it will be quoted when appropriate.

This proposal would be entered into if an agreed upon questionnaire is printed for the purposes stated in the objectives. I maintain final approval of the questionnaire.

I require a signed statement from the survey's sponsors stating the rights listed above. This is to assure that I will receive the figures and tabulations at the completion of the survey, and copies of any conclusions drawn by physicians connected with the survey. As a consultant, I feel that my conclusions should also accompany the completed survey, and the survey will be copyrighted in my name for any use other than by the sponsors the agreement is signed with.

I agree to these terms of Sponsorship for the Sunlight Sensivity Survey.

Sponsor_____Medical Field_____

Copyright Signature_____

Date_____

Witness_____

Witness_____

THE COLLABORATOR OF THIS SURVEY WOULD HAVE THE SAME RIGHTS LISTED ON THIS AGREEMENT - ANY PART OF IT IS NEGOTIABLE BEFORE SIGNING.

	Sjogren's (n=10)	SLE (n=20)	RA (n=20)	SSc (n=22)	Other Rheum Dis (n=15)	OA (n=20)	Controls (n=30)
(36)	1		2	1		1	
(37)		3	1		1		
(38)	1	3		1			
(39)	1	1	1		1	1	
(40)	1	1					
TOTAL	59	124	46	42	25	41	21
Proportion of patients answering frequently or almost always	7/10=70	11/20=55	6/20=30	9/22=41	10/15=67	9/20=45	8/30=27
No of positive responses per patient responding positive	59/7=8.4	124/11=11.3	46/6=7.7	42/9=4.7	25/10=2.5	41/9=4.6	21/8=2.6
Proportion of positive numbers	5.88	6.22	2.31	1.93	1.68	2.07	0.7

(D) Eye Problems. After sunlight exposure, do you experience any of the following?

		Never	Rarely	Occasionally	Frequently	Almost Always
(21)	eye pain	____	____	____	____	____
(22)	double vision	____	____	____	____	____
(23)	visual blurring/ loss	____	____	____	____	____
(24)	twitching of eyelids	____	____	____	____	____

(E) Nasal/Oral Problems. After sunlight exposure, do you experience any of the following?

(25)	sneezing	____	____	____	____	____
(26)	cold sores	____	____	____	____	____
(27)	ulcers in mouth/ throat	____	____	____	____	____
(28)	speech disturbance (repeating, garbled, stuttering)	____	____	____	____	____
(29)	loss of voice/ hoarseness	____	____	____	____	____

(F) Muscle/Joint Problems. After sunlight exposure, do you experience any of the following?

(30)	joint pain	____	____	____	____	____
(31)	joint swelling	____	____	____	____	____
(32)	muscle pain	____	____	____	____	____
(33)	muscle weakness	____	____	____	____	____

(G) Eating (Intestinal Problems). After sunlight exposure, do you experience any of the following?

(34)	excessive hunger	____	____	____	____	____
(35)	poor appetite	____	____	____	____	____
(36)	excessive weight gain	____	____	____	____	____
(37)	excessive weight loss	____	____	____	____	____
(38)	nausea/vomiting	____	____	____	____	____
(39)	constipation	____	____	____	____	____
(40)	diarrhea	____	____	____	____	____

Please circle the diagnosis which best applies to you.

Sjogren's Syndrome Lupus Rheumatoid Arthritis Osteoarthritis Another Type of Arthritis (specify type) _____

Accompanying Patient

Friend

Family Member

Thank you for your assistance.

March, 1988

SUNLIGHT SENSITIVITY SURVEY

This survey is being conducted by the Falk Arthritis Clinic to determine some of the effects of sunlight on persons suffering from certain types of arthritis and those who do not have arthritis. Your response will be kept anonymous.

When you are exposed to sunlight, do you experience any symptoms afterwards? Please think about this question each time you answer the questions below.

A) General Problems. After sunlight exposure, do you experience any of the following?

	Never	Rarely	Occasionally	Frequently	Almost Always
(1) fever/chills	____	____	____	____	____
(2) shortness of breath	____	____	____	____	____
(3) rapid heartbeat	____	____	____	____	____
(4) menstrual irregularity	____	____	____	____	____
(5) skin itching	____	____	____	____	____
(6) skin rash	____	____	____	____	____

B) Head/Mental/Sleep Problems. After sunlight exposure, do you experience any of the following?

(7) headaches	____	____	____	____	____
(8) fatigue/exhaustion	____	____	____	____	____
(9) irritability	____	____	____	____	____
(10) anxiety	____	____	____	____	____
(11) depression	____	____	____	____	____
(12) inability to concentrate/ mental dullness	____	____	____	____	____
(13) number confusion/ reversal	____	____	____	____	____
(14) difficulty falling asleep at night (insomnia)	____	____	____	____	____
(15) sleeping excessively long in morning	____	____	____	____	____

C) Ear Problems. After sunlight exposure, do you experience any of the following?

(16) earache	____	____	____	____	____
(17) loss of hearing	____	____	____	____	____
(18) dizziness	____	____	____	____	____
(19) ringing/buzzing in ears	____	____	____	____	____
(20) vertigo (sense of spinning or your environment spinning)/loss of balance	____	____	____	____	____

Discussion

These preliminary data suggest that patients with Sjogren's syndrome and SLE have symptoms which immediately follow sunlight exposure (2.0 - 3.0 more frequently than normal controls). Other rheumatic disease patients also have a disproportionately increased frequency for such symptoms (1.5 - 2.6 times controls).

A number of variables which we did not evaluate should be noted. We did not control for the use of non-steroidal antiflammatory or antimalarial drugs, which were frequently used by these patients. We did not attempt to determine if Sjogren's syndrome alone accounted for these findings, which is possible considering that secondary Sjogren's is frequent in patients with SLE, RA and scleroderma.

The important conclusion is that these symptoms interfere with the daily activities of the patients involved, thus creating a degree of disability. We hope that further understanding of these symptoms and attempts to address their cause and treatment will be the subject of research by health professionals with knowledge and interest in this area.

Thomas A. Medsger Jr.

Thomas A. Medsger, Jr., M.D.
Professor of Medicine and Chief,
Division of Rheumatology &
Clinical Immunology

January 23, 1989

UNIVERSITY OF PITTSBURGH ARTHRITIS CLINIC
SUNLIGHT SENSITIVITY SURVEY

Introduction

Carol Woods, a patient with Sjogren's syndrome, called my attention to her own extreme sensitivity to the effects of sunlight. After exposure to sunlight, she experienced a number of symptoms which she felt were causally related. In an attempt to assist her in understanding whether such symptoms were unique or universal, we modified a survey which she had designed and conducted.

Methods

An instrument was designed based on the patient's own perceptions. The resulting 2-page questionnaire was used in a survey in the Falk Ambulatory Care Center's Arthritis Clinic at the University of Pittsburgh School of Medicine between July and October, 1988. One hundred seven consecutive patients and 30 normal persons (usually friends or first degree relatives) accompanying patients at the time of their clinic visit were asked to complete a 40-item questionnaire (attached). A registered nurse explained the questionnaire and the appropriate responses to each person who agreed to complete it. The questionnaire requested one answer for each of 40 questions as follows: "never"; "occasionally"; "frequently"; or "almost always".

Results

We separated patients according to their primary rheumatic disease diagnosis. Included were 10 patients with primary Sjogren's syndrome, 20 with systemic lupus erythematosus, 20 with rheumatoid arthritis, 22 with systemic sclerosis (scleroderma), 20 with osteoarthritis, and 15 with other rheumatic diseases. Thirty controls without rheumatic conditions were also included, as noted above.

The proportion of patients in each diagnostic category who answered any question as "frequently" or "almost always" is shown in Table 1. All rheumatic disease patient groups and a higher proportion of "frequently" or "almost always" respondents (30-70%) than controls (27%). The most impressive findings were for persons with primary Sjogren's syndrome, other rheumatic diseases, and SLE (55-70%). When examined for the number of positive responses per responding positive patient, similar results were found; SLE (11.3/patient), Sjogren's (8.4/patient) and RA (7.7/patient) were the highest.

