Complementary and alternative medicine (CAM) encompasses a broad range of therapies, including vitamins, acupuncture, nutritional supplements, and traditional healers. An estimated one in three adults uses some form of CAM therapy each year. In chronic medical conditions such as cystic fibrosis, the incidence is even higher, with estimates as high as 60-75 percent of all patients. Pediatric pulmonologist John Mark undertook a two-year fellowship in Integrative Medicine under the tutelage of renowned physician Dr. Andrew Weill at the University of Arizona, prior to coming to Stanford last year. Integrative medicine brings together CAM and Western medicine to achieve a balanced, holistic approach to health care. Dr. Mark is working with the patients and CF team at Stanford to educate and determine which therapies can be successfully integrated into the care of people with chronic lung diseases such as CF.

CAM includes therapies that are complementary to Western medicine as well as alternative treatments. Alternative medical systems include homeopathic, naturopathic, and traditional Chinese and Ayurvedic treatments. (Ayurvedic treatments come from India and include diet, meditation, exercise, herbs, massage, exposure to sunlight, and controlled breathing.) Mind-body interventions, such as hypnosis, meditation, and guided imagery seek to enhance the mind’s capacity to affect bodily function and symptoms. Biologically based therapies include dietary supplements such as herbs, foods, vitamins, and other natural substances. Manipulative and body-based methods encompass chiropractics, osteopathy, and massage. Energy therapies include biofield therapy and bioelectromagnetic therapy.

People use CAM therapies for many reasons: traditional values and beliefs, providing a sense of empowerment and control over one’s health, etc. CAM therapies also are considered by some to be more “natural” and therefore of benefit to improving or maintaining health. Some employ CAM therapies to promote overall health and not just to treat symptoms with conventional medications. Many also feel that conventional medications are without emotional or spiritual benefit or that they may be associated with side effects or significant risks.

Discussing CAM with Your Physician

CAM therapies benefit many individuals through improved nutrition (e.g. vitamin supplements), reduced stress (e.g. meditation and massage) and improved fitness (exercise). Working with a physician familiar with both Western medicine and CAM enables individuals with CF to feel confident that risks and benefits of CAM therapies are not in conflict with needed medical therapies. CAM techniques and treatments can complement CF care, providing useful tools for maintaining physical and psychological health, managing pain and improving nutrition.
Our Approach to Integrative Care

At the Packard CF Center, the CF clinic team routinely asks which CAM therapies are being used, and if they are being used in place of, or in addition to conventional therapies. The CF team discusses the merits of all therapies and identifies any risks or potential harmful effects or interactions. The CF team will also help monitor and evaluate whether a combination of therapies is beneficial over time since many CAM therapies (such as acupuncture, homeopathy and dietary changes) require a significant duration of use to realize a benefit. The team will also assist in determining if a CAM therapy provider is appropriately licensed (which varies from state to state depending on the CAM therapy). Our ultimate goal is to maintain an open mind and balanced approach, to counsel about benefits as well as potential risks and engage patients and families in a meaningful discussion based on reason and evidence, not prejudice or emotion.

This integrative approach to CF care at LPCH is being lead by John Mark, MD, who joined the CF team at Stanford in July 2005. Dr. Mark was a practicing pediatric pulmonologist who became the first pediatric physician to receive training in integrative medicine at the University of Arizona. He was awarded a NIH fellowship in CAM pediatric research in 1999, and conducted pediatric research in CAM therapies at the Program in Integrative Medicine at the University of Arizona. Dr. Mark has brought this expertise to our CF Center as well as to the Packard medical staff and residents through lectures and medical education about CAM therapies and their use with, not instead of, conventional medications and therapies. He plans to have health care providers at LPCH actually experience CAM as well as learn more about therapies such as acupuncture, therapeutic teas and tinctures, healing touch, and manipulative therapies (e.g. massage and osteopathic manipulation). Familiarity with the modalities will enhance communication and understanding between patients and the CF team.

Our team of health care professionals seeks to assist in finding a balance in the lives of the children and adults who seek care at our clinic. Our goal is to provide healing oriented medicine that takes account of all aspects of the patient, including body, mind and spirit and to work with our patients and families to make use of all appropriate therapies, both CAM and conventional.

