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5715 BENT BRANCH ROAD
BETHESDA, MD 20816
PHONE 301-320-2686/4910
FAX 301-320-0048

INSTITUTE FOR FAMILY-CENTERED CARE



January 27, 1994

Kristine Gebbie
National AIDS Policy Office
750 17th Street, NW, Suite 1060
Washington, DC 20503

Dear Ms. Gebbie:

Joan Milne suggested I write to you about the Family Leadership Conference to be held March 4-6 near Baltimore, Maryland. We would be greatly honored if you could join us for some portion of the meeting. Several of the families who will be attending the conference heard you speak at the Pediatric AIDS Demonstration Projects Meeting in November and were greatly inspired. I know that other family members would welcome the opportunity to meet you, even briefly.

The goal of the conference is to build the leadership and advocacy skills of families affected by HIV and AIDS. At least two family members -- birth, foster, and adoptive parents, as well as extended family members -- from each of the 44 federally funded Pediatric AIDS Demonstration sites will attend the conference. The conference will build a mutual support network for these families and provide them with the skills and information to work on behalf of affected families in their home communities. A particular emphasis of the conference is the building of family-to-family networks in communities throughout the country. As you well know, families dealing with HIV have for too long been isolated and stigmatized and forced to deal with this devastating illness without adequate emotional and social support.

Enclosed is the agenda for the meeting. If you are able to attend, it can easily be modified to fit your schedule. Ideally we would like you to speak for 10-15 minutes, with a few minutes for questions. Your interest and participation would mean a great deal to the families. We have convened a number of conferences for families affected by HIV over the last four years and they are always powerful experiences. I believe you would be deeply affected by the commitment, strength, and integrity of the families and would greatly enjoy the opportunity to meet with them. We very much hope you can join us.

Please let me know if I can provide additional information about the Family Leadership Conference. I look forward to hearing from you.

Sincerely,

Ibbey Jeppson, Ph.D.
Director, Pediatric HIV Programs

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The Children's Hospital, Boston

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Advancement of Teaching

MARTHA BIL MANEVICH, AIA.
Planning and Design Consultant

PHILIP PIZZO, M.D.
Chief of Pediatrics, Head, Infectious Disease Section
National Cancer Institute, NIH

MICHAEL B. ROTHENBERG, M.D.
Co-author *Dr. Spock's Baby and Child Care*

VIRGINIA RICHARDSON
Parent Training Manager, PACER Center

KAREN SCHROCK
Chief, Center for Substance Abuse Services
Michigan Department of Public Health

WILLIAM E. SCHWAB, M.D.
Associate Professor, Department of Family Medicine
University of Wisconsin

EDITH M. SELIGSON, M.S.
St. Christopher-Ortlie Services for
Children and Families

TERRI L. SHELTON, PH.D.
Associate Professor of Psychiatry and Pediatrics
University of Massachusetts Medical Center

REED V. TUCKSON, M.D.
President
Charles R. Drew University of Medicine and Science

BERNICE WEISSBOURD
President, Family Focus

MICHAEL WEITZMAN, M.D.
Professor and Associate Chair of Pediatrics
University of Rochester School of Medicine



INSTITUTE FOR FAMILY-CENTERED CARE

5715 Bent Branch Road Bethesda, MD 20816 Phone: 301/320-2686/4910 FAX 301/320-0048

Family Leadership Conference

March 4-6

Maritime Institute

Linthicum Heights, Maryland

“Making Connections”

Draft Agenda

This three day conference will focus on building participants' leadership potential. Presentations will highlight personal skills, family-to-family support, and partnerships with providers. Participants will have the opportunity to develop their own *Individual Leadership Plan*, a personal description and action steps, for improving services and support for children and families affected by HIV.

Friday, March 4

2:00-5:00 Arrival and registration

5:00-7:00 Dinner -- this is an informal, family-style meal

7:00-9:30 **Welcome and Introductions** -- participants will have a chance to get to know each other and share their stories

Saturday, March 5

8:00-9:00 Breakfast

9:00-9:45 **“Personal Leadership: Connecting with One's Own Power”**
Linda Horton, Baltimore

This is a large group session for all participants. This session will set the tone for the conference and discuss the leadership potential of all families.

9:45-10:00 Break

- 10:00-12:00 "Building Personal Leadership"**
Small group sessions with facilitators to lead activities and discussions on building personal leadership skills. Participants will begin work on their *Individual Leadership Plan*.
- 12:00-1:00** Lunch -- Welcome and comments from the Maternal and Child Health Bureau
- 1:00-1:30 "Extending Leadership: Connecting with Other Families"**
Felicia Jordan -- Director, Project Uptown, Detroit, MI
This is a large group session on the power of family-to-family support and networking. Examples from communities around the country will be presented.
- 1:30-1:45** Break
- 1:45-3:45 "Being a Support Parent: Building Skills"**
Small group sessions with facilitators to lead discussion and activities to help participants learn how to support other families and build family-to-family support networks in their own communities. Participants will continue work on their Individual Leadership Plan.
- 3:45-4:00** Break
- 4:00-5:00 Workshops:**
- Developing Juggling Skills During Stress and Change -- Larry Edelman
 - Secrecy and Disclosure Around the Diagnosis -- Mary Tasker
 - Supporting Brothers and Sisters who aren't Infected but are Affected -- Jenny Jones
 - Youth Living with AIDS -- Antigone Hodgins
- 5:00-6:00** Dinner
- 7:00-8:30 Evening support groups (each will have a facilitator)**
- recovery group
 - dad's group
 - grandmother's group
 - youth group
 - group for families who have lost a child
- 8:30-10:30 Dance party** -- a time for fun, prizes, music, and laughter.