A Laser Shooting Out a Computer

Eye Spasms Beaming Sunlight at the Brain

written by

Carol Woods

Illness is boring, uncomfortable, sometimes painful and it limits activities. It is frustrating and difficult to deal with, but hopefully, you are not alone in dealing with it. You may have support from the medical profession which is advanced and specialized in today's world. Medications to aid chemically in defending your body against illness, tests to define the problem, and operations that are becoming ever safer and ever more complex are at our disposal.

The family is also a basic support in times of illness. Informing them of what to expect from the patient and teaching them how best to treat symptoms or any complications that might come along is now the accepted practice of most doctors and modern health facilities.

But, what if the patient does not fit the criteria of any illness, yet they are in many ways sick and even disabled? What if present day tests have not been helpful in the evaluation of their condition?

Sadly, but quite honestly, many of them have been labeled "neurotic," told they have "symptoms without clinical evidence," and they have not been given realistic help. Added to guilt of being ill and unable to function normally, having to pay excessive amounts of money searching for medical help, and the fear of becoming helpless, is the fact that somehow the patient is responsible for the condition, emotionally.

Most definitely emotions can cause physical symptoms. This article, however, deals with physical conditions that are not made evident by present testing techniques, and that may, on the surface, appear to be emotional. It deals with a patient who has unusual chemistry, asks that her illness be taken seriously, and explains what the patient believes is the cause of the medical problems. It asks that light sensitivity and all that is connected with it be RESEARCHED.

Seven years ago in June, one day before my menstrual period began, I developed tendinitis in my right hand while pulling weeds all day in the hot sun. The tendinitis turned to arthritis and affected my left wrist also. I had a severe case of conjunctivitis in my eyes following the tendinitis. From this time forth, my menstrual periods became troublesome, with extreme nausea, exhaustion, dizziness so severe that I had to lay flat at times, eye pain, SEVERE HEADACHES and abdominal cramps. These problems escalated and the time before the menstrual flow began that they occurred came earlier, days, then weeks, before the period; and the time the symptoms stayed active became longer after the flow began. Added symptoms came with the periods also, wrist pain, then wrist pain and elbow pain, until all joints were involved. Eye pain was definitely connected with wrist pain from onset.

The month of January activated new symptoms and I would have very little energy until after June. This was recognized after three new years passed. The symptoms definitely have seasonal features.

In January of 1981, while hospitalized, I had a dizzy spell where I had to lay flat, my temperature dropped and I began to have double vision. My rheumatoid factor rose from 1:1200 to 1:1600. (Patients with Rheumatoid Arthritis often have rheumatoid factor circulating in their blood, but it can occur with other diseases also. A titer tells how much of the factor is present. Usually a titer of 1:160 or greater is abnormal.) My rheumatoid factor has been as high as 1:3200.

However, I have never had an elevated Sedimentation Rate. (Blood is allowed to settle in a test tube for an hour and the amount that it settles is the Sedimentation Rate. Over 20 mm per hour is abnormal and indicates illness of some type. Mine had never gone over 21 mm per hour.)

Physically, I could hardly stand up, walk or do more than lay in bed. I couldn't concentrate enough to read, and I had to prop my head up on pillows because I was too weak to hold it up. If I did the least thing physical, I would have to take a nap lasting from 1 hour to 3 hours. My legs felt empty, not solid, and I was extremely concerned about my health.

After the dizzy spell in the hospital in January of 1981, I became aware that sunlight hurt by eyes, after leaving the hospital. In June of 1981, I had a hysterectomy to remove fibroid tumors. At that time, I had a lot of complications. I had an ileus (intestinal slowdown), hematoma (localized swelling filled with blood) and my white cell count (leukocytes - the fighters) did not multiply to fight infection as they should. With all these complications, and I couldn't eat for a week- I was fed by intravenous - I had no increase in Sedimentation Rate, no elevated white cell count, and my temperature never went past 99 degrees. I was visibly swollen and seriously ill, yet my tests came out normal.

About twenty days after the hysterectomy, I had a severe, painful and long lasting escalation of my illness, complete with joint pain and back pain. At this time, all my tests were normal though I was in excruciating pain. I have long ago concluded that current testing is not adequate to evaluate my medical problems.

I have gone from one specialized medical field to another, frightened, confused, feeling inadequate to deal with this illness and desperately seeking help. The illness has been diagnosed as Rheumatoid Arthritis, Fibromyositis, Psychoneurotic fibromyalgia, and Sero-Negative Lupus Erythematosus. Most recently Sjogren's Syndrome, Rapid heartbeat, Inner-Ear Dysfunction, plus rashes, and eye infections.

In June of 1981, after the hysterectomy, and four years after the onset of tendinitis, my eyes were diagnosed "keratitis sicca," meaning dry eyes. This is one of the manifestations of Sjogren's syndrome. I had complained of burning, itching eyes since the tendinitis.

My major complaints throughout my illness have been dizziness and eye spasms. The dizziness makes it impossible for me to concentrate or focus. I don't have total control of my mind's functioning while dizzy. I get numbers mixed up as 486 being recalled as 684. My memory gets bad, even for something said only a moment earlier, and I repeat myself and get confused easily. The phrases "scatter brained" or "losing my mind" seem appropriate. The dizziness can cause me to lay flat instantly, give me headaches and extreme nausea and fatigue. It makes me feel stupid and

causes me to withdraw socially. It throws me off balance, especially with changes in head movement.

It has amazed me that doctors I have gone to for help ignore this complaint - pass it off as neurotic - and cannot seem to comprehend that the dizziness is physical and it affects my communication with them. It is so much quicker and easier for them to label me "neurotic," and convince themselves that I am over-reacting to my illness.

I believe I am thought of as the crazy lady who writes a lot, and who comes in with a list of her symptoms. Without my lists, I forget! Communicating with doctors has been extremely difficult because of the dizziness and the fact that I AM EMOTIONAL ABOUT THIS ILLNESS.

After many arguments with physicians, because I know the dizziness is connected with menstrual periods and eye pain; - I live with it - it was diagnosed in January of 1983 as being right inner-ear dysfunction. An otolaryngologist with new and specialized equipment in vestibular testing made the diagnosis.

Since January of 1983, my sunlight sensitivity has become so severe that I must keep my curtains closed in my home and wear strong sunglasses outside in daylight. After living with this light sensitivity progression for seven years, I think I understand my illness and I believe research is desperately needed in regard to eye spasms.

In the following paragraphs, I have outlined my beliefs about the nature and cause of my illness.

The light sensitivity is caused by an inter/action between a hormone and sunlight which causes the eye to spasm, focusing sunlight inwardly like a laser to a place in the brain that acts as a solar collector. My tendinitis (hormone connected) began an allergy reaction which makes me more sensitive to the ultra-violet rays of the spasm; and in my case, these rays are focused incorrectly because of the inner-ear dysfunction, missing their target and hitting my "computer" (brain) instead.

The inner-ear dysfunction can be traced to pre-school ear infections or an ear infection fourteen years ago. The dizziness came after the tendinitis seven years ago and is definitely connected with eye pain.

The ultraviolet rays from the sun that inter/act with the hormone are more prevalent from January until June. They act as an energy source and the part of the brain collecting them is a type of battery. I believe sleep helps store or distribute this energy.

I have felt light jab me in the eye and knock me flat on my back causing dizziness, headaches, severe nausea and fatigue. My first experience of being aware that light caused this reaction was January of 1983, which was 5½ years after the onset of the light sensitivity. I have experienced this reaction four times, and I am extremely protective of myself from sunlight.

Focusing problems run in my family and they are connected with hormones and rheumatic problems. Eye spasms have been diagnosed and treated from my daughter, age nine to twelve, and they may be connected with rapid eye growth.

The solar collector theory explains my illness and makes sense of it to me. The eye spasm (laser) shoots out my brain (computer) instead of reaching its target, the solar collector, and causes a variety of health problems.

The solar collector theory would explain dizziness and eye pain after tendinitis. A solar collector, somewhat like a battery, would explain instant reactions caused by my illness like instant exhaustion, instant starvation, instant colon attacks.

It is like a timer set off, and you can't predict it's reactions from one minute to the next or control it at all. It would explain the empty feeling in my legs that sleep revitalizes. I think energy flow slows down and doesn't reach the part of the body farthest from it correctly.

The body tries to adapt protectively to the sunlight sensitivity by keeping me awake at night, actually making me feel more alert after midnight, and making me need sleep during daylight hours. The amount of light taken in, and your sensitivity to it, governs sleep patterns. Light sensitivity varies with seasons, menstrual cycles, hormonal balance, weather and numerous other factors I am sure. The solar collector also has a great deal to do with appetite, and how your body stores, eliminates or utilizes foods. I think it has a lot to do with weight control.

Talking about eye spasms and my belief that there is a part of the brain that acts as a solar collector gets varied reactions. Some doctors are open-minded enough to consider it, and a few have ventured remarks like, "Perhaps the pineal body is the collector." (It is a glandular body of uncertain function located in the brain.) "It cannot be the pituitary, it would be too deep in the brain for the light to reach."

The doctors' most common reaction is to refer me to another specialist, preferably a psychiatrist. When I tell them I have seen one and he is my biggest supporter, the eye doctor sends me to the Gynecologist to check for the hormone, then the Rheumatologist sends me to the eye and ear specialist who refers me to a Neurologist again because I do not fit into their medical system. They don't even know where to send me for research.

I don't believe current testing can evaluate my problem. Although my light sensitivity is extreme; eye spasms and light sensitivity are not uncommon. The research would be valuable to many. New tests checking ultraviolet light's effects on eyes and brain, and hormonal tests in connection with eye performance are needed.

The fact that BLOCKING SUNLIGHT FROM MY EYES HELPS CONTROL MY ILLNESS is very important and needs to be researched. For pre-menstrual syndrome, insomnia, Alzheimer's Disease, Rheumatoid Arthritis and Lupus Erythematosus victims, the effects of light need to be determined.

I feel it would take a group of researchers which would consist of Rheumatologists, Ophthalmologists, Otolaryngologists, Neurologists, Gynecologists, Allergists, along with specialists in computers and lasers. Experts in solar energy and microwaves might be useful in this research also. Today's tendency to specialize could hold back

New Zealand Black and White Mice (commonly used for research of Lupus) could be given a hormone and kept under ultraviolet light. The hormone, dosage, amount and type of ultraviolet light should be closely monitored and the animals should be examined frequently for eye changes. The type of light should also be calculated and different types of light used, including very fast microwaves. Sleep patterns should be monitored also, as well as eating and bowel movements to note changes. Female mice should be checked at breeding and during pregnancies to see if there is increased sensitivity to light at these times. The purpose of these tests would be to connect a hormone to light by way of eye spasms, identify the hormone and type of light which interact.

BLOCKING SUNLIGHT FROM PATIENTS WITH RHEUMATIC ILLNESSES OR ALZHEIMER'S DISEASE totally, having them wear strong sunglasses outside, curtains closed inside or special protective eyeglasses which have top and side protection. This should be selected patients with specific problems and they should have a similar control group who continues normal exposure to sunlight.

The people blocking the sunlight should be very aware of any exposure to light from florescent lights at work to television light. They should note any changes in their sleeping patterns, eating patterns, bowel movements and if there is any change in their symptoms. Of special interest should be any eye changes. Women should note any changes in their menstrual cycle, it's length, time between cycles, changes in flow, amount of days flow is present, amount of pain present, and any increase in symptoms at time of flow.

Because the factor in the light that is harmful is more prevelent from January until June (it may be possible that the hormone connected in the light sensitivity is more prevelent at this time), the research needs to be scheduled to include time in each six months period, Oct, Nov, Dec, and Jan, Feb, March. for example.

These people should be checked against the control group to see if BLOCKING LIGHT (specifically sunlight), helps control symptoms. Do they have less complaints, are any changes in sleep patterns, eating, bowel movements, menstrual cycle, symptoms noticable? DOES BLOCKING SUNLIGHT HELP CONTROL SYMPTOMS?

The use of asperin should also be noted in both groups as I believe it is a factor in controlling the light sensitivity.

A group of researchers including Rheumatologists, Immunologists, Opthalmologists, Otolaryngologists, Neurologists, Gynecologists, Allergists, along with specialists in computers and lasers is needed to look specifically for the hormone or chemical connected with the eye spasms, eye spasms themselves and ultraviolet light's target in the brain (solar collector). Possibly specialists in solar energy and microwaves might be useful in this research also. Is there part of the brain chemically receptive to light or microwaves, and is there part suited as a solar collector battery? What path could the light waves take to get to the solar collector? Could the amount of microwaves the solar collector could hold be calculated by it's chemical composition and size?

I have particular interest in plaques and tangles found in Alzheimers disease and would be interested in any testing regarding the paths they form in the brain and their chemical make-up, as well as any information on how light interacts with these chemicals.

Research connecting young girls with a hormone during their period of rapid eye growth which begins to activate the process of menstrual cycles may be useful in identifying a hormone or chemical that interacts with light.

this research if these fields are not connected and looking specifically for the hormone, eye spasms and the ultraviolet light's target in the brain.

This illness has changed my lifestyle dramatically. I no longer work as a secretary. I cannot work near windows or under ultraviolet light without becoming dizzy. My altered sleeping pattern which is progressive has me sleeping from 5 a.m. until 3 p.m.. If I interfere with it, I don't just get tired; I get sick. It is difficult adjusting to waking up and cooking dinner. My heart rate has increased along with light sensitivity and I tire unbelievably quickly and get out of breath easily.

One doctor said "I should get a job and keep busy." I said, "I'd love too, if I could stand up, stay awake, think straight and my eyes would quit hurting." Sleeping 14 to 18 hours a day and living in a house with curtains drawn is not my choice. Wearing weird hats to protect myself from sunlight and wearing sunglasses that look like they come from another planet are not my chosen fashions either, especially when I go to the bank and the tellers get nervous.

My greatest wish is to be normal again and to work, but with the warm weather I seem to get more exposure to sunlight because I am outside more or opening doors, and I am already getting severe headaches and having troubled breathing. The light sensitivity is progressive.

Because of my altered sleeping pattern, I see my family only in the evening and I don't feel I have time to do the things I need to do as a wife, mother and homemaker. I am constantly behind in my work and I don't feel I have time for many relationships outside my home. I used to be active and much more involved in my community and church.

My concentration level is low, so I don't read very often, and I once loved to read. I resent the fact that doctors don't understand my communication problems and I need to write them letters. Writing letters takes time and I have less waking time so my time is valuable to me.

Because I have unusual chemistry and medical records to prove it, and because I have lived with progressive light sensitivity, and an illness that doesn't fit defined criteria; I feel that I am the person best qualified to understand my medical problems.

There is enough evidence that not to research eye spasms and their cause and effects at this time would be negligent. It is important that they be talked about and researched.

I believe that many patients, especially women, who are now receiving the "neurotic treatment" from the medical profession have light sensitivity problems. Because of the lack of clinical evidence at the present time, emotional disturbances do need to be considered. If, however, the problems are connected to sunlight, seasonal symptoms, altered sleeping patterns or the menstrual cycle; I would not accept that as the answer. I sincerely believe the answers may be possible at this time, with proper research. I hope that other persons with these or similar symptoms will stand up and be counted so that we can get on with the task of RESEARCH.

Bright light, big therapy

Science is illuminating a host of maladies—with dramatic results

By Stephen Rae

One week before the space shuttle *Endeavour*'s lift-off in January 1993, astronaut Don McMonagle rose at 3:45 A.M. and entered the Johnson Space Center light chamber to reset his body clock. A former conference room outfitted with 390 ceiling-mounted fluorescent lamps, the chamber has proved a boon to astronauts like McMonagle, who'd be awake from 1:30 A.M. to 5:30 P.M. (Houston time) on the mission and needed to adjust his biological rhythms.

