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WHCCAM Meeting Testimony, January 23, 2001 [6]

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The Role of Ayurveda in 21st Century US Healthcare

Presented to **WHCCAMP** *by*

Swami Sada Shiva Tirtha, D.Sc.
President, Ayurveda Holistic Center
& School of Ayurveda

January 23, 2001

Mr. Chairman and commission members, my name is Swami Sada Shiva Tirtha. I am the president of the AHC & School of Ayurveda offering consultations, pancha karma spa therapies and certification & Ph.D. programs. I hold a Doctor of Science in Ayurvedic Medicine.

It is spirit that we are talking about here, not herbs or yoga or drugs. Spirit is the core therapy. Ayurveda unlike any science offers a spiritual dimension. Love, care & compassion are the essence of Ayurvedic healing– more than mundane therapies.

Healthcare must fit into a spiritual paradigm. We cannot mold traditional medicine into the allopathic system without destroying its spiritual effectiveness.

Therefore it is crucial that an Ayurvedic expert be represented on your commission or at the very least on a secondary panel. If you are to be effective and taken seriously, the commission must include representatives of the original healing sciences or run the risk of overlooking the essence of healthcare.

Along with love, care & compassion, Ayurveda contains a complete & profound science.

It diagnoses the root cause of illness with unique pulse taking methods and treats in an individualized manner with herbology, nutrition, aromatherapy, yoga, massage, etc. More than 2,000 research studies have proven Ayurveda effective, safe and inexpensive.

In my center we have consistent success with
OB-GYN: PMS, menopause, bone-loss, cysts & natural hormone balance
Seniors: age-reversal, memory loss, brittle bone, arthritis
Special: Parkinson's, MS, Fybromyalgia

Ayurveda is cost-effective: Medicare & Medicaid patients won't have to choose between paying for food or medicine.

My pilot research study on seasonal allergies found a savings of 2 billion dollars for a 6-month allergy season compared to allopathic treatment-costs. Apply this comparison to digestive diseases, & we would save hundreds of billions of dollars a year.

There should be as much press coverage for alternative medicine as there is on allopathic drugs – pass an 'Equal Air Time Bill'. In a time when western medicine has no answers for many diseases, causes deadly side effects and exorbitant pricing, it is a crime that people can't hear about these alternative medicine successes. Create proactive holistic-health laws. Don't just fight unfair label and freedom of information law attempts. Create bills that punish the truly criminal injustices of current healthcare.

Set up a website database for practitioners to submit their case studies and research findings to inform practitioners & citizens. Use these databases to report to the press.

I encourage a national & state "practitioner regulatory committee" based on the Minnesota model. In NY we are not allowed to practice Ayurvedic massage without undergoing a lengthy, costly process to obtain a license in Swedish massage. Yet a licensed masseur can practice Ayurvedic massage with only superficial training.

Increase alternative medicine funding and set up an office to help practitioners write research grants and choose the best statistical analysis methods (e.g., regression, t-test).

Other Suggestions & Thoughts

Whole herbs are safer than allopathic medicine. JAMA reported that 4th leading cause of death in the US is due to prescription drugs. This is 2½ times more deaths than is caused by AIDS.

Hold educational symposiums several times a year for holistic and allopathic professionals to meet to bridge the semantic gap.

There should be an equal partnership between traditional and allopathic decision-makers. Rigorous research methods and spiritual integrity must both be maintained.

The essence of alternative medicine, to use a computer industry label, is an open platform, that is you cannot patent herbs or healing and thus deters pharmaceutical companies from investing in or supporting alternative medicine. There needs to be a paradigm shift away from the old views of how to make money on the sick, and find new ways to make money from the healthy. The use of spas, prevention, rejuvenation etc. will bring people for the pleasure of it and the cost-savings of prevention will still be better than compared to treating disease, side effects and complications.

There should be more research on cost-effectiveness comparisons between traditional and modern medicine therapies for each disease. These can include prevention costs vs disease-treatment costs.

Research Study:
Cost Comparison between Ayurvedic & Allopathic Methods in Treating Seasonal Allergies
By Swami Sada Shiva Tirtha, D.Sc.

Abstract

Background: Seasonal allergy symptoms affect almost 10% of all Americans. The treatment of these pervasive symptoms often require decongestants and antihistamines to control allergic rhinitis with or without ocular involvement. Treatment is costly and adverse drug reactions are common with these medications, some of which may be quite serious.

Method: In a preliminary study on the cost-effectiveness of Ayurvedic treatment of seasonal allergies, 5 subjects received a combination of herbs and nutritional therapies according to their constitutional profiles and their specific symptoms.

Results: In all cases significant or complete allergy relief occurred within two days to two weeks, and eventually reporting complete relief. Long-term follow-up evaluations in two subjects for four and five years showed that as long as the subjects followed their Ayurvedic nutritional regimens, no seasonal allergy symptoms recurred. The allergy symptoms did return, however, only when the subjects discontinued their therapies. Cost comparisons showed that over a six month allergy season, Ayurveda-treated subjects spent between $0 and $147, while the average cost for physician visits and OTC or prescription drugs cost approximately $535 for the same 6 month allergy season provided no adverse drug reactions occurred. The costs rose significantly when drug side effects occurred, ranging from $735 to $1,070. [Costs based on estimates from two allergists]. 10% of Americans (27+ million people) with seasonal allergies translates into more than $2 bill extra costs in allopathic care.

