

Walk for Paige

T H E C H R I S T E N S E N ' S C F N E W S L E T T E R

DID YOU KNOW :

- More than 10 million Americans are unknowing, symptomless carriers of the defective CF gene.
- More than 80% of patients are diagnosed by age three; however, nearly 10% of newly diagnosed CF cases are age 18 or older.
- The average life expectancy for people with CF increased to 35 in 2005!

INSIDE THIS ISSUE :

Great Strides	1
CFF Symbol	1
Up Close and Personal	2
Cutting Edge	2
Ironman	2
CFF Calendar	3
About CF	3

G R E A T S T R I D E S M A D E I N H U D S O N , W I

On September 17th, 2005, while driving toward Hudson, WI to participate in our first Great Strides Walk for CF, I turned around and asked Paige, "Do you know who we are walking for today?" Paige hesitantly said, "The cabin?" I smiled, shook my head, and repeated my question. Paige raised her eyebrows and said, "The barn?" Again, I smiled, shook my head and repeated the same question. This time, Paige looked down in thought, then whipped her head up with a huge smile on her face and said, "ME!"

In total, 56 walkers showed up to walk for Paige, and our entire team completed the 6.2 mile walk. Our youngest walk-

ers were Jake and Logan Kohler, coming in at almost 3 months of age, and our oldest walker was my aunt, Mary Erickson, coming in at 72



Team Walk for Paige

years of age.

Our team raised a total of \$5,651, which made us one of the event's top fundraising teams. Overall, this event raised more than \$53,000 for

lifesaving CF research; a \$10,000 increase over last years total. We thank each and every one of you who walked, or sponsored a walker, for making this event such a success. Your support keeps our family going on a daily basis. Together we *will* make a difference for Paige.



A special thank you to Rebecca Maras and Corey Richart for designing and printing our Walk for Paige t-shirts!

T H E S T O R Y B E H I N D T H E C F F O U N D A T I O N S Y M B O L

Mary Weiss became a volunteer for the CF Foundation in 1965 after learning that her 3 little boys had CF. Her duty was to call every social, civic and service organization seeking financial support for CF research. Mary's 4-year old son, Richard, listened closely

to each call his mother made. After several calls, Richard came into the room and told his Mom, "I know what you are working for." Dumbstruck, since Mary knew Richard did not know that he had cystic fibrosis, she asked, "What am I working for, Richard?" "You

are working for 65 Roses," he answered so sweetly. Mary was speechless. She went over to him and tenderly pressed his body to hers. He could not see the tears running down Mary's cheeks as she stammered, "Yes Richard, I'm working for 65 Roses."

U P C L O S E A N D P E R S O N A L



Paige getting a vest treatment during her June 2005 hospital visit.

On most days, having a daughter with cystic fibrosis doesn't

feel like the end of the world. The hour of daily vest therapy, the multiple trips to the pharmacy each week, the thirty-plus pills Paige needs each day, and

the monthly doctor visits have all become our new accepted state of normal.

But some days, this diagnosis feels so unfair. Some days it's hard to make your daughter take the "icky" medicine 3 times a day despite her woeful pleas. Some days it's hard to take her away from fun activities for her vest treatment when the other kids get to stay and play. Some days it's hard to realize that your daughter's life will be filled with 'musts' instead of choices. Some days it's hard to live with the

fear that each illness might mark the beginning of the end.

God has chosen Paige to be an angel among us. She reminds our family daily to appreciate how blessed we are. She inspires and strengthens us with her courage. She gives our lives a new purpose.

We will not let this disease win. We refuse to lose Paige to cystic fibrosis. We will never be able to fully express our thanks to you for helping us fulfill this new purpose.

C U T T I N G E D G E

Ninety cents out of every dollar raised by the Cystic Fibrosis Foundation (CFF) goes to life-saving research. Here are a couple of the exciting studies your contributions are making possible:

Anylam Pharmaceuticals Inc. is using cutting-edge technology to restore the proper function of the CFTR protein. In most people with CF, CFTR protein is made, but is unable to reach the cell surface. The

goal of this study is to determine whether the CFTR protein can be redirected to the cell surface by using a new technology called RNAi (or RNA interference). By using RNAi technology, Anylam hopes to silence or regulate specific genes. If this can be successfully accomplished, the next step will be to develop a RNAi therapy that can be used in people with CF.