WEBSITES FOR CHECKING CAM RESEARCH & INFORMATION

- National Center for CAM: http://nccam.nih.gov
- MedWatch: http://www.fda.gov/medwatch
- Canadian Health Directorate: http://www.hc-sc.gc.ca/hpfb-dgpsa/nhpd-dpsn/index_e.html

MAJOR CLASSES OF COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM)

<table>
<thead>
<tr>
<th>ALTERNATIVE MEDICAL SYSTEMS</th>
<th>MIND-BODY INTERVENTIONS</th>
<th>BIOLOGICALLY-BASED THERAPIES</th>
<th>MANIPULATIVE &amp; BODY-BASED METHODS</th>
<th>ENERGY THERAPIES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Homeopathy</td>
<td>Biofeedback</td>
<td>Dietary supplements</td>
<td>Chiropractic</td>
<td>Biofield therapy</td>
</tr>
<tr>
<td>Naturopathy</td>
<td>Guided Imagery</td>
<td>Herbs</td>
<td>Osteopathy</td>
<td>Bioelectro-</td>
</tr>
<tr>
<td>Traditional Chinese</td>
<td>Hypnosis</td>
<td>Foods</td>
<td>Massage</td>
<td>Magnetic Therapy</td>
</tr>
<tr>
<td>Ayurvedic Treatments</td>
<td></td>
<td>Vitamins</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Natural Substances</td>
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</table>
Some examples of therapies used with great success among persons with CF include:

- Guided imagery and self-hypnosis to help cope with and manage stress and pain associated with procedures such as shots and PICC line insertions;
- Meditation and massage to achieve deep relaxation and improved sleep;
- Nutritional supplements such as Omega-3 fatty acids.

Integrative medicine combines mainstream medical with CAM therapies for which there is scientific evidence of safety and effectiveness. If no such evidence exists (which is common since there is little CAM research in CF, especially in children), then the potential CAM therapy is balanced with the risk and benefit for the individual, just as the risks and benefits of conventional therapies are weighed. More importantly, health care providers recognize the growing scientific evidence on the effectiveness of many CAM therapies such as stress reduction, and its role in the management of chronic conditions. Integrative medicine encourages patients and practitioners to work together in the development of a health care management plan that draws from proven Western as well as CAM therapies.

Risks of CAM

CAM therapies are not without risk. By definition, CAM therapies are used with conventional medicine (complementary), and they are often used in place of conventional medicine (alternative). In serious, treatable conditions like CF, an inappropriate replacement can lead to progression of lung disease and/or nutrition problems. Some dietary supplements, the number one CAM therapy used by persons with CF, can pose problems due to the considerable variation in purity and potency of products. Contamination with heavy metals and other harmful substances have been reported. Since dietary supplements are regulated only as food products and not drugs, the Food and Drug Administration does not regulate them. Studies have found that the primary active ingredients across brands of supplements varies from 0 percent to 200 percent of the advertised content. Dietary supplements are not required to have pre-marketing testing for safety and efficacy. Furthermore, persons with CF frequently take prescription medications that have potentially harmful drug-supplement interactions. Many patients use more than one type of dietary supplement, thereby exponentially increasing the risk of adverse events.
Vitamin A in CF: Role, Function and Sources
Second in a Series on Vitamins, Minerals and CF

Vitamin A, also called retinol, is a fat-soluble vitamin that is poorly absorbed by people with pancreatic insufficiency. It is best known for its role in vision. In ancient Egypt, it was known that eating liver, which subsequently was shown to be rich in vitamin A, could cure night blindness. Vitamin A is essential for growth, bone and tooth development, and for the regulation of the immune system. Of importance in CF is its role in formation and maintenance of mucus secreting cells that line various organs, including the lungs. Even a mild deficiency can cause a decrease in the functioning of the lung’s ciliary cells that help to sweep mucus out of the airway and maintain the mucus barrier to bacteria and viruses. Vitamin A helps regulate the immune system, and it may help lymphocytes (a type of white blood cell) fight infections. Recent laboratory evidence suggests vitamin A could even have protective effects on the respiratory status of persons with CF.

Severe vitamin A deficiency sometimes occurs in newly diagnosed infants. Vitamin A deficiency accompanies severe zinc deficiencies, since zinc is required to transport vitamin A stores from the liver to body tissues. Deficiency can also be caused by inadequate intake of proteins, calories, and zinc (as seen in protein-energy malnutrition, a condition sometimes found in CF). One recent study found 10 of 44 adolescents with CF had at least a mild deficiency of vitamin A. In vitamin A deficient individuals, cells lining the lungs lose their ability to remove bacteria and viruses. Current research seeks to determine the consequences of subtle deficiencies.

