

Heartland Chapter of Cystic Fibrosis Foundation: Helping with both National and Local Efforts

By Amy Hempe

A breath in. A breath out.

One of the most basic functions of life is something most of us take for granted. For those born with cystic fibrosis, however, the ability to breathe freely is a blessing.

Cystic fibrosis is an inherited disorder that can cause damage to the lungs, as well as the digestive system and other internal organs. Sufferers liken the condition to breathing through a straw. Airways get clogged and inhalation becomes a strained activity, with wheezing and coughing often accompanying the effort.

Today, there are approximately 30,000 cystic fibrosis patients in the United States. A person cannot catch cystic fibrosis but is born with it due to both parents being carriers of the disease. While it is not massively widespread, it can nevertheless be a devastating condition for those affected. Treatment requires receiving therapies at a cystic fibrosis care center – there are one hundred and ten nationwide – in addition to daily management of one's health.

The Cystic Fibrosis Foundation (CFF) has spent nearly 70 years combatting the disease. Fifty years ago a child born with cystic fibrosis would be unlikely to live to see kindergarten, yet medical advances today have allowed patients to live well into adulthood, usually to middle-age.

Local CFF Heartland Chapter Executive Director Dana Wilson says that "we sure have come a long way," but states that there are still enormous hurdles.

Many of these hurdles are being met with massive fundraising efforts from local CFF chapters. Most local chapters in the US, including the Kansas City Heartland Chapter, were established around 1955. Since then, fundraising has provided the base for chapters' overall mission: to raise money for increased research and development, and to provide support for local cystic fibrosis patients.

What Dana Wilson calls the "bread and butter" of their fundraising efforts is the annual Great Strides Walk. Occurring four times in the greater Kansas City area every May, this walk allows individuals and teams to bring in thousands of dollars in pledged donations. Locally, the Great Strides Walk occurs in Theis Park and participants walk for three miles, often in support of a family member or friend who is a cystic fibrosis patient.

One of the teams you'll meet at the Theis Park Great Strides every year is the one named "Serving Up A Cure," led by Heartland CFF Board Members Paul and Stephanie Freeman. In 2017, they raised over \$22,000 dollars for the foundation in the name of their son Henry who is a cystic fibrosis patient. Impressive as their fundraising number is, there were two teams that raised more money this year: Two Charmed Ducharmes and Amber's Amblers raised approximately \$29,000 and \$25,000, respectively. Overall, the Heartland Chapter raised over \$1 million dollars from Great Strides, and has hopes to maintain this.

The donations are crucial. Without them, there would not be the enormous medical advances being made. Wilson points to two drug therapies that have transformed the lives of thousands of cystic fibrosis patients. These FDA-approved drug therapies, named Kalydeco and Orkambi, go after the basic genetic defect causing the condition rather than just attack symptoms.

Wilson stated, for the first time ever, young children with cystic fibrosis can receive these drug therapies. The expectation is that they will be able to live full lives with a normal human life-span.

These treatments are revolutionary and exciting. The goal is that ninety-five percent of cystic fibrosis patients will benefit from these drug therapies by 2026. Such advances require millions of dollars in research funds, so in

addition to fundraisers, congresspersons must also be lobbied. Paul and Stephanie Freeman have added that task to their duties while also participating annually in the March on the Hill – a yearly Washington D.C. event where volunteers meet with members of Congress to discuss policies that affect the cystic fibrosis community.

Drug therapies and medical progress are still only part of the CFF mission. They also serve to as a support system for the cystic fibrosis patients and families. Whether it is helping patients navigate insurance mazes or guiding them through new transitions in life such as going off to college, they have a staff of people ready to provide advice, assistance, and moral support.

The diagnosis of cystic fibrosis can feel calamitous. Patients can experience depression and grow alienated from others. Yet there is always hope. Wilson describes a cystic fibrosis patient in the community whom she met when he was in his twenties. He was





sickly and struggling with day to day activities. With the help of the CFF research and development efforts, he has made a dramatic change to where he is