Conclusions: The Ayurvedic treatment of seasonal allergies based upon one's constitutional profile and specific symptoms is safe, effective, and considerably less costly than traditional western therapies. Future studies including larger groups of subjects are needed to further evaluate this cost-effective holistic approach to allergy treatment.

Research Study Cost-Effective Comparison Data

	Allopathy	**Ayurveda**
Cost of Initial Visit	$125	$50-100
Cost of Follow-up	$50-85	$25-50
Follow-up Time	2-3 weeks	2-3 weeks
Number of Visits	2 visits minimum	1-2 visits minimum
Cost of Therapy	$60-80/month	nominal - $12/month
Lost Days of Work/School	1-2 days	0 days
Side effects	Possible	None
Cost of Side Effects	Dr. Visit: $125 Cortisone injection: $25-45 Follow-up Visit 3-5 days later: $50-150 Prednisone (if required): $35-40 Emergency (if rushed to hospital with serious reaction): $300-500 (x-rays, lab tests, injection) Next day Primary care Dr. visit: $85-150	n/a
Cost: 6-month sample (April-Sept) Allergy patient with no side effects	**$535**	**$0 - $147**
Cost for a 6-month sample (April-Sept) Allergy patient with **side effects**	**$735-$770** with hospital **1,035-$1,070**	**n/a**

Sampling of Ayurvedic Scientific Research

amalaki-acute pancreatitis-10
amalaki/haritaki/bibhitaki-cholesterol-induced atherosclerosis-10a
amalaki/bibhitaki/haritaki/amlavedasa (yellow dock)-HIV-24/antimicrobial-24a
arjuna-antianginal,cardioprotective-13 & 13a/angina pectoris 13C/cardiac tonic and current uses include treatment for angina, hypertension, arrhythmias, and congestive heart failure. 21
arjuna/guggul-ischemic heart disease (inadequate blood flow to heart leading to angina pectoris/heart attack)-13d
cancer-13b/arjuna, nirgundi-anti-bacterial-9
ashwagandha and shilajit cognition enhancing, memory, Alzheimer's-2a/antioxidant-2b
bakuchi-nutritional source of genistein and daidzein isoflavones-18/asthma-18a
bhuamalaki-HIV 30 & 30a
bilwa-antifungal-16
black pepper-anti-bacterial/penicillin-15/antioxidant-15a
black pepper, cumin-colon cancer-36
brihati-antitumor-38
chirayata-antimicrobial-1/hypoglycemia-1a/12b
cinnamon/cumin-anti-bacterial-11
coriander-cholesterol/triglicerides-11a
cumin/basil-anti-carcinogenic-12
cumin and turmeric-antiatherosclerosis, anti-inflammatory, antithrombotic-40
fenugreek-diabetes-32
ginger-nausea, vomiting, headache, arteriosclerosis-41, 41b/rheumatism-41a
ginger, pippali, coriander, musta, cumin, cinnamon, asafoetida, triphala-indigestion-41c
gotu kola - psoriasis - 22/ antioxidant/memory enhancing, epilepsy, insomnia, sedative-22a
gotu kola, shank pushpi, ashwagandha, licorice, vacha, sarpagandha-schizophrenia-22b
guduchi-immunity-26/ liver disease 26a/jaundice 26b/diabetes type II -29/ joint swelling in adjuvant arthritis-37
guduchi, turmeric, bilwa, karella-urinary tract infections-26c

guggul-cholesterol/atherosclerosis-19, 19a/superior to nitroglycerin-reducing chest pain and dyspnea of angina-21
gurmar-suppression of sweet tastes-12a, 12b/diabetes-27
gurmar, neem, shilajit-diabetes-27a
haritaki, bhringaraj, tulsi-antibacterial-23
ishabgol-irritable bowel syndrome-17
kapikachu-Parkinson's-8/ diabetes-33
kushta-anti-tumor-7/hepatitis B-7a/kutki- hepatitis B-31
licorice- antimicrobial-42/atherosclerosis-42a/anti-viral-encephalitis-42b
manjishtha-anti-tumor-6-6a/ antioxidant-6b/ antiviral-6c
neem-malaria, anti-parasitical-4
nirgundi-anti-inflammatory-5a
punarnava, guduchi, haritaki, ginger, barberry-immunity/T-cells-25/liver-25a
punarnava, bhringaraj, chirayata, arogyavardhini, mandur bhasma-liver/bile-25b
saffron-antitumor-35
shatavari-gastric emptying time-3
shilajit-peptic ulcers and anti-inflammatory-2, 28
trikatu -absorption/bioavailability-14
turmeric-gallstones, cholesterol-20/ibuprofen substitute, anti-inflammatory-20a/ anti-carcinogenic-20 B/anti-inlfammatory, antispasmodic, liver/bile-39
turmeric and cumin-cancer lesions-20c/antitumor-20d

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Swami Sada Shiva Tirtha, D.Sc.
Curriculum Vitae

