

### **CFW Thanks NUTRICIA for joining the Burke Bear Campaign**

Nutricia recently purchased 40 Burke Bears and joined the Burke Bear Campaign.

Nutricia is a leader of specialized products sold around the world meeting the nutritional needs of babies and others with special dietary concerns. To learn more about Nutricia, please visit their website <http://www.nutricia.com/>.

The Burke Bear Campaign supports CFW projects and sends this lovable Boyd LTD collectable teddy bear, named for a young boy who died from CF, to those wishing to support our mission.

To learn obtain your own Burke Bear visit:

[http://www.cfww.org/campaigns/BURKE\\_index.asp](http://www.cfww.org/campaigns/BURKE_index.asp)

### **CFW ONLINE TOOLS**

CFW's website provides a wealth of information to the CF community

- Read Dr. Jim Littlewood's presentation on European Standards of Care for Patients with CF
- See what your national CF association is doing
- Read about CFW's partnership with the World Health Organization to get pancreatic enzymes on the list of necessary drugs
- Download a worldwide list of CF clinics
- Search our library of articles online in seven languages
- Sign up to receive monthly email updates about CFW's work
- Ask the experts your CF-related question
- Purchase a painting from our charitable art gallery and find out how you can set up your own fundraising event

<http://www.cfww.org>

### **WILLIAMSON REFLECTS ON CF DEVELOPMENTS**

Rumours, rumours! During the past year, rumours have been circulating that there have been several promising new drugs developed that may be useful in treating people living with CF. Over the past thirty years, those who have CF have seen great improvements in treatment already, with better antibiotics, mucolytics, nutrition, physiotherapy and even transplantation. However, we all hope for further improvements. I have heard of two promising leads from the U.S. and France, one of which is a new mucolytic and the other a drug that may "traffic" the mutant (DF508) CFTR protein to the surface of the cell, where it could function more or less normally.

It is important to remember, however, that many promising leads don't make it to the finishing post. Any new drug has to pass international tests, to make sure it is SAFE and EFFECTIVE. This

is to protect patients from harm, and the health care system from a financial burden that brings no corresponding benefit. The doctors and scientists working on new drugs are just as committed as the patients and families to "make things better", but it requires a bit of patience while all the safety checks and control trials are carried out. In the long run, that is best for everyone.

- Bob Williamson, University of Melbourne

#### **SAVING LIVES BY REMOTE CONTROL**

Glasgow, Scotland - A joint effort from medical tech company e-San and mobile giants O2, the experiment has demonstrated how the current wave of phones equipped to carry data has given physicians the ability to enjoy two-way, real-time contact with patients together with advanced personalisation features - critical elements in successful disease management.

Stuart McWilliam, head of product development at Oxford-based e-San claimed, "It's better healthcare, it's cheaper healthcare and it's healthcare that fits into sufferers' lives, working around the way they want to pass their time rather than allowing illness to dictate the pace and set their timetables."

These are bold claims, but if the initial results from e-San's recent trial are anything to go by, they may not be far wide of the mark. Conducted in conjunction with Bristol University, the study tested the company's disease-specific hardware modules, each of which attach to mobile phones and take relevant measurements from CF and asthma patients, such as peak flow measurements and other measures of breathing strength.

**Source:** "Saving lives by remote control: The mobile phones carried by millions could potentially have huge healthcare benefits, according to a recent trial", The Herald (Glasgow), August 9 2005.

#### **VITAMIN D REPLETION REGIMEN FOR CYSTIC FIBROSIS PATIENTS DID NOT WORK**

USA - The recently published vitamin D repletion regimen suggested by the Cystic Fibrosis Foundation's Consensus Panel on Bone Health for replacing the vitamin in CF patients has been called by researchers who tested it "strikingly ineffective." Out of 66 adults with CF, only 5 patients who had been treated with 50,000 international units of the vitamin per week for eight weeks had their serum levels corrected to the recommended degree.

Researchers have been considering other health issues unique to the adult CF population. One issue is bone health because studies

of bone density have determined that despite a young age, approximately 20 to 25 percent of adults with CF have osteoporosis and another 40% have osteopenia. (Osteopenia is low bone volume due to inadequate replacement of bone loss from normal disintegration. Osteoporosis is abnormal loss of bone tissue, causing fragile bones that fracture easily.)

An adequate supply of vitamin D is needed for the body to absorb calcium from food and incorporate it into bone. A deficiency of vitamin D leads to abnormal bone growth and repair. Of the 134 adults with CF in this study, 109 (81.3 percent) were found to have vitamin D levels below the recommended 30 ng/ml. The authors noted that further research is required to determine the optimal level of vitamin D needed in order for CF patients to maximize calcium absorption and maintain bone health.

**Source:** "Vitamin D Repletion Regimen For Cystic Fibrosis Patients Did Not Work." American Thoracic Society Journal, July 2005 Issue 2.

**Further Info:** American Thoracic Society [www.thoracic.org](http://www.thoracic.org)

#### **COMPUTERIZED SHIRT MONITORS BREATHING OF PATIENTS WITH CF**

USA - The Lifeshirt developed by VivoMetrics collects respiratory data through a miniature, portable computer system. It measures breathing, heart, posture and activity data via electrodes and wires embedded in the garment that surround the patients' rib cage and abdomen. The sensors measure such body signals as blood pressure, blood oxygen saturation, periodic leg movements, temperature, carbon dioxide levels and coughs. An electronic diary captures all the input and keeps track of it minute by minute. The doctors' clinical trials, funded by the Cystic Fibrosis Foundation, are looking at the unique wired wear as a non-invasive way to get needed medical data with the least amount of hassle for patients.

"We're hoping to be able to detect change in the clinical status of sick CF patients when they come into the hospital," Dr. Scott Donaldson said.

Dr. Stephanie Davis is planning to start her experiments on children 3 to 6 years old with CF, transmitting data from electrodes embedded in the Spandex cloth to small collection computers in a shirt pouch for later removal and clinical analysis.

The children's trial is to evaluate the LifeShirt in about 100 patients at five medical centers. They'll compare the shirt against two more traditional measures of lung function - spirometry (blowing into tube attached to a meter box to measure

air flow and volume) and forced cillometry (a newer technique for measuring lung capacity on children and others unable to use Spirometers effectively).

**Source:** Computerized shirt monitors breathing of patients with CF, The Herald-Sun (Durham, NC), June 7 2005.

**Further Info:** [www.vivometrics.com](http://www.vivometrics.com)