Foods Rich in Vitamin A

Vitamin A is available in two forms. Pre-formed vitamin A is present only in animal products, including dairy products (especially whole milk products), liver, and fish oils. The body also can make vitamin A from carotenoids (such as beta-carotene), compounds that are found in brightly colored fruit and vegetables, such as carrots, cantaloupe, squash, sweet potato, kale, and apricots. The more brightly colored the better! Vegetarians need to be particularly concerned about eating sufficient carotenoids to meet daily requirements.

Risks of Excess Vitamin A

Vitamin A toxicity can occur when too much is eaten, however, it is uncommon in CF with standard vitamin A supplementation. Excess vitamin A may be associated with osteoporosis, a condition that is also a major complication of CF, hence it is important to take adequate and not excessive doses. Vitamin A levels in the blood are measured on an annual basis in most CF centers to ensure appropriate levels are maintained.

Strategies to Optimize Vitamin A Levels

- Take vitamin supplements as prescribed.
- Choose brightly colored fruits and vegetables as part of your high caloric intake.
- Have fat-soluble vitamin levels measured annually.

Sources of Vitamin A

<table>
<thead>
<tr>
<th>Food</th>
<th>International Units</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chicken liver, 3 oz</td>
<td>12,325</td>
</tr>
<tr>
<td>Milk, fortified skim, 1 cup</td>
<td>500</td>
</tr>
<tr>
<td>Cheese, 1 ounce</td>
<td>284</td>
</tr>
<tr>
<td>Carrots, boiled, 1/2 cup</td>
<td>13,418</td>
</tr>
<tr>
<td>Spinach, 1/2 cup cooked</td>
<td>11,458</td>
</tr>
<tr>
<td>Cantaloupe, 1 cup</td>
<td>5,411</td>
</tr>
<tr>
<td>Spinach, raw, 1 cup</td>
<td>2,813</td>
</tr>
</tbody>
</table>

Individuals with CF typically require 5,000 to 10,000 IU of daily vitamin A, based on age and nutritional status of the individual.
Stanford/LPCH Pilot Exercise Program for Patients with CF

The Stanford/LPCH Exercise Program is enrolling people with CF in a pilot program that will lead to implementation of a center-wide exercise initiative. The program is a cooperative effort between the CF Center, Stanford's Health Improvement Program and New Day Wellness Foundation, a nonprofit organization founded by Dr. Julie Desch. People committed to improving their stamina and strength and to adhering to CFF clinical care guidelines will be assigned to a “wellness coach” who will help design an individual exercise program.

The Exercise Team will work with the CF Center staff to:

1) Understand the importance of regular physical activity;
2) Offer individualized training programs for motivated children and adults with CF;
3) Provide weekly phone “wellness coaching” sessions to monitor progress, modify the program and teach motivation skills;
4) Collect pre and post exercise program measurements of strength, endurance, pulmonary function, and quality of life;
5) Achieve integration of regular exercise into the clinical management with progress reports to the CF team.

Program Features

The new program’s philosophy is, “If you can breathe, you can exercise.” Our goal is to work with participants to design a program that maximizes fitness potential and teaches techniques and routines that will become part of a daily routine. Participants must commit to regular “wellness coaching sessions” and a minimum of quarterly CF clinic visits.

Components include:

- Comprehensive fitness assessment at Stanford’s Health Improvement Program, before the program begins and after 6 months;
- Two outdoor group exercise classes to learn techniques;
- Each participant will receive a stability ball, foam roller, and resistance tubes;
- Weekly phone sessions with a certified “wellness coach” to assist in vision and goal setting, motivational tools, feedback and education;
- Individualized exercise program that includes cardiovascular, strength and flexibility training tailored to the age and ability of each participant;

Wellness coach will provide the initial assessment and a minimum of quarterly reports to the CF clinical team;
Wellness coach will work with CF team to relay the message that exercise is part of clinical care, and to find ways to integrate it into the daily CF regimen.

Registration Process

The initial pilot program will involve 6-12 adults and children over the age of 12 with CF. For more information email Dr. Julie Desch (julie@newdaywell.org) or ask your CF physician, Julie Matel, RD or Kristin Shelton, RT.
Adult CF Program Developments

Dr. Daya Upadhyay has joined the Adult CF team following her appointment as an assistant professor in the Department of Medicine, Division of Pulmonary and Critical Care. Dr. Upadhyay received her pulmonary training at Northwestern University in Chicago. It was the large Adult CF program at Northwestern that stimulated her interest in CF. She is an epithelial cell biologist with a 5-year NIH award to study air pollution-induced lung injury.