1974 Initiated into Indian meditation
1975 BA Interdisciplinary Studies
1976 Certified meditation teacher
1980 MA Non-Verbal Communication Research
1988 Ayurveda Certificate - Ayurvedic Institute
Opened Ayurvedic Holistic Center
Advanced private study with Benares Hindu University professors in India
Met spiritual teacher (guru) in India
1989 Ayurveda Certification - American Institute of Vedic Studies
Founded Hindu non-profit monastery in US -
named Swami Narayan Tirtha Math to promote spirituality and Ayurveda
1990 Published spiritual book, Yoga Vani by Swami Shankar Purushottam Tirtha
Advanced private study with Ayurvedic doctors in Himalayas
Developed one of the first line of Ayurvedic herbal products in US
1991 Founded the International School of Ayurveda–
(One of the first Ayurveda schools in US)
Advanced private study with Ayurvedic doctors in Himalayas
Received initiation into monkhood (sannyas) as swami from Guru in India
1995 Published second spiritual book, Guru Bani by same author
1997 Created one of the first online Ayurveda websites – now a top-3 Ayurveda site.
1998 Wrote the Ayurveda Encyclopedia
Completed Ayurveda scientific research study on cost-comparisons
1999 Earned Doctor of Science (D.Sc.) in Ayurvedic Medicine (first in the US)
2000 Research study published in the American Ayurveda Journal – July
Wrote the Ayurveda Primer E-Book/interactive multimedia CD-ROM

Miscellaneous

Ayurveda Encyclopedia – Amazon.com top 3 bestseller in Ayurveda category in US, UK, Japan & France. 8,000 copies sold through Dec. 2000
Government advisor – US Senate, NCCAM, Nat'l. Council for Alternative Medicine
University lecturer – John Hopkins University, Penn State
Special advisor to the Ayurveda Acupuncture Board of Accreditation of Australia

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001. testimony	Judy Schneider (partial) (1 page)	01/23/2001	b(6)

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[001]

January 23,2001
Judy Schneider
(b)(6)
Staten Island, N.Y. 10314
(b)(6)

I am here tonight wearing two hats. One is a member of The Executive Board of the Feingold Association of the United States, the oldest support group in the country for children with attention, behavior and learning problems. The second hat is that of an M.O.M.

When my daughter Kori was two and a half, she was on her way into autism. I kept saying , "There's a wall there. I can't get through the wall!" She was having psycho-motor seizures where she would wake up in the middle of the night with her legs and arm's flailing . She also showed signs of developmental delay. The Dr.'s recommended medicating her. It was at that time, 1978, my mom read an article about a new program, The Feingold Diet, that used dietary management to help these children. After 3 days on the program I had a new child. The seizures went away, she was sleeping through the night for the first time since she was born and she began to grow both physically and mentally. By the time she was in third grade she was in the gifted program and is currently a New York University graduate. By simply changing the brands of food in my daughter's diet she has become a productive member of society. In fact, she recently starred in an off-Broadway production where she played Miranda in The Tempest.

I request the Commission consider the following:

1. Parents need to be given, by their medical professionals, all the options for the treatment of attention, behavior and learning problems. One of these strategies needs to be dietary management which has been used successfully by the Feingold Association for 25 years.
2. The Feingold Program which costs $77 for the first year and $48 for renewal of materials, needs to become a reimbursable medical expense.
3. Additional research needs to be funded . One area which needs to be studied is the role enzymes play as part of this disorder. An interesting study was done in 1994 at Birmingham University, U.K. by Dr. Rosemary Waring . It showed an enzyme, phenol sulfotransferase (PST) which rids the body of phenolic compounds, was found in an extremely low level in her Autistic/ADHD population. Since most artificial flavors, colors and certain preservatives are phenolic based, without this enzyme present these foods may need to be removed from the diet. If this enzyme is the culprit a simple test needs to be standardized similar to the P.K.U. test to determine the level of this enzyme especially in children.
4. Dr.'s who select dietary management as the appropriate method of treatment for their patients, need to be protected from prosecution. I would like to bring to the Commission's attention the fact that Dr. Robert Sinaiko has been put on probation without the right to practice medicine by The Medical Board of California for prescribing

dietary management for an ADHD patient after medication had been unsuccessful. According to the California Board "ADHD is a psychiatric disorder whose only treatment is pharmacological." I heartily request that this situation and that of other Dr.'s in the same category needs to be reviewed.
5. We need to understand the role of the pharmaceutical lobby in decisions being made by both medical professionals and medical boards in excluding dietary management as a treatment option. Dr. Sinaiko was about to standardize a test to predict which children would benefit from dietary management just prior to his enditement.

I would to end my comments by sharing a true anecdote. When my daughter was about to enter high school we had a discussion about drug use. She simply said, "Ma. I don't do artificial flavors and colors why would I do drugs!"

FEINGOLD® ASSOCIATION OF THE UNITED STATES

Membership/Information Office
127 East Main Street, Ste 106
Riverhead, NY 11901

Telephone 631-369-9340
FAX 631-369-2988

January 23, 2001

Dear Commission Members,

It is my distinct honor and privilege to speak as President of the Feingold Association of the United States on behalf of the hundreds of thousands of families we have assisted over the past 25 years in addressing behavior, learning and health problems through dietary intervention. The service we provide remains unique and unduplicated, in our mission to generate public awareness of the potential role of foods and synthetic additives in behavior, learning and health problems, and to support our members in the implementation of the Feingold Program.

