

## The Challenges of CF

One in 31 people reading this is likely to be a symptomless carrier of the gene for cystic fibrosis. If two carriers have a child, there is a 1 in 4 chance that their child will have the disease.

Managing CF requires daily medications, time-consuming treatments, and numerous doctor visits and hospitalizations that drain family resources. Emotional and financial burdens can far exceed a family's means, even with health insurance.

Thick mucus blocks small tubes and ducts in the respiratory, digestive and reproductive systems leading to chronic lung infections and malnutrition. For many, other organs also become seriously compromised.

### Symptoms may include:

- Salty taste to the skin
- Persistent coughing
- Recurrent lung infections or pneumonia
- Wheezing or shortness of breath
- Poor growth/weight gain in spite of a good appetite
- Frequent greasy, smelly, malformed stools or difficulty in bowel movements.

A physician, preferably at a CF treatment center, should examine a child or adult with any of these persistent symptoms. Remember, *early diagnosis prolongs life.*

Cystic fibrosis affects over 30,000 Americans.

### ***Do You Know Someone With CF?***

**CFRI**<sup>TM</sup> Cystic Fibrosis Research, Inc.  
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## Our Mission

Cystic Fibrosis Research, Inc. (CFRI) exists to fund research, to provide educational and personal support, and to spread awareness of cystic fibrosis, a life-threatening genetic disease.

## Our Vision

As we work to find a cure for cystic fibrosis, CFRI envisions informing, engaging and empowering the CF community to help all who have this challenging disease attain the highest possible quality of life.

*CFRI would like to thank Digestive Care Inc., makers of PANCRECARB® (pancrelipase), delayed-release capsules, buffered and enteric-coated microspheres, for generously sponsoring the printing of this brochure.*



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Cystic Fibrosis Research, Inc.

*Growing Stronger Every Day*



***Walker***  
***Tuscon, Arizona***

## We are Sharing Education

- CFRI annually supports a post-doctoral fellowship and the CFRI New Horizons Campaign to further CF research.
- Our annual National Cystic Fibrosis Family Educational Conference, an event for those with CF and their families, features leading experts in CF medical research and clinical treatments.
- The Conference presentations are taped and distributed upon request to the global CF community at minimal cost.
- The CFRI annual Teen & Adult Day Retreat provides support, education and fun in a safe environment for people with CF.
- *CFRI News* is delivered directly to 15,000 households, sharing valuable CF information with those who need it most.
- CFRI is actively engaged with those impacted by CF Newborn Screening in California and across the country.

*~ Get involved in 2010 ~  
Make a donation to CFRI today!*

## Family and Community Support



### *Full Speed Ahead!*

Walker is the first child born in Arizona to be diagnosed with CF through newborn screening.

When he was 1½ years old, his grandmother attended the CFRI National Family Education Conference and took home a lot of new information that has been valuable to the whole family. Today, Walker is thriving, thanks to early diagnosis and wonderful team support.

CFRI keeps the CF community up to date.

*Knowledge is power!*

## And Critical CF Research

Children with CF born in the 1970's were expected to live 11 years. Today, children like Walker can expect to live more than 37 years. But, life with CF is challenging and costly - we still need a cure. Our research takes us closer.

### **CFRI: Growing Our Research**

In 2009, CFRI increased our funding of CF research by almost 50%! We continue to support four new fellows this year through our Elizabeth Nash Memorial Post-doctoral Fellowship.

Research continues at UC Berkeley under Terry Machen, Ph.D., and at SDSU under Forest Rowher, Ph.D. In addition, we are now funding two *new* projects:

1. Daniel Hassett, Ph.D. at the University of Cincinnati/College of Medicine is studying how nitrite can combat *Pseudomonas aeruginosa*.
2. Dieter Gruetner, Ph.D. at UCSF is evaluating the amount of CF gene expression required to restore enough cell function to minimize the physical features associated with CF.



*Growing with your help!*