Dr. Upadhyay states, “Care of adults with CF provides me an opportunity to practice challenging clinical medicine and science. Science is an essential component of advancements in medicine and the treatment of CF. I look forward to collaborating with the outstanding basic and translational research programs and clinical trials on CF at Stanford.” She was nominated for a Stanford faculty teaching award in 2006, and is initiating a CF training curriculum for pulmonary fellows.

Dr. Upadhyay emigrated from Bombay in 1992 to extend her pulmonary training and research at New York University, Albert Einstein School of Medicine, and Northwestern. At Stanford, she has worked as an adult pulmonologist and basic science investigator since 2002.

Dr. Upadhyay is committed to elevating the clinical and scientific level of our CF Center and expanding her research into CF. Her initiatives to date include:

- A new Wednesday clinic day to improve access for adults with CF.
- A CF training program for seven Pulmonary and Critical Care fellows to include an adult CF rotation with intensive inpatient and outpatient training in CF.
- Integration of CF scientific presentations into the weekly “Pulmonary Medicine and Biology Grand Rounds”, a scientific series hosted by the Divisions of Adult Pulmonary and Critical Care Medicine, Pediatric Pulmonary, Allergy and Critical Care Medicine, and the Center for Excellence in Pulmonary Biology at Stanford. This conference aims to enhance scientific education and promote collaborative research among physicians and scientists campus-wide.

Dr. Upadhyay’s appointment underscores the profound institutional commitment to the Adult CF program. The Adult CF team continues a strong collaboration with the pediatric pulmonary group to ensure adult access to our excellent CF team. The collective experience of our CF physicians is without parallel in California. The Center’s search for a preeminent senior leader for the adult CF program is proceeding, in collaboration with the Department of Medicine, and will most certainly benefit with the addition of Dr. Upadhyay, an outstanding and experienced pulmonologist who joins Dr. Paul Mohabir as part of the growing Adult CF team.

**FLU AND PERTUSSIS VACCINES RECOMMENDED**

The number of pertussis, or whooping cough, cases in California is at its highest point in 30 years, with more than 2,200 cases reported in 2005. Katrina Kretsinger, a medical epidemiologist with the Center for Disease Control’s National Immunization Program, said pertussis is “the most poorly controlled disease among all the diseases for which there has been a vaccine available for some period of time.” Federal and state officials are recommending pertussis booster shots for teens and adults who have not received a booster in the past five years. Pertussis is highly contagious and can prove fatal in young children and persons in frail health. Please discuss the need for a pertussis booster and flu shot with your primary care or CF physician.

Remember to get your flu shot! Adults and adolescents also need to check with their physician about the need for a Pertussis (Whooping Cough) booster if it has been more than five years since vaccination.
Lucile Packard Children’s Hospital

David Weill, MD was named Director of Lung Transplantation at Stanford. Dr. Weill came from National Jewish Hospital at the University of Colorado, one of the largest lung transplant programs in the country. Dr. Weill is working to bring greater integration of the CF and lung transplant programs as part of his vision.

Dr. David Cornfield was the keynote speaker at the CFRI annual membership meeting in May. Dr. Richard Moss, CF Center Director is on sabbatical until March 2007. His plans include a visiting professorship in China and research on ABPA with colleagues in India.

CURRENT RESEARCH STUDIES
For the first time in history, there are more CF drugs in clinical trials than patient volunteers to test them! Our center needs YOU to help test new therapies to speed the arduous process of clinical trials. Both speed and success depend on people with CF to participate. Don’t assume “someone else” will be one of those subjects — we all need to be part of the cure.

Please consider participating in a clinical trial for CF research. For more information, visit www.cfcenter.stanford.edu, contact our research coordinators, or talk to your physician. The following trials are currently underway at our center (“closed” indicates recruitment is complete and trial is in progress):
• Infant and toddler pulmonary testing (closed)
• Dry Powder TOBI
• Induced Sputum: evaluation of anti-inflammatory agents
• Inspire drug for correction of salt and water abnormalities (closed)
• CF pre-diabetes intervention trial
• NAC (closed, Phase II results pending)
• Aztreonam for inhalation
• EPIC trial for early treatment of pseudomonas

GIFT TO FUND PETE JUDGE MEMORIAL CF PROGRAM
Pete Judge was a surfer, card player, friend, avid reader, music lover, and 45-year-old adult with cystic fibrosis. The compassionate care provided by Stanford CF staff led Pete’s family and friends to found the Pete Judge Memorial Fund to develop programs to improve quality of life for CF center staff and individuals with CF and their families. Pete’s parents, Julia and Thomas Judge, brought courage, joy and compassion into the world as they provided for two children with CF. Throughout his life Pete demonstrated kindness, wisdom and a determination to be a human being separate from his disease. He and his parents deeply appreciated the caring received from Stanford staff that went beyond treatments and medications. They hope to give back to the Stanford CF community through this fund.

CF NEWBORN SCREENING BILL PASSED
California will become the 22nd state to provide universal newborn screening for Cystic Fibrosis thanks to the efforts of the Stanford CF community. LPCH government relations director Sherri Sager orchestrated the legislation authored by Fremont Senator Liz Figueroa. Sponsors included CFRI, CFF, the March of Dimes, the California Children’s Hospital Association, the Children’s Specialty Care Coalition, and the California Association for Nurse Practitioners. The Public Health Institute held a Symposium to educate legislators. Numerous persons with CF, physicians, and family providing testimony testified during hearings. The legislation was initiated at the request of LPCH physicians and local CF teen Molly Pam.

Funding for screening was passed in the state budget, with a target start date of August 2007. Each year approximately 100 Californians are born with CF, but many are not diagnosed till long after birth. Only half are diagnosed by six months of age and at least 10% are diagnosed as adults. State geneticist Martin Kharrazi lead the state’s efforts to design a program to reflect the unique genetic profile of the California population. The test will use the blood spots already collected at birth to screen for other diseases.
CF EDUCATION DAY – MARCH 11, 2006

More than 100 people attended the annual LPCH/Stanford CF Education Day on March 11 at the Stanford Medical School. Featured speakers included Carlos Milla MD, Director of the top-rated University of Minneapolis CF Center, Ron Gibson MD, Director of the University of Washington CF Center, gastroenterologist Jackie Fridge MD, and Terry Robinson MD, Mary Helmers, RN, Julie Matel, RD and John Mark, MD of Stanford.

Dr. Milla presented research on the integral link between nutritional status and lung function that is informing nationwide clinical initiatives that focus on improving nutritional status. Julie Matel and Dr. Fridge followed with discussions of G-tube benefits, timing for intervention and placement. Dr. Gibson discussed research and clinical initiatives focused on early treatment interventions to prevent and eradicate infections, including an update on results of the TOBI trials and the importance of the current EPIC trials to document the value of preventing infections and treating new signs and symptoms aggressively. Nurse coordinator Mary Helmers discussed transition to adult protocols at Stanford.

Scott Wakefield videotaped the day. Copies of the program are available as a set of five CDs for $5 or five DVDs for $12 through CFRI in Mountain View. Contact David Sohoo at progmgr@cfri.org.

NEW LPCH PFT LAB OPENS

The new LPCH Pulmonary Function Lab provides state-of-the-art comprehensive lung function testing to children and adults with CF. Kathy Aveno, RT and Ken Hirose, RT oversee CF annual pulmonary function testing (PFT), an important aspect of CFF clinical guidelines that provides physicians with a detailed assessment of lung function trends that are not readily apparent from spirometry. The new lab was made possible by a gift from the Hedco Corporation, a long-time supporter of the CF Center at LPCH.

CYSTIC FIBROSIS CENTER AT STANFORD

Center Physicians: Richard Moss, Director; Carol Conrad, David Cornfield, Terry Robinson, Lauren Witcoff, Nanci Yuan, John Mark, Paul Mohabir, Daya Upadhyay

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Miguel Huerta, Patient Services Coordinator (650) 498-2655
Katherine Boyle, RN Pediatric Coordinator (650) 736-1359
Mary Helmers, RN Adult Coordinator (650) 736-1358
Kristin Shelton, Respiratory Coordinator (650) 724-0206
Julie Matel, Nutritionist, Dietitian (650) 736-2128
Joanne Asano, Social Work (650) 736-1905
Research Coordinators (650) 736-0388

For Urgent Issues:
Monday–Friday 8:30–5:00 pm contact RN Coordinator
All Other Times (ask for Pulmonary Physician On-Call) (650) 497-8000

Visit our website at http://cfcenter.stanford.edu for more information about our center and CF.

To subscribe to this newsletter please call or email Judy Kirby at (650) 724-3474 or jkirby@stanford.edu