The Feingold Program should be properly recognized as the "cornerstone" of care it can be in providing a baseline to allow for a clear diagnostic picture to be assessed. Those who may be affected by dietary factors can be identified through a simple trial which poses no risk, and then the most appropriate treatment can be determined. The use of the Feingold Program does not exclude the use of any other treatment modality, and can be used as part of a multimodal approach to address the problems associated with, for example, ADHD and autism -- issues commanding current national attention. This understanding is particularly important in light of the concerns being expressed regarding the use of drugs in addressing the needs of children under the age of six.

When used appropriately, drugs can offer many benefits, but they are not always used properly for children with behavior, learning or health problems. We would like to insure that children receive careful screening to rule out the many things that can trigger attention/behavior problems. We believe that inadequate attention is given to ruling out underlying medical conditions, and initiating stimulant or other medications without considering such conditions may only mask their symptoms and make them harder to identify.

Access to information regarding the use of dietary intervention must be assured, and health care providers must be able and responsible to present accurate information about all available treatment options based on experience and research without fear of reprisal. In this way, there is opportunity for informed choice and participation as a full partner in care decision-making. The case brought by the California Medical Board against Dr. Robert Sinaiko raises grave concerns about jeopardizing such access through supportive physicians.

Compelling evidence on the use of diet as a non-drug therapy for ADHD was presented by Dr. L. Eugene Arnold at the National Institutes of Health (NIH) Consensus Development Conference on ADHD in 1998. The final statement noted "Some of the dietary elimination strategies showed intriguing results suggesting the need for future research." Despite this comment, there was no follow-through in the listed research suggestions, no further mention of the need to resolve concerns by continuing to search for underlying causes.

Additionally, often repeated but erroneous information abounds from even respected sources. Some of this misinformation is found in government sources such as the National Institute of Mental Health web site stating, "restricted diets have not been scientifically shown to be effective." [see www.nimh.nih.gov/publicat/adhd.cfm]. Such inconsistency undermines credibility.

The Assistant Surgeon General, Dr. Marilyn Gaston, sent a designated speaker to be our keynote presenter at our 25th Annual Conference which addressed the relationship of diet to behavior, learning and health. It specifically focused on ADHD and autism, issues of public health concern about which we were able to express our desired goals for participation in the ongoing search for answers.

I have come forward in good faith to present concerns to the NIH, the Assistant Surgeon General, and to you today. In light of its long-standing, unique contributions and commitment to the future, the Feingold Association would deeply appreciate consideration in the following areas:

1. Utilization as a resource providing a simple, cost-effective, first-line approach to facilitate diagnosis and determination of the most appropriate intervention in behavior, learning and health problems such as ADHD and autism

2. Inclusion in any current and future efforts to address public health concerns related to diet and behavior, learning and health

3. Assistance in mandating and funding further research needed to address unresolved issues related to diet, such as those documented in the NIH Consensus Development Statement on ADHD

Thank you for your consideration of these issues about which we share concern, and we are grateful for the opportunity to provide any additional insight.

Sincerely,

Kathleen Bratby, MSN, RN
President
Feingold Association of the United States
Clinical Assistant Professor
SUNY at Stony Brook
School of Nursing

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002. testimony	Sandra Ehrenkranz (partial) (1 page)	01/23/2001	b(6)

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[002]

I am a person with ADHD, the mother of a highly successful son with ADHD and grandmother to his child with ADHD. My family has successfully implemented the Feingold Elimination Diet and find that it results in a significant improvement in ADHD and its co-morbidity's.

The Feingold Program, as Dr. Feingold's elimination diet came to be known, eliminates all artificial colors, artificial flavors, and the preservatives BHA, BHT, & TBHQ. For some people it, eliminates aspirin and a group of fruits and vegetables related chemically to the salycilate in the aspirin.

The Feingold Association was founded by parents, in order to give support and make it easier for people who wish to implement the program. The Feingold Program addresses the symptoms and co-morbidity's of ADHD. The Feingold Program should be the first choice a physician offers parents of young patients. It seems reasonable that for the pre-school age child it should be the optimum choice.

We are here to help every person who wishes to try the Feingold Program. Over the past 25 years the Feingold Association, has developed a system to research ingredients in food and non-food products. A booklet is available that lists products, by brand name, that meet the standard of the Feingold Program. We are the only organization providing this service. Because the current legislation regarding labeling is not sufficiently stringent for children who respond to the Feingold Program the likelihood of success by just reading labels is low. The failure is often blamed on the Program rather than the method they used to implement it. The Feingold Association is run by volunteers whose families have benefitted from the program, many of us with 20 or more years of experience. We have come to understand that for some children the program needs to be individualized, with the elimination of other allergenic foods. Symptomatic improvement is often striking.

In addition to the brand name food list we also supply a fast food list, medication guide, mail order list, resource list, telephone help line, and internet support group. The Feingold Association's news letter updates the food and non-food product list, it also contains relevant, informative articles.

As members of the White House Commission you should know that the Feingold Association would be pleased if the government insisted on full disclosure of all ingredients used in processing and packaging a product. All these ingredients should be listed on the product. It would make it easier to follow the program and obviate the need for our product research center.

