

New Horizons: Care of Body, Mind and Spirit Cystic Fibrosis Research, Inc. Holds 18th Annual Conference

By Georgia Brown

Cystic Fibrosis Research, Inc. (CFRI) celebrated 30 years of research, education and support by helping CF patients reflect on their mental and physical health outside of standard CF care. The United States Adult Cystic Fibrosis Association (USACFA) co-sponsored the event, which was held August 5-7, 2005 in Redwood City, California.

The CFRI conference provided the latest information on CF treatment, research and services to people with CF (PWCF), their families, and their caregivers. Lectures and workshops provided information on how to improve the body, mind and spirit of PWCF. CFRI offers information on their website www.cfri.org on how to purchase a recording of each session. Their newsletter, available in PDF format from their website, offers lecture overviews. Members of USACFA who attended the event wrote articles about their observations and experiences for the *CF Roundtable* newsletter (www.cfroundtable.com).

While CFRI packs their conference with medical information, they also offer opportunities for participants to attend focus and support groups. Focus group sessions offered open discussions on transplantation, adoption and child rearing, working, schooling and other aspects that affect the lives of CF patients.

Dr. Ran D. Anbar, Professor of Pediatrics and Medicine at the SUNY Upstate Medical University in Syracuse, discussed meditation and its use in CF management. Dr. Anbar, who is the Director of the CF Center in Syracuse, became involved with hypnotherapy seven years ago. While many people equate hypnosis with embarrassment in front of a crowd at a comedy show, according to Dr. Anbar, hypnosis is a normal state of mind. The American Medical Association recognized hypnosis as a medical term in 1958, thus there is medical benefit from hypnosis. He studied self-hypnosis techniques and uses it extensively for his patients with CF. Daydreaming is self-hypnosis when you tune out the mundane and focus on something more interesting. If you have ever driven somewhere and arrived at your destination with little knowledge of the trip, then you have experienced self-hypnosis.

Dr. Anbar teaches his patients how to use this altered state of consciousness to their advantage. His patients use self-hypnosis for relaxation and for pain management. He showed a video describing the various techniques he uses in health management, then led a self-hypnosis workshop. CF patients who use this technique must want the benefits such as help with coping, playing an active role in disease management and wanting a technique that promotes self-reliance while building self-esteem. Please note, Dr. Anbar stressed that if a person did not want self-hypnosis to work then it wouldn't.

Dr. Julie Desch, President and founder of New Day Wellness, discussed exercise and its importance for people with CF. A CF survivor herself, Desch spoke on "Living Well with Cystic Fibrosis: Fitness and A Health Lifestyle." Dr. Desch advocates a good diet, regular exercise, weight control and stress management for people with CF. She asserts that a balance of energy affects our health. It is important to be chronically well (positive energy) instead of chronically ill (negative energy). One way to become well is to exercise regularly. Some of the benefits of exercise for people with CF include:

- Improved breathing efficiency
- Diminished anxiety
- Decreased fatigue
- Improved quality of life
- Lowered resting heart rate

- Increased energy
- Improved sleep
- Improved mucus clearance (exercise prompts coughing)

The FITT principle was also discussed – an exercise plan that incorporates controlled *frequency* of workouts, *intensity* of the exercise, *type* of activity and *time* devoted to the activity. She mentioned activities such as yoga, tai chi, hand weights, stability ball, and resistance tube as being beneficial. Doing these activities at home helps to avoid the bacteria found in gyms and activity centers.

It is important to note that there is a lack of data on the benefits of exercise in people with CF because there have been few studies to measure the results of exercise on people with CF. Nevertheless, the benefits of exercise for people with CF are the same for people without CF – improved wellness.

If you are interested in the information provided at the conference, I highly recommend visiting the CFRI website.

Georgia Brown is a 35-year-old CF survivor living in Ohio, USA. She holds bachelor and masters degrees in Communication Studies. She spends her time doing volunteer work for CF organizations, conducting research, and attending CF conferences to learn more about disease management in an effort to share information with others in the CF community. She also enjoys traveling, scrapbooking and sports.