The development of new in-

haled antibiotics is vital to provide more options to treat respiratory tract infections in people with CF. Corus Pharma is making great progress in moving aztreonam, an antibiotic that kills *Pseudomonas aeruginosa* (a more dangerous strain of bacteria for CFers), through the clinical trial process and toward the marketplace.



"Sometimes our light goes out but is blown into flame by another human being. Each of us owes deepest thanks to those who have rekindled this light"

A N I R O N M A N W I T H H E A R T

Very few people would question the fact that Ironman triathlon is one of the most grueling events in the world of sport. The commitment, discipline and ambition necessary to complete a 2.4 mile swim, 112 mile bike ride and 26.2 mile run are nothing short of inspirational.

The Janus Charity Challenge

captures this inspiration in a powerful way by encouraging Ironman participants to raise funds for a charity of choice.

Shortly after learning of Paige's diagnosis, a colleague of mine, Eric Distad, informed me that he would like to participate in the Janus Charity Challenge using a charity of my choice.

On September 11, 2005, en-

during 94° weather and a heat index of 100, Eric completed his first triathlon in 13 hours and 49 minutes. Eric placed 835 out of 2073 participants and raised over \$1300 for life-saving CF research. Congratulations Eric, and thanks to everybody that donated money. You give our family hope!



Eric competing in the Wisconsin Ironman.

CF CALENDAR



THE CHRISTENSEN'S CF NEWSLETTER

Minnesota Chapter
1611 West County Road B
Suite 221
St. Paul, MN 55113

Phone: 651-631-3290
Fax: 651-631-3296
E-mail: www.cff.org

October 10, 2005

JCs Cooking for a Cure, Oakdale, MN

November 12, 2005

Breath of Life Gala, Minneapolis, MN

May 6, 2006

Great Strides Walk, Minneapolis, MN

*MARK YOUR CALENDARS AND JOIN OUR
FAMILY FOR THIS WALK AROUND THE
LAKES!*



Cowgirl Paige

WHAT IS CYSTIC FIBROSIS?

CF is a genetic disorder that Paige inherited from Paul and me. Both Paul and I were unknowingly carriers of a genetic mutation. Neither of us has CF since we each only have one copy of this mutation (1 in 29 Caucasians are unknowingly carriers of CF). Paige has CF because she inherited two copies of this mutation from Paul and me.

This genetic mutation makes certain cells lining Paige's tear ducts, sweat glands, nasal passages, lungs, stomach, pancreas and intestines not function properly. Instead of these cells producing a thin, protective mucous like they do in you and I, Paige's cells produce a thick, oppressive mucous. Due to this overly sticky mucous, Paige gets blocked tear ducts, has constant

nasal congestion, sweats a lot (increasing her risk for dehydration and overheating), has mucous sitting in her lungs collecting various bacteria, has acid reflux, and has a blocked pancreas that is unable to break down the food she eats (leading to malnourishment, a swollen tummy, and eventually diabetes).

Of all of the organs affected by CF, the lungs are the most vulnerable. As Paige gets older, the bacteria that take up residence in her lungs will get more aggressive. The more aggressive the bacteria, the more scarring and inflammation Paige will have in her lungs. Eventually, the scarring and inflammation will lead to lung failure. If lung transplantation is not successfully

performed, lung failure will result in death.

Paige will be kept as healthy as possible until a cure for cystic fibrosis can be found. Her lungs will be managed with antibiotics, nebulizers and vest treatments. A high fat/high calorie diet will be followed to keep her height and weight within the normal range. She will take pills called enzymes with every bite of food to break down the food and provide nourishment to her body. Her reflux will be managed with medication, and her nasal congestion will be controlled with a nasal spray, Ibuprofen and eventually sinus surgery.

For more information about CF, visit www.cff.org.