Respectfully submitted to the White House Commission
January 23, 2001
by Sandra Ehrenkranz
(b)(6) Stamford, CT 06905
(b)(6)
email: sandy@feingold.org

JANUARY 23, 2001

- Members of the Committee, Ladies and Gentlemen of the audience good afternoon. My name is Janice Pingel and I live in Scarsdale, New York.
- I have had two bona fide cures with the help of Accupuncture, of that I am certain. - In 1990, after eight years of excruciating lower back pain, which no medical doctor could help me with, I turned to Alternative medicine, which was Accupuncture. I turned to it, but with no expectations of success. Six sessions later I left that office, pain free. I have never had another seizure; that was eleven years ago.
- In 1996 I suddenly developed severe leg pains. This time I went directly to Accupuncture treatment to my present doctor, Doreen Chen. After eight treatments and the consumption of Chinese Herbal tea, I left her office healed with no further problems.

- Now to my present situation:
In 1997 I was diagnosed with uncurable neuro-endrocrine cancer of the lung with metastises to the liver. I began very aggressive Oncology treatment with Dr. Sara Sadaw and at the same time returned to Dr. Chen for bi-monthly needle treatment to support my immune system. At that point my oncologist would allow no consumption of herbal tea from Dr. Chen. A small remission occured and I was out of treatment for six months. I continued with Dr. Chen and was now able to drink her tea. That was sometime in 1998.

- In October 1999 I returned to Dr. Sadaw for weekly treatments of Taxol, which continues to this day. At the same time a new tea, Cordyseps-Militaris was released in China for treatment of lung, liver and kidney cancer. This time I prevailed upon Dr. Sadaw to allow it to be part of my

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treatment. She was very openminded to this request and agreed.

- CT scans are given every three months. In September of 2000 my scan showed all leisons in the lung are gone and Cancer growths, which had covered the liver were decreasing.

- Both Dr. Sadaw [who has written testimony on my case to my insurance Company] and Dr. Chen believe as I do that the Combination of allopathic and homeopathic Medicines are having a Cureative effect on my Kind of Cancer at this present time. My January 10th CT scan also showed very positive results in tumor stabilization.
- Thank you very much for allowing me to share my story.

Mrs. L. W. Pinsel
(b)(6)
Scarsdale, NY 10583-2724

(b)(6)

REMARKS BEFORE THE WHITE HOUSE COMMISSION ON COMPLEMENTARY AND ALTERNATIVE MEDICINE

New York City Town Meeting

January 23, 2001

Joan F. Runfola, ACSW, LCSW
Associate Executive Director
Cancer Care, Inc. - New Jersey Division
Co-Chair, Special Interest Group on CAM
Association of Oncology Social Workers

I. Remarks based on having counseled people with cancer for over 20 years re: medical decision-making, particularly about CAM.

A. Also embarked on own medical decision-making process two years ago when diagnosed with breast cancer.

II. Use of CAM

A. Reported use ranges from 9% to 85%. Information about CAM is highly available through word of mouth, media, and internet, but often reliability of that information, especially on the internet, is questionable.

B. Although medical consumers review much of the information available about various CAM (and other) approaches, decisions are often made based a combination of:

1. Anecdotal evidence (e.g., experiences of friends and family)
2. Incomplete or inaccurate information (not based on science)
3. Personal beliefs and preferences

C. 35-72% don't discuss their use or intended use of CAM with their physicians.

D. Most physicians lack adequate information to guide patients in pursuit of CAM.

III. Propose that this Commission uses a reputable web site, such as its own, or that of The Center for CAM (of NIH), which includes a list serve, where physicians, other health care professionals and the public can have ongoing access to:

A. Latest facts about proven effectiveness of various CAM modalities, including:

1. Type of research conducted to reach conclusions
2. Method by which treatment or modality is administered

3. Indications
4. Risks (including side-effects) and benefits

B. Questions to ask practitioner when considering particular CAM approach, and practical considerations (e.g., cost, impact on lifestyle) to discuss when deciding about use of CAM (e.g., see attached Cancer Care *Brief* on "Making an Informed Decision about Complementary and Alternative Treatments to Manage Cancer).

C. Resources to locate qualified CAM practitioners (see attached handout "Resources to Find CAM Practitioners"), and list of qualifications one should seek when choosing a CAM practitioner (e.g., licenses or certifications).

D. Guidelines for both health care professionals and patients to use to communicate with one-another about use of CAM.

IV. Education of physicians/health professionals about CAM

A. Recommend revisions in medical school requirements to include CAM (for those that don't already include these).

B. Recommend states revise continuing education unit requirements to include minimum number of hours related to CAM and development of standardized model similar to EPIC Program (which is on end-of-life care) for CAM.

CANCER CARE Briefs

Cancer Care, Inc.
National Office
1180 Avenue of the Americas
New York, NY 10036
(212)221-3300

Cancer Care Counseling Line
1-800-813-HOPE(1-800-813-4673)

Cancer Care Inc.
241 Millburn Avenue, Suite 241-C
Millburn, NJ 07041
(973) (201) 379-7500

CONSIDERING YOUR OPTIONS: MAKING DECISIONS ABOUT ALTERNATIVE AND COMPLEMENTARY APPROACHES IN CANCER MANAGEMENT

If you or a family member have been diagnosed with cancer you may have gathered information about available treatments to help you and your physician determine the best approach for you. The therapies which have been offered by your physician are most likely *conventional* treatments. However, in recent years much attention has been given to the area of *alternative* and *complementary* approaches. You might be curious as to what these are and if they could be a helpful part of your regimen. This *Brief* will attempt to explain these approaches and help you obtain information to assist you in your decision-making process.

What are Alternative and Complementary Treatments?