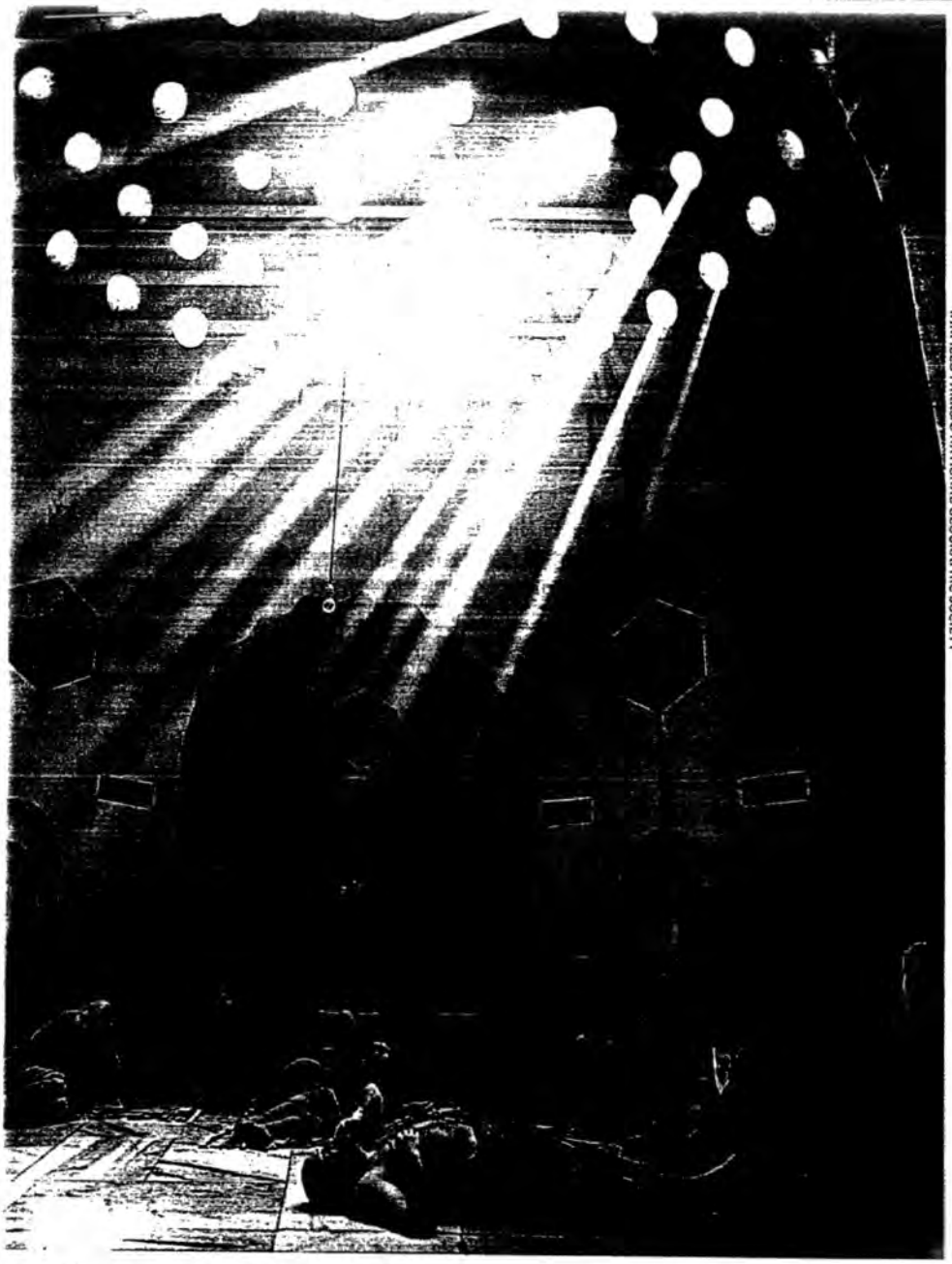
Before light treatment, astronauts preparing to work the graveyard shift toughed it out, forcing themselves to stay awake at night and often resorting to sleeping pills to catch some shut-eye during the day. Nevertheless, they'd often blast into the heavens feeling like hell. Since NASA turned on the lights in 1990, however, astronauts have had no problem dealing with rocket lag.

Precisely timed bright-light exposure (for McMonagle, a total of ten two- to four-hour sessions throughout the week before launch) can advance or delay the body's circadian (daily) rhythm so it hungers for Roquefort dressing at 7 A.M. and falls asleep at noon. The circadian pacemaker regulates a host of interrelated biological processes—including body-temperature fluctuation, hormone release, heart rate, blood pressure, and the sleep-wake cycle—that run on a roughly 24-hour schedule.

The use of bright light to reset biological rhythms is one of several innovations to follow recent findings on the effect of light on humans. We now know that the light-dark cycle also synchronizes human rhythms to the 24-hour day.

Central to running the human body clock is a cluster of 10,000 neurons, about the size of the head of a pin, called the suprachiasmatic nucleus (SCN). Situated in the hypothalamus, a region at the base of the brain that helps regulate parts of the nervous and endocrine systems, the SCN takes its cues from light in the environment, which it monitors via the retina. It responds to light and darkness by sending messages to other parts of the brain and body that influence the rhythms of systems throughout the body.

In 1989 a team of Harvard researchers reported that bright light administered at strategic points in the circadian cycle could reset the body clock. Light equivalent to daylight just after dawn was shone on volunteers in daily five-hour sessions over the course of three days. When the light came in the latter half of the night, body clocks advanced to an earlier phase; when it came late in the evening or in the first half of the night, body clocks were delayed to a later hour; when it came during the day, the light had little effect.



WINFIELD PARKS/© NATIONAL GEOGRAPHIC SOCIETY

Shafts of light flicker through the steam of this Turkish bath in Istanbul.

The first two exposures reduced the strength of the cycle, while the third "set" the clock to the new hour.

NASA contacted Charles A. Czeisler, Ph.D., M.D., the study's principal author and director of the Laboratory for Circadian and Sleep Disorders Medicine, Harvard Medical School and Brigham and Women's Hospital. Since manned space flight's early days astronauts had had trouble adjusting their body clocks, and the Agency invited Czeisler and other experts to a workshop in Houston that resulted in the first real-world body-clock-resetting tests.

Light treatment is now routine for all crew members slated to work odd hours or launch late at night. Karen Stewart, Ph.D., a Chicago-based body-clock researcher, has used the technique on ground crews at the Marshall Space Center in Huntsville, Alabama, as well. "We think circadian shifting works very well and the crew is very supportive of it," says NASA spokeswoman Kari Fluegel.

Jet lag

Most of us don't travel in rocket ships, but we do fly in jet airplanes. Suddenly crossing time zones throws our entrenched rhythms out of kilter with our destination's light-dark cycle. The result is jet lag. After crossing several time zones it can take a week or longer for the body clock to right itself. While that's happening we feel awful, perform poorly, and don't sleep well.

The Harvard discovery led to a promising treatment for jet lag: After flying, the authors concluded, we need only spend parts of the next two days outdoors—the equivalent of the first two bright-light sessions— to be synchronized to local time with the coming of dawn on the third day. Or we can begin to adapt to the new time zone before leaving. "If I'm going to Europe for a week or more, I'll reschedule the timing of my sleep-wake cycle with the use of bright lights prior to my departure," says Czeisler, "and arrange to have meetings while I'm being exposed to the lights at the proper time."

Disturbed sleep in the later years

Light treatment (sometimes known as phototherapy) is also proving useful in fighting age-related sleep disturbances. Of the then-29 million people in this country over age 65, a 1990 National Institute on Aging report said more than half had some type of sleep complaint. One-third of older Americans reported wakening too early at least several times a week. The NIA report debunked the notion that older adults require less sleep than younger ones.

Most age-related sleep disturbances spring from changes in the body clock. "The circadian pacemaker may be one of the few things that speeds up as we get older," Czeisler says. "And when it speeds up, that means we get to the same point in our day at an earlier hour." The 20-year-old who falls asleep at midnight and rises at seven may sleep from 11 P.M. to 6 A.M. by age 65; at 70, he/she may have trouble staying awake past 10. To counter this troublesome shift, researchers are exposing older patients to bright light in the early evening to delay their sleep-wake cycles.

Photopheresis

In a hospital room in the Hunter

continued on page 84

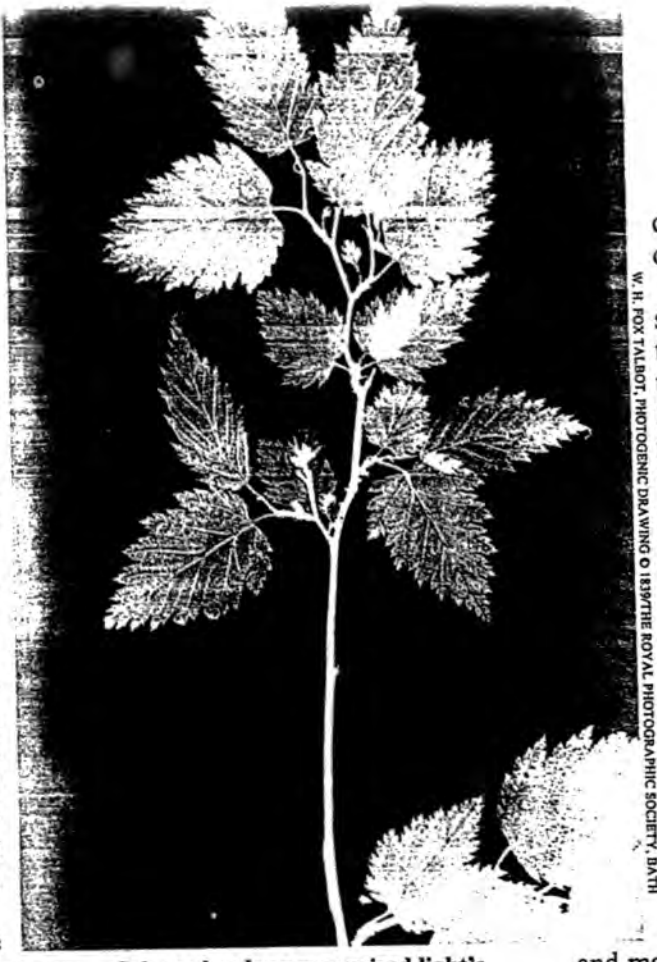
Bright light
continued from page 38

Radiation Building, part of the Yale School of Medicine, a patient in his 70s lies asleep in a bed. As he dozes, his blood courses through a tube in his arm and flows into a machine the size of a portable dishwasher at his bedside. Spinning the blood, the machine separates his healthy red blood cells from his ailing white ones, routing the latter through a field of ultraviolet light produced by a bank of 24 fluorescent bulbs. The man has cutaneous T-cell lymphoma, a cancer of the immune system in which certain white blood cells called T-cells proliferate wildly, eventually overrunning the body and causing death within three to four years.

Thanks to a procedure called photopheresis, this patient may beat the odds. An hour before, he'd ingested psoralen, a drug made from a Nile River weed that is activated by ultraviolet light. In the body, psoralen is soaked up by abnormally reproduced white blood cells—his cancerous T-cells, for example. As the light shines on the T-cells the psoralen inside them is activated, crosslinking their DNA and impeding their ability to reproduce. Then the healthy cells and the irradiated sick ones are reinfused into the patient.

Psoralen is an example of a light-sensitive substance being groomed as one of the next generation of chemotherapy drugs. "It has very few side effects," says Francis P. Gasparro, Ph.D., a research scientist in Yale Medical School's department of dermatology. "It doesn't make people sick or cause hair-loss. Because you treat the malignant cells outside the body, only a few normal cells are exposed to the drug"—very different from standard chemotherapy.

But light-activated psoralen does more than merely impede cancer cells' ability to reproduce. It seems to modify the cells' structures so that, back in the body, they stimulate the immune system, which then attacks both treated and untreated malignant cells as foreign invaders, like viruses.



W. H. FOX TALBOT, PHOTOGENIC DRAWING © 1839/THE ROYAL PHOTOGRAPHIC SOCIETY, BATH

Science has long recognized light's importance to plants and animals; its human application is recent.

The treatment has yielded convincing results in cutaneous T-cell lymphoma, which strikes 800 to 1,000 Americans annually. "The overall survival is impressive," Gasparro says. About one-quarter of the patients remain symptom-free five years after treatment, and another 50 percent show some improvement. The treatment has yielded encouraging results in scleroderma—a disease in which the immune system attacks skin tissue—rheumatoid arthritis, and lupus. Now it's being used experimentally in the treatment of juvenile diabetes and AIDS-related complex (ARC).

Seasonal affective disorder

In addition to treating cancer and body-clock disturbances, light is being enlisted to fight emotional disorders. Growing evidence suggests that seasonal variations in light levels can have a profound impact on mental health.

This is clearest in people suffering from seasonal affective disorder (SAD), an affliction that strikes an estimated 5 million Americans. A recurring annual ailment marked by abnormal sleep patterns, fatigue, weight gain, withdrawal from friends and family, and depression of clinical depths, SAD strikes the majority of sufferers as days shorten in late October or November, holding them in its grip for three to four months every year.

As far back as 400 B.C. the Greek physician Hippocrates observed that seasonal changes could cause physical and mental changes, and many of us (one estimate claims some 35 million Americans) suffer from lesser forms of the winter doldrums. We all tend to sleep more during winter's long nights, yet may still feel tired and less productive; and many of us put on a few pounds. SAD patients have it much worse: Though they may be outgoing and vivacious in the summer, they find themselves increasingly despondent and anxious as winter approaches, in some cases consumed with thoughts of suicide and unable to get out of bed. Work and family relations are jeopardized. Then, sure as spring follows winter, the days lengthen—and their depression lifts.

It wasn't until the early 1980s that scientists at the National Institute of Mental Health recognized the depression as a distinctive, cyclical entity; in 1987, the American Psychiatric Association deemed SAD a true affective (mood) disorder, listing it in the *Diagnostic and Statistical Manual of Mental Disorders*, third edition, revised. But this was one case where recognition of an illness was nearly simultaneous with the discovery of a treatment: light therapy.

Psychiatrists still don't know what causes SAD (there seems to be a genetic predisposition, and like other types of depression, it strikes women more often than men). But it seemed clear that winter's decreased amount of daylight, rather than its lower temperatures, was central. (In some patients a string of overcast days in midsummer can trigger symptoms, and the disease is not unknown in warm climates.) Working on that assumption, researchers began artificially extending patients' daylight hours. They exposed them to fluorescent lights of an intensity of 2,500 lux—far brighter than ordinary room light, which is about 500 lux or less—for a total of two hours daily. The results were astonishing: Severely depressed patients who'd resisted anti-depressant drugs showed dramatic improvement in a week or less.

Because many diseases produce symptoms of depression, experts caution against self-diagnosis of SAD and the unsupervised use of light boxes. "You can overdose on light—people have gone into manic states—so we feel you should be monitored," says Robert N. Moreines, M.D., a psychiatrist and associate medical director of the Princeton Psychiatric Center in New Jersey and co-author of *Light up Your Blues: Understanding and Overcoming Seasonal Affective Disorders* (PIA Press, 1989).

Nonseasonal depressions

If light can combat winter depression, can it also work against the nonseasonal kind? Results are preliminary, but evidence suggests it might.

Working at the Veterans Affairs Medical Center in San Diego, Daniel Kripke, M.D., professor of psychiatry at the University of California at San Diego, has been using light therapy since 1981 on patients hospitalized for depression. "The benefit we're seeing is actually more than you would expect to see with antidepressant drugs in a comparable time period," he reports. Kripke admits no one really knows how light fights depression; as in SAD, however, he believes it may work through the body clock or by affecting melatonin levels.

Meanwhile, investigators continue to explore a novel therapy that may turn out to be good for what ails you. That cat basking in sunlight on the window ledge may be telling us something. ■

The author is a New York journalist. His most recent contribution to MODERN MATURITY *was "Wrapping the Human Package" (June–July 1991).*

Modern Maturity Magazine Feb, 1994

THE WHITE HOUSE

WASHINGTON

June 23, 1994

The Honorable Ann Walker
Special Assistant to the President
The White House
Washington, D.C. 20500

Dear Ms. Walker:

Thank you for your letter of May 12 regarding the blood supply.

I have reviewed the issues you raised in your letter concerning hemophiliacs and HIV, the Institute of Medicine (IOM) study, and the safety of the blood supply and the American Red Cross (ARC). More detailed information is enclosed.

Currently our blood supply is among the safest in the world. Today there is very little chance of getting HIV from a blood transfusion. Clotting factors obtained from donated blood are equally safe. Nearly all people infected with HIV through blood transfusions received those transfusions before 1985, the year it became possible to test donated blood for HIV.

More than 13 years have passed since people began to die of AIDS. We have learned a lot about HIV and AIDS since 1981. As you will see from the material I have attached, the hemophilia patient advocacy groups have alleged the Federal Government made inappropriate decisions with the blood supply during the period of 1982 to 1984. I want to emphasize that the issues surrounding the blood supply are extremely controversial and litigious. The United States has been named as a party in several of the cases.

The IOM study that was commissioned by the Department of Health and Human Services, and began last November, will identify methods to improve public health decision-making and public health policy to better protect the blood supply in the future. However, the study will not seek to determine liability or affix blame for any individual or collective cases of HIV transmission during this time period. I believe that recommendations resulting from this study will be helpful in strengthening our capacity to ensure the safety of the Nation's blood supply

against challenges in the future.

I understand the National Hemophilia Foundation wants a Congressional investigation of this issue and has drafted legislation for compensation for persons with hemophilia who are living with HIV/AIDS and estates of the deceased. Some countries' governments, for example France and Canada, have provided compensation for individuals with hemophilia who were infected through the blood supply.

As for the ARC and the letter from the veteran lab technician, I understand the Food and Drug Administration (FDA) investigated this case last year and found no major compliance violations. In May 1993, FDA obtained a consent decree that placed the ARC under court supervision. In the consent decree, the ARC agreed to establish and document managerial control over training and quality assurance.

Thanks to new tests and advances in science, our blood supply is safer than it ever has been. Before a test to detect HIV in the blood was developed and approved in 1985, the ARC performed only two tests for infectious diseases. Today they do eight tests on each unit of blood. I understand ARC is undergoing what they call "the total transformation of how we collect, process, and deliver one-half of America's blood supply...the creation of a state-of-the-art system that can quickly incorporate medical technology as it evolves."

At the same time, the FDA is increasing its regulatory role over the blood industry. The Government and private sector are working together on these issues. Just last month, the Centers for Disease Control and Prevention issued "Guidelines for Preventing Transmission of Human Immunodeficiency Virus Through Transplantation of Human Tissue and Organs." These guidelines were developed through a collaborative process with industry, physician associations, academic institutions, scientists, and representatives from the agencies in the Department of Health and Human Services.

I hope you find this information helpful. If you have any questions, please let me know.

Sincerely,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

Enclosure

Overview

Exclusion of prospective blood donors based on their acknowledged risk behaviors for human immunodeficiency virus (HIV) infection began in 1983. In 1985, when tests for HIV antibody became available, screening prospective donors of blood, organs, and other tissues also began. Both measures have reduced markedly the transmission of HIV via these routes.

Twenty seven adults/adolescents and two children developed AIDS after receiving blood screened negative for HIV antibody. Six additional adults developed AIDS after receiving tissue or organs from HIV-infected donors. Three of the six received tissues or organs from a donor who was negative for HIV antibody at the time of donation.

Hemophilia

There is a separate reporting category to the Centers for Disease Control and Prevention (CDC) for hemophilia/coagulation blood disorder as an exposure category to HIV. This issue is related to the safety of the blood supply, but slightly different. There is great concern about what exactly happened concerning the transmission of HIV by antihemophilic factor during the period 1981 and 1982.

Many hemophiliacs were infected with HIV due to contaminated clotting factors and other blood products. The hemophilia community believes that some means should have been available earlier to protect recipients of antihemophilic factor from HIV. Unfortunately, it is always easy to look back and second guess past decisions in the light of subsequent events. It should be emphasized that the Food and Drug Administration (FDA) made decisions in 1982 and 1983 about the antihemophilic factor and other blood products based on the information available at that time, balancing the need to protect the blood supply against the need to maintain a supply of vitally needed products.

During that same time period, 1982 and 1983, FDA was working very closely with a number of concerned groups, including the National Hemophilia Foundation, the American Red Cross (ARC), the American Blood Resources Association, the Council of Community Blood Centers, and the Pubic Health Service Interagency Committee to develop a consensus of appropriate steps to decrease the likelihood of blood or plasma donation by individuals who might be at increased risk for transmission of AIDS.

For a time there was considerable debate about the underlying factor responsible for the immunoregulatory defect. Theories about possible etiologies included a transmissible infectious agent, drug use, chronic antigen stimulation (for example, the continued use of homologous antihemophilic factor), and

spermatozoa exposure. What was perceived as an unnecessary delay was the result of the need to collect information and make an informed decision that would both prevent the spread of disease and maintain the availability of these vitally needed resources.

Recall also during this time period, the causative organism was not known. As with any other disease, it is close to impossible to develop a specific test for an unknown organism. Also, during that time, information on the extended latency period of HIV infection, during which a person is apparently healthy although infected was not fully realized.

It is unclear, then, what other criterion could have been used in 1982 and early 1983, based on the knowledge available then, that would have permitted recall of contaminated lots without recalling all lots of antihemophilic factor, which would have deprived hemophiliacs of any source of vital clotting factor. Recall of all antihemophilic fact also was not considered because of the lack of knowledge of the level of risk. While it is true that not every bleed is life-threatening for a hemophiliac, clotting factor concentrates have had an enormous impact on the morbidity and mortality of hemophilia which cannot be underestimated. Removing them from the marketplace would have had enormous implications for this group of individuals.

Blood and plasma was already being tested for Hepatitis B virus antigen at that time, and a positive result was already cause for discarding the blood or plasma and deferring the donor. Screening alone, even by a specific, let alone a nonspecific test, would not have made antihemophilic factor safe with respect to HIV transmission. The reason is that screening tests for HIV are not 100 percent sensitive. Because antihemophilic factor is made from very large plasma pools, it remains likely that contamination by HIV still occurs in some of the pools. Product safety therefore depends as much or more on virus inactivation during manufacturing as it does on screening. The same consideration would have applied in 1982 and 1983. Donor screening for antibodies to hepatitis B or for abnormal T-cell ratios prior to the availability of specific antibody screening, would not have rendered the products safe.

Heat treatment of clotting factor concentrates was introduced voluntarily by manufacturers in 1983 to 1984 in an effort to reduce transmission of hepatitis viruses. In retrospect, "dry" heating, which was not very effective for prevention of hepatitis transmission, turned out to be highly effective for near elimination of the risk of HIV. The FDA worked rapidly with manufacturers to improve methods of viral inactivation, which are now used in the preparation of all plasma derivatives.

The tragedy which occurred through transmission of HIV by blood products cannot be reversed. There have been substantial changes

which have made the current blood products almost completely safe, as the AIDS epidemic continues.

Recent Steps Taken to Increase the Safety of the Blood Supply

The introduction of screening tests for hepatitis, HIV, and other infectious diseases has significantly increased the safety of blood over the past couple of decades. But the use of these tests, the use of new technologies, and an increase in the number of blood products being produced, have also made blood banking far more complex than ever before.

Blood banking is a very different operation than it was just 5 years ago. That simple fact has enormous implications for the safety of our blood supply. Today, blood banking has become a manufacturing industry. An industry that must conform to high standards and quality control requirements comparable to those of pharmaceutical companies or other regulated industries.

Like any regulated industry, blood banks are responsible for ensuring the safety of their products. FDA can provide support and guidance but it is fundamentally the blood bank's responsibility to comply with the rigorous standards that are necessary to protect our blood supply. We are committed to holding blood banks to those standards.

Every year about 12 million units of blood are collected in the United States. About half of the donations occur at Red Cross blood banks and the remainder at other community blood centers or hospitals.

FDA has established five steps of overlapping safeguards that start at the blood collection centers and extend to the manufacturers and distributors of the blood products made from the donated blood.

- The first step or level of precaution is to eliminate "high risk" donors by encouraging those whose blood may pose a health hazard to exclude themselves, and by evaluating their behavioral and medical history as a basis for deferral.

- The second safeguard is constant updating of a list of unsuitable donors and checking donors' names against the list to prevent use of their blood.

- The third consists of testing the blood for such blood-borne agents as HIV, hepatitis, and syphilis.

- The fourth safeguard enforced by FDA is a quarantine of all donated blood until tests and other control procedures establish its safety.

- The fifth safeguard, is the blood collection centers are obligated to investigate incidents, audit their systems, and correct deficiencies.

The FDA's stepped up inspection program over the last several years has revealed breaches in one or another of these layers at far too many blood banks. The most significant of these have occurred in the areas of inadequate training of the staff conducting the screening tests, poor recordkeeping so that suspect units of blood cannot be readily tracked dow if a problem is discovered, and problems in the required donor deferral registry intended to keep high risk donors out of the system.

One of the FDA's biggest challenges in enforcing blood bank requirements has been to get the ARC into compliance without interrupting the Nation's blood supply and without unnecessarily alarming the public.

On May 12, 1993, the FDA obtained a consent decree that placed the ARC under court supervision. In the consent decree, ARC agreed to establish and document managerial control over training and quality assurance. ARC also agreed to hire a director of training to be responsible for all training functions, including the establishment, implementation, and maintenance of a comprehensive training program.

This was one of the strongest enforcement actions taken by the FDA. It was followed by strengthening enforcement activities across the entire blood industry.

IOM Study

In April 1993, several members of Congress, including Senator Graham, called for the Inspector General to conduct an investigation of "the issue of HIV transmission among hemophiliacs through contaminated blood products." Instead the Secretary of Health and Human Services, working with the Assistant Secretary for Health and the Deputy Assistant Secretary for Health (Science), decided that an independent body should conduct a review, not the Inspector General.

In July 1993, the Department contracted with the Institute of Medicine (IOM) National Academy of Sciences to conduct an indepth review and evaluation of the transmission of HIV through blood and blood products in 1982 through 1986. This evaluation will include a thorough review of the amount of information and technology available to decision makers during this period, and the scientific basis of the decisions made about HIV transmission through the blood supply.

As stated in the letter from Senator Graham and Representative Goss in January 1994, this study was greeted with mixed response.

Overall the Institute of Medicine study was viewed as a necessary first step of this complex issue. However, the hemophilia community "who are personally involved with this tragedy have expressed concern that the study could drag on too long and yield inconclusive results about the chain of accountability in the genesis of this crisis in the early 1980s."

The IOM's study of HIV Transmission Through Blood Products will be carried out by a committee of approximately 12 experts. A liaison committee consisting of relevant experts from the FDA and the CDC will provide the committee with specific subject matter expertise.

Because of the devastating impact of HIV/AIDS on the hemophilia community, the death rate among hemophiliacs tripled between 1979 and 1989. Over 50 percent of Americans with hemophilia A (the most common form of hemophilia) have been infected with HIV from contaminated blood products. Through December 1992, 2,426 individuals with hemophilia had been diagnosed with AIDS, and 1700 (70 percent) of these individuals have died.

Today, the risk of getting AIDS from blood products has been virtually eliminated since 1985 because of new screening procedures and safer clotting medicines. The National Hemophilia Foundation (NHF), a New York advocacy group, recently drafted legislation to compensate AIDS infected hemophiliacs and their families.

Under the Foundation's proposal, those hemophiliacs would be eligible for financial help for medial bills and family support from Medicare and Social Security. The legislation would also create a special trust fund to meet the needs to people who have been financially devastated by AIDS. It would also provide $250,000 to persons with hemophilia who are HIV positive and to the estates of those who have died of AIDS.

The Foundation states "we are pursuing this on the basis that the Federal Government had a major responsibility in monitoring the safety f the blood supply. We're not casting blame. We're saying the system didn't work." Others, especially a group called the "group of 100" want "heads to roll" and point to the French officials who received jail sentences.

Also, the family of Jason Christopher (a friend of Ricky Ray who died 2 years ago of AIDS at age 11) received $2 million in damages after suing the drug company that produced the blood concentrate Rhone-Poulenc Rorer/Armour Pharmaceuticals.

As recently as May 16, 1994, at the first meeting of the IOM Committee, Jonathan Botelho, Chair of the NHF Board of Directors, testified the NHF would like Congress to concurrently investigate and uncover "all the facts and documents that are essential to a

thorough investigation of this tragedy."

Current Programs for Hemophiliacs

- The Health Resources and Services Administration's (HRSA) National Hemophilia Program provides funding for the "Federally Funded Treatment Center Projects." The National Hemophilia Program was initiated in 1975 to develop a system of comprehensive services to persons with hemophilia and other bleeding disorders and their families. Current funding for comprehensive hemophilia treatment centers is $5.2 million.

- CDC and HRSA will provide $7.6 million in this fiscal year to continue to support the National Hemophilia HIV Infection Prevention Project. The Hemophilia Treatment Centers will maintain and expand their outreach, peer education, and prevention activities to their at-risk patients and to persons with hemophilia not currently under the care of a Treatment Center. This agreement is a continuation of a cooperative effort between CDC and HRSA that has assisted in this area since 1986.

- Last year, CDC began a surveillance initiative on a Minimal Data Set for Risk Reduction for Persons with Hemophilia. This program was designed to reduce complications, disability, and death resulting from hemophilia and other bleeding disorders. The program's goals were to reduce the human and financial burden of bleeding disorders by focusing the national emphasis further away from end stage rehabilitation programs towards prevention and early intervention.

THE WHITE HOUSE
WASHINGTON

May 12, 1994

Carlos / George / Andrew
Please collaborate on developing a reply

Kristine Gebbie
National AIDS Policy Coordinator
Office of National AIDS Policy
1750 17th Street, N.W.
Suite 1060
Washington, D.C. 20503

Dear Ms. Gebbie:

Recently, Senator Robert Graham's office sent me the enclosed material, substantiating reports that at least half of the hemophiliacs in the U. S. contracted HIV from contaminated blood product transfusions. The contaminations occurred in a two year period -- between 1982 and 1984.

In a letter to HHS, Senators Kennedy and Graham, and Congressman Goss requested an investigation into the contaminated blood. Secretary Shalala commissioned the Institute of Medicine of the National Academy of Sciences to study the issue.

Although the House Energy and Commerce Committee has not scheduled hearings, the problem of contaminated blood is before the public. The NBC news magazine program "Dateline" presented a report on December 14, 1993 outlining some of the serious questions surrounding this issue. Furthermore, in an urgent and confidential letter to Senator Graham, a veteran lab technician with the American Red Cross accused the organization of distributing contaminated and improperly tested blood.

One of the hemophiliacs who died of AIDS as a result of a contaminated transfusion was Ricky Ray. As you remember, President Clinton selected the Ray family as Faces of Hope and keeps in touch with them. Louise Ray is actively involved and concerned about the Red Cross connection to this.

Your review of this issue would be greatly appreciated. Please let me know how we should proceed.

Sincerely,

Ann Walker
Special Assistant to the President
Director of Communications Research

against challenges in the future.

I understand the National Hemophilia Foundation wants a Congressional investigation of this issue and has drafted legislation for compensation for persons with hemophilia who are living with HIV/AIDS and estates of the deceased. Some countries' governments, for example France and Canada, have provided compensation for individuals with hemophilia who were infected through the blood supply.

I believe we should allow the IOM study to proceed and closely monitor the hemophilia patient advocacy groups efforts to get Congress to pass legislation. While I have not yet considered all of the issues surrounding the proposed legislation that is under discussion, I have some concerns that Congress will legislate compensation for hemophiliacs and not all groups. In fairness, Federal compensation should be given to all infected individuals regardless of risk or method of infection.

As for the ARC and the letter from the veteran lab technician, I understand the Food and Drug Administration (FDA) investigated this case last year and found no major compliance violations. In May 1993, FDA obtained a consent decree that placed the ARC under court supervision. In the consent decree, the ARC agreed to establish and document managerial control over training and quality assurance.

Thanks to new tests and advances in science, our blood supply is safer than it ever has been. Before a test to detect HIV in the blood was developed and approved in 1985, the ARC performed only two tests for infectious diseases. Today they do eight tests on each unit of blood. I understand ARC is undergoing what they call "the total transformation of how we collect, process, and deliver one-half of America's blood supply...the creation of a state-of-the-art system that can quickly incorporate medical technology as it evolves."

At the same time, the FDA is increasing its regulatory role over the blood industry. The Government and private sector are working together on these issues. Just last month, the Centers for Disease Control and Prevention issued "Guidelines for Preventing Transmission of Human Immunodeficiency Virus Through Transplantation of Human Tissue and Organs." These guidelines were developed through a collaborative process with industry, physician associations, academic institutions, scientists, and representatives from the agencies in the Department of Health and Human Services.

6/27/94

Kristine:

Per your request, the second paragraph on page 2 have been deleted.

Thx,
Betina

June 22, 1994

ACTION MEMORANDUM

TO: Kristine M. Gebbie

FROM: Alice M. Litwinowicz

SUBJECT: Letter to Ann Walker on the Blood Supply -- YOUR QUESTION

This is in response to your note regarding the paragraph on the second page of a letter to Ann Walker regarding the blood supply and asked "What does this mean?"

That paragraph was framing a very complex issue in the context that litigation is pending and advocacy groups are pushing for a Congressional investigation and monetary compensation. The paragraph was advising caution must be exercised when providing a written response to the original question: "Please let me know how we should proceed."

This paragraph expresses support for the study that is currently underway by the Institute of Medicine, under contract to the Department of Health and Human Services. I considered including this sentence: "We are confident that the study will not show any impropriety by the government." However, rejected it on two counts: 1) I thought it might be too "conclusive" since the study just started in November; and 2) I did not believe you would be totally supportive of such a statement.

The second part of the paragraph before editing read: "I have some problems in the area of compensation for only certain groups, that is, persons who were infected through the blood supply, and not for other exposure categories or risk groups, such as men who have sex with men or injecting drug users or their partners." I wanted to communicate that there is no "right or wrong way" to have become infected with HIV. I do not believe you want to be against compensation altogether, especially since all the sources I contacted believe it will happen eventually. I added the clause in front of the sentence, "While I have not yet considered all of the issues surrounding the legislation that is under discussion" for a couple of reasons:

- the legislation hasn't been introduced in the Congress

and therefore the "draft" language that HRSA obtained from the hemophilia advocacy groups, and shared with me, may change; and

- there may be other things in the bill that you will be asked to comment on later on and this would allow you enough "wiggle room."

Working with George, I have further modified the paragraph and hope it is satisfactory. Alternatively, we can delete the paragraph. I have included a page WITHOUT the paragraph.

I hope this helps. Please call me if you have any questions.

JUN 23 1994

THE WHITE HOUSE

Dear Jean -

I have asked the National AIDS Clearinghouse to send you some information on HIV. I'm so sorry to learn of the death of your brother. Please do stay involved in our efforts to educate people about HIV & AIDS - yours can be an important voice, and a legacy from your brother.

My best wishes — Barbara Bush

May 27, 1994

Dear —

My name is Jenn and I am 17 yrs old. I live in a small town in Vermont. I am doing, or I was doing a research paper on Aids. Could you please send me more information on Aids so I can be more educated, and let others be more educated, because the people today are going to be infected and affected. My brother with Aids ~~has~~ died 6 months ago because of Aids. Please send me more information so I can learn the facts. Thanks.

Jenn Lundrigan

Jenn Lundrigan
RR Box 4310
W. Rutland, Vt 05777.

THE WHITE HOUSE

WASHINGTON

June 24, 1994

Mr. Sam Scott
c/o Project AHEAD
375 Woodside Avenue
Bldg. W-3
San Francisco, California 94127

Dear Mr. Scott:

Thank you for your letter of inquiry regarding our activities for young people who are infected with HIV. As you know, the President appointed me National AIDS Policy Coordinator out of his commitment to take positive steps to end the HIV/AIDS epidemic. We are committed to stopping the spread of HIV, caring for those already infected and finding a cure as soon as possible.

The President is very concerned about providing care to those with HIV/AIDS. Since taking office he has increased funding by 89.4 per cent for treatment and services through the Public Health Service. The creation of the National Task Force for AIDS Drug Development will streamline drug development and encourage government-private collaborations. President Clinton's Health Security Act will provide guaranteed health benefits for all Americans, regardless of their HIV status.

The policy staff of my office collaborates with other governmental agencies on HIV/AIDS prevention, services and research. In this effort we focus on policy issues which impact young people, both those infected and affected by HIV disease.

With regard to provision of care for those infected with HIV, we collaborate with Health Resources and Services Administration (HRSA) and the Social Security Administration. These offices are directly responsible for the provision of services to those persons living with AIDS. Particularly, the Maternal and Child Health Bureau of HRSA administers the Ryan White Title IV programs which provides for primary HIV care services for pediatric and adolescent communities. Early access to treatment is a primary goal.

We are always open to ideas regarding the formulation of national

policies that affect young people. I have shared your letter with Frances E. Page RN, MPH of my staff, who has worked extensively with persons with HIV disease. Feel free to contact her at 202-690-5560 to discuss your concerns.

Sincerely yours,

Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator

Maritime Institute
of Technology
& Graduate Studies

What are you doing
Specifically For Young
People who Are infected
with HIV? & who in your
office is doing it?

Please Respond

SAM SCOTT
C/O Project Ahead
375 Woodside Ave.
bldg. W-3
San Francisco, CA.
94127
(415) 753-7875

JUN 27 1994

THE WHITE HOUSE

Dear Corinne —

Thank you for the "goody bag" and T-shirt from the American Indian Clinic. I appreciated your contributions to the discussion at the AIDS Regional Board, and look forward to hearing more about your work in the future.

Best wishes — Christine

The original American Indian Free Clinic Established 1969

The American Indian Clinic, Inc.

AIDS PROGRAM

9500 East Artesia Boulevard, Bellflower, California 90706

AIDS EDUCATION is available to you as an individual at home, school or in a group setting.

This workshop will cover:
Are you at risk in getting AIDS?
(Answer these questions)

1. Have you ever used IV drugs/alcohol?
2. Have you had more than one partner within the last 10 years?
3. Have you had a gay/bisexual experience within the last 10 years?

If you answered yes to any of the above you may be at risk for getting AIDS.

Come learn:

1. PREVENTION is the KEY.
2. RESOURCES are available for testing sites in your area.
3. SUPPORT group resources.

For further information, **PLEASE CALL** (310) 920-7227 ask for **CORINNE TANON.**

As Indian people, we are not open to talking about the subject of sex, however, because of the threat it has on us as Indian people we must share this information in a culturally sensitive manner before it wipes us out like the smallpox epidemic.

"SNAG CAREFULLY"

Clinton Presidential Records
Digital Records Marker

This is not a presidential record. This is used as an administrative marker by the William J. Clinton Presidential Library Staff.

This marker identifies the place of a publication.

Publications have not been scanned in their entirety for the purpose of digitization. To see the full publication please search online or visit the Clinton Presidential Library's Research Room.

The American Indian Clinic, Inc.

11 pgs

The American Indian Clinic, Inc.

Headquarters and Clinic
9500 E. Artesia Boulevard
Bellflower, California 90706
310/920-7227
fax 310/920-5677

American Indian
Eagle Lodge
824 Atlantic Avenue
Long Beach, CA 90813
310/436-3991
FAX 310/495-1095

Satellite Sites

American Indian
Temporary Shelter
1330 South Long Beach Boulevard
Compton, CA 90224
310/537-4594

American Indian
Main Artery
1330 South Long Beach
Boulevard
Compton, CA 90224
310/537-0103

The American Indian Clinic, Inc.

Location and access to the AIC / Services

Medical Department - Prenatal

Medical Department - Nutrition / WIC

Dental Department - Health Education

Research & Development - Cancer Research Consortium

Eagle Lodge - Substance Abuse Programs

Prevention Newsletter - American Indian Television

Main Artery - Temporary Shelter