Sunday, March 6

- 8:00-9:00** Breakfast
- 9:00-9:30 "Making Connections: Building Leadership Through Collaboration and Advocacy"**
Geneva Morrison, Mary Tasker, and Sheri Rosen, Newark, NJ
This large group session will discuss collaboration and advocacy and share ways that families can build partnerships with professionals in their programs and in their communities.
- 9:30-9:45** Break

9:45-11:30 "Families as Advocates and Collaborators: Building Strength"

Small group sessions with facilitators to lead discussion and activities to develop collaborative skills. Participants will continue work on their *Individual Leadership Plan*.

11:30-12:00 "Putting It All Together" -- a wrap-up session and discussion of next steps for the *Individual Leadership Plans*.

12:00-1:00 Brunch

1:00-3:00 Networking for those who wish to stay or have later flights

3:00 p.m. Checkout

Families & HIV

Problem -

the virus has spread at least in part
due to disrupted families

the recognition of the virus has
disrupted families

Families have been separated from ~~network~~ ^{community}
by the virus - by the community
in fear / self protection

Unexpected benefit

the virus has led families together

the virus has created new communities

Core lesson from the epidemic

the voice of the person living with
the struggle must be heard

in decisions on caring / treating

in decisions on research ^{parents & children together}

in development of policy

in telling the world the story

? new challenges as child grows -

as the joys of adolescence

Key political ?

health reform

Universal !!

will keep Ryan white & other spec. programs
as wrap around

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INSTITUTE FOR FAMILY-CENTERED CARE



March 17, 1994

MAR 21 1994

Kristine Gebbie
National AIDS Policy Office
750 17th Street, NW, Suite 1060
Washington, DC 20503

Dear Ms. Gebbie:

Thank you so much for joining us at the Family Leadership Conference on March 6. Your candor and expertise were greatly appreciated by the participants. As always, I was so impressed by your grace under pressure and by the honest compassion and concern you show to families struggling with HIV and AIDS.

The families who participated in the Leadership Conference are already working in their home communities to improve care and services to children and families affected by the epidemic. The opportunity to meet with you was further validation of the importance of their work. Thank you again for sharing part of your Sunday with us.

Sincerely,

Ibby Jeppson
Director, Pediatric AIDS Projects



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REALITY

A Newsletter By and For Youth Living with HIV

My Coming of Age by Alfredo Lopez

I am an 18-year-old Latino who is gay, and I'm HIV positive. I came out when I was 16 years old, but I'd had sex with other men since I was 15. Before I took the antibody test, I didn't talk about AIDS or safe sex. I was afraid if I brought it up I'd be rejected by a sex partner. In the end, no one talked about it a lot. None of my teachers talked about it either; there was no real AIDS education in the classroom.

Testing

The first time I tested I was 16 years old; my results came back negative. I hadn't been infected, so I figured that my sexual activities were okay and I didn't change. I decided to test again, one year later, because two of my friends were testing at the same time. I planned my second test around my vacation, in the spring. I chose a family planning health clinic three cities away from suburbia and my home. I didn't want to run into anyone I knew.

I was afraid that I might be positive. But I couldn't believe it when I was. I cried for a while and shouted, "Fuck I can't have my own kids." After I calmed down, my counselor directed me to services for HIV-infected youth: a nurse practitioner, a support group, and a case manager. I really didn't want to use the services provided in my county so I went to the neighboring one. I wanted to keep this anonymous from everyone I knew, especially my parents.

Support from Friends

I feel kind of a release when I tell my friends that I am HIV positive. Many know that I am gay but only a few know about the HIV. I'm afraid if I tell more,

they'll reject me. Those I do tell are very supportive and caring and want to know if I'm taking care of myself.

Surprisingly, my strongest support for being gay and having HIV has

come from the place I never thought it would: high school. High school failed me; the teachers never taught me about AIDS, and because of that I have HIV. My best support, however, had come from two teachers. I speak with them at least once a week.

The support for *cont'd on page 2*

TABLE OF CONTENTS

TESTIMONIAL.....	1,2
BAY POSITIVES.....	1,3
POEM.....	3
DISCLOSURE.....	3
SPEAKER'S BUREAU.....	4,5
HERBAL TREATMENTS.....	6,7
ORDER FORMS.....	8

BAY Positives Is Now An Agency!! by Scott Miller

Empowerment is an important tool in the fight against HIV, and San Francisco young people with HIV are at the forefront of the HIV positive youth empowerment movement. In 1990, a volunteer-based support group assumed important leadership roles, and began to plan for the future. HIV positive youth facilitated groups and offered one-on-one support. The group began to view itself as an emotional support program, and it took the name "Bay Area Young Positives," or "BAY Positives." BAY Positives members were disappointed at the lack of youth-specific and youth-sensitive HIV services. As far as the members knew, they were the only program run by and for HIV+ young people. To answer their needs, the members worked to create a youth-run agency. In 1993,

after years of hard work, the dream became reality.

Back in January 1993, BAY Positives members became a California nonprofit corporation, and in July, the federal government gave BAY Positives nonprofit status. This nonprofit corporation status allowed the group to apply for grants and other money to serve youth with HIV. Successful requests were made to the San Francisco AIDS Foundation's AIDS Walk, to the local Department of Public Health's Ryan White CARE funding programs, and other sources of money.

Bay Positives created a Board of Directors made of young people with HIV and knowledgeable community professionals. HIV+ young people are the majority of the Board, making sure that BAY Positives *cont'd on page 3*