Alternative approaches are those methods (such as Laetrile, certain nutritional-metabolic therapies, and Hoxsey herbs) which are not commonly offered by the medical community and which do not involve the use of standard cancer therapies. The term *alternative* refers to the fact that they are usually used *instead of* standard treatment. *Complementary* approaches, on the other hand, are those methods (such as nutrition, imagery, or prayer) which are often used in conjunction with *conventional* treatments. These are often employed to improve quality of life while on standard treatment or after treatment has ended. The combined use of *complementary* treatments with standard treatment is now called *Integrative* medicine, a term you may hear more of in the future. Both *alternative* and *complementary* methods tend to be referred to as *unconventional* treatments, whereas methods offered by mainstream physicians tend to be called *conventional* treatments. One of the drawbacks of *unconventional* approaches is that little scientific data exists on the potential benefits of these therapies. Some studies have produced results, however. One group of studies indicates that certain types of relaxation techniques and meditation can not only improve quality of life, but can enhance functioning of the immune system.(1) In addition, certain types of cancer patient support groups have been shown to prolong life.(2) Most *unconventional* approaches, however, have not yet been subject to the rigors of clinical trials (scientific studies that would prove their efficacy—see Cancer Care's *Brief* "Don't Be Afraid of Clinical Trials: They Could Improve the Quality of Care You Receive"). These approaches have not undergone approval by the FDA (Food and Drug Administration), and therefore are not often covered by health insurance.

1.Brown, D. and Fromm, E., *Hypnosis and Behavioral Medicine* 32:19, 1987; Goldberg, B., *International Journal of Psychosomatics* 32:34, 1985;Hall, H., *Journal of Clinical Hypnosis* 25:92,1982-83;Kiecolt-Glaser,T.et al., *Health Psychology* 4:25,1985; and Schneider,J. et al., Uncirculated monographs, Michigan State University, College of Medicine,1983.
2. Spiegel,D. et al., *Lancet* 2:888, 1989; Fawzy, F. et al., *Archives of General Psychiatry 50:681, 1993.*

Are Alternative and Complementary Approaches Effective?

In spite of the fact that most *alternative* and *complementary* methods have not been scientifically proven, there is reason to believe that some may have benefit. Some of these are in the process of being evaluated by the *Office of Alternative Medicine* of the National Institute of Health. In addition, a few of these methods have had some scientific documentation of efficacy (notably the psychological approaches) while others have reported *anecdotal* information about improved quality of life or impact on cancer. This means that people who have been treated by these approaches, and their practitioners, report positive results. While these methods could possibly have benefit, these types of reports are not considered to be proof of efficacy by the *conventional* medical community. One might wish to consider the fact, however, that what is *conventional* today (such as chemotherapy, radiation, and even handwashing to prevent infection) was once regarded as *unconventional.*

Why Would One Consider Using Alternative and Complementary Approaches?

Many people who have been diagnosed with cancer feel the need to take an active part in medical decision-making in order to feel a greater sense of control. They express a desire to do everything possible to manage symptoms, pain,

and treatment side-effects and to improve general well-being. Some may also hope to maximize the chances of a positive effect on their disease. All of these are legitimate reasons to explore *alternative* and *complementary* treatment options.

There are other reasons people give for investigating these approaches. Sometimes their physician has not given much promise of standard treatment having an impact on their disease. Others fear that treatment side-effects will be so debilitating that the possible benefits (particularly if considered unlikely) are not worth the adverse reactions. In these instances, a conversation with the medical team can offer information about realistic treatment expectations and medications that are available to relieve side-effects.

Evaluating the Options

Making decisions in an era when there is so much discussion about the broad range of treatment options can be confusing and overwhelming. It is important to know what types of questions to ask your physician. The questions you would ask regarding *unconventional* methods are really no different than those you would ask about standard treatments. Some of these questions are:

—How does this method work?
—How effective is it likely to be for my type and stage of cancer? (ask for statistics if interested)

3. Baily, H., *Vitamin E, Your Key to a Healthy Heart.* New York: Arco Books, 1971; Garrison, F.H., *History of Medicine,* 4th ed. Philadelphia: W.B. Saunders 435-437, 1929; Gilman, A, *Am. J. Surg.*105:574, 1963.

—Have clinical trials or other types of scientific studies been done to prove the efficacy of this treatment for my type of cancer? If not, what evidence is there to show its effectiveness?
—What is the goal of this approach? How long would it be likely to take to achieve this goal, and for how long might the benefits last?

Possible goals:

—Cure
—Remission (remove detectable signs of cancer)
—Shrink tumor
—Reduce pain, discomfort
—Prolong life
—Improve quality of life (how?)
—Stabilize disease
—Prevent metastasis (spreading)
—Improve immune functioning (body's natural ability to fight disease)
—Improve overall health of body, mind, and/or spirit (describe)
—What type of protocol/regimen does this method involve? How difficult is it to maintain (e.g., change in lifestyle, time involved, etc.)?
—What are possible side-effects and after-effects?
—Can this method be used in conjunction with or after standard treatments, and which ones?
—What are the credentials and/or training of the practitioner and does s/he have hospital privileges?
—What is the cost and will my insurance cover it?
—Can I speak to other patients who have my type of cancer who have undergone this approach?
—What will be done to monitor my condition on an ongoing basis?

It may be helpful to write down your questions ahead of time and bring them to the appointment, record the answers you've been given, or bring someone with you to help you remember your questions and what was discussed with the practitioner. Ask yourself: Is this a regimen that will fit with my daily routine and financial situation? Does this approach conform philosophically with my beliefs? Can I practice this method and still have an open, congenial relationship with my oncologist? Do the treatment and its benefits sound too good to be true? What do my instincts tell me about the best approach for me? Will my family/close friends support and assist me with this treatment if needed?

It helps to get as much information as you can from a variety of perspectives regarding the treatment(s) you are considering. The Office of Alternative Medicine mentioned above can be contacted at (888)644-6226 for a report on their findings. There are other organizations that specialize in this effort. You can get information about them and about relevant reading materials from Cancer Care. Finally, the Internet has information on many *complementary* and *alternative* methods--but be cautioned that there is no mechanism for evaluating these approaches on-line. While Cancer Care makes no judgement about any type of treatment, we urge you to make informed choices to ensure you select the most effective and least harmful methods for you.

SOURCES TO FIND PRACTIONERS OF TRADITIONAL/COMPLEMENTARY APPROACHES

(Keep in mind to ask practioner's expertise in cancer if you currently have cancer)

Acupuncture

American Academy of Medical Acupuncture
4929 Wilshire Boulevard, Suite 428
Los Angeles, California 90010
(800)521-2262 or (323) 937-5514
Fax: (323) 937-0959
Web site: www.medicalacupuncture.org

Biofeedback

Biofeedback Certification Institute of America
10200 West 44th Avenue, Suite 304
Wheat Ridge, Colorado 80033
(303) 420-2902
E-mail: BCIA@resourcenter.com
Web site: www.bcia.org

Counseling/Support Groups
(for cancer-related issues)
To receive individual, family, or group counseling or to get a referral to a qualified professional cancer counselor call:

- Cancer Care, Inc. (1-800-813-HOPE)
- American Cancer Society (1-800-ACS-2345) to be referred to local unit
- The social service department of your local hospital or where you or your family member are being treated.

Guided Imagery Therapy

Academy for Guided Imagery
P.O. Box 2070
Mill Valley, California 94942
(800) 726-2070 or (415) 389-9324
Web site: www.interactiveimagery.com

Massage Therapy

American Massage Therapy Association
820 Davis Street, Suite 100
Evanston, Illinois 60201-4444
(847) 864-0123
Fax: (847) 864-0123
Web site: www.amtamassage.org

If you currently have cancer call for service or for referral to qualified cancer massage therapist:

Cheryl Chapman, RN, NCTMB
11 Short Hills Avenue
Short Hills, NJ 07078
(973) 376-3190

Naturopathy

American Society of Naturopathic Physicians
8201 Greensboro Drive, Suite 300
McClean, Virginia 22102
(877) 969-2267 or (703) 610-9005
Web site: www.naturopathic.org
(Directory is $10)

Traditional Chinese Medicine

Institute for Traditional Medicine
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American Association of Oriental Medicine
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Note: The Alternative Health Plan (818/226-264-2768, E-mail www.AlternativeInsurance.com) is a health insurance company that covers both conventional and alternative treatments. There is a one-year preexisting condition clause. Other insurance companies (such as Oxford in Conn., tel. (800) 444-6222) are opening up shortly for such coverage. Contact Foundation for Advancement of Innovative Medicine (877/634-3246, E-mail www.faim@fcc.net) for up-to-date information as this changes.

ADDITIONAL RESOURCES

Marquis Who's Who: ABMS Medical Specialists PLUS: The Official ABMS Directory of Board Certified Medical Specialists, 1999.
Provides background information on individual physicians certified by member boards of the American Board of Medical Specialists. Includes certification, recertification and subcertification; medical schools and year of degree; fellowships and academic appointments; current academic/hospital appointments; address, telephone, and fax numbers.

Choices by Marion Morra and Eve Potts, Avon Books,1994.
Up-to-date sourcebook for cancer information, including guidelines for choosing physicians and hospitals; on making decisions about treatment; information on cancer medications and modern therapies; latest research procedures; and diagnostic technology.

Barbara Sarah, C.S.W. White House Commission on Complementary Medicine
January 23, 2001

I address today you wearing three hats: one as the co-chair of the National Association of Oncology Social Workers Complementary/Alternative Medicine Special Interest Group, the second as the chair of the Complementary Medicine Committee and the Coordinator of the Oncology Support Program at Benedictine Hospital in Kingston, NY and third as an eight and a half year breast cancer survivor.

Wearing my first hat, I am in contact with professional oncology social workers from around the country who are being flooded with questions from patients about what CM treatments and procedures to pursue. This is especially true at that point in time when they have to make decisions about whether to conform to conventional treatments only or after conventional treatment is finished and they want to be able to do something to maintain good health.

In my second hat, I am working at a small upstate New York hospital where doctors and patients alike need more information to stay up-to-date with current research and practice. Our hospital wants to set up a CM center and we want to be able to offer our patients reliable services to help them stay healthy. Consistently, the most popular of my support group programs is our regular Complementary Medicine Discussion Group, where patients share information and practitioners come to make presentations. People are hungry for information yet I have to post disclaimers before our presenters speak, because I cannot necessarily endorse the information that is offered.

In my third hat as patient, I made a decision following my lumpectomy and axillary node dissection and after doing research and asking a lot of questions, not to do the conventional adjuvant treatments of chemotherapy and radiation that were recommended. I did do acupuncture and yoga, mistletoe and supplements. I began to meditate, got involved in an immune system study at a medical center. I altered my diet. I changed jobs and began working as an oncology social worker and became a passionate breast cancer advocate /activist. I became a personal example of the use of CM.

In all three roles I face daily a quagmire of information about Complementary Medicine: doctors, patients, other healthcare professionals and I, myself, have questions about the reliability of information flooding us from all sides. We need to have regular contact with a trustworthy, scientific national source that evaluates and promulgates this information and makes it available to us on a regular basis. We need doctors who are educated about the use of CM and who can spread the word to their colleagues. Patients are reluctant to tell their doctors about their use of complementary medicine because so many doctors have insufficient training on the subject. We need up-dates on CM through the Internet or hard-copy bulletins to other healthcare professionals such as social workers and nurses. They are the people who are in daily contact with patients who are desperate for information. We also need well-informed patient advocates who can pass information along to patient groups.

I propose that a Complementary Medicine Advocate Corps be established composed of designated educated and trained representatives from the above mentioned groups who would be regularly up-dated by the National Office on CAM on current research. These people could then disperse this information to their respective networks through existing publications, e-mail lists and gatherings of their special interest groups. Let's enlist those of us on the front lines to get that accurate information out to the public through a organized system of networking.

Members of the commission

Thank you for allowing me to speak here today.

I am here on behalf of The Coalition For Natural Health;

I am both a certified nutritionist and a cancer survivor.

I am not a doctor or a scientist.

I am also not a guinea pig or a statistic.

Being told that a blood test indicated a second bout with cancer was upon me led me to study nutrition.

Putting the information I obtained during my studies into practice saved my life.

No allopathic treatments were used to accomplish this.

I share the reason for my good fortune, the macrobiotic diet and life style, with everyone who will listen.

Macrobiotics has been used for thousands of years to successfully treat many illnesses.

The health benefits of diet are substantiated by the work of such famous Medical Doctors as Dr. Sherry Rogers, Dr. Dean Ornish, Dr. Lorraine Day, and Dr. John McDougal.

It saddens me to know that some oncologists totally disregard diet and nutritional supplements as being effective tools in the cancer battle.

For doctors to make such remarks to patients who are counting on them to have all the answers is bias arrogance, bordering on criminal behavior.

If my source of information is correct, cancer is the number two cause of death in the US.

Drug reactions are number three.

First do no harm?

I have witnessed the prescribing of prozac for an individual with extreme chemical sensitivities simply because the doctor did not know what else to do for her.

My own daughter's elementary school psychologist recommended my daughter be put on ritalin when she had a hand eye coordination problem which was cured by doing eye exercises.

No drugs were or are being taken by my daughter.

She is now a second year college student with a B average.

Though I graduated from the National Institute of Nutritional Education, I am not allowed to legally call myself a certified nutritionist in New York State, while in most other states I can.

The American Dietetic Association feels they should be the only kid on the block when it comes to nutritional information and education.

A more uniform ruling on the credibility of Certified Nutritionists is sorely needed.

The American diet is nutrient deficient, but Medical Doctors have little or no nutritional education.

The public needs more information on the benefits of a healthy diet and nutritional supplements.

In an effort to educate the public, supplements should be allowed to list on their labels, any known health benefits as well as risks.

Ideally, nutritional education should begin in elementary school.

School lunches should reflect a knowledge of healthy eating practices.

At the present time, French fries are the number one seller in school cafeterias.

What has happened up to now proves that common sense can not be legislated or drug induced.

Without question the medical profession does an excellent job when it comes to dealing with acute and emergency care.

It is also obvious that the medical profession is in need of help when it comes to dealing with degenerative diseases, and I am positive Alternative Medicine and therapies can provide what is needed.

Virginia Langley CN

White House Commission Meeting Jan 23 2001

To enable complementary and alternative medicine (CAM) to become more accessible and transparent, we need to win the complete trust of the conventional medical community, which is still suspicious if not hostile in many instances and on many occasions. It needs to be made clear that although CAM practices may be unconventional and its mode of action [eg in case of acupuncture] may not even be fully accountable by current biological sciences, but we need to ultimately judge CAM by outcome data. Quality clinical data is extremely costly to generate. Unfortunately, the trickle of public and private funding available for formal trials will make such data unavailable for many CAM modalities and interventions for a long time to come. This has to do with commercial issues such as patentability as well as profitability besides policy matters, and as such will need to be solved on a macro level over a period of time. Another important avenue to instill trust in CAM in the conventional medical community is to bolster CAM training for our young doctors and ancillary health providers. Although limited CAM curricula has been introduced into most medical schools, serious and in-depth CAM teaching, training and practice is sorely lacking at the internship/residency/fellowship levels, thus leaving most MD CAM practitioners largely self-taught or even self-professed. The overall quality of post-graduate CAM education can be enhanced with appropriate rotations in CAM during postgraduate training. Integrated offers of CAM related workshops and symposia during major annual medical conferences sponsored by the major medical societies and institutions. Education is much less expensive than research and over time may yield a higher return. It is imperative that a new generation of physicians and other health care providers develop crucial new awareness about CAM necessary for them to learn, accept, and practice it for the health and well-being of their patients.

Raymond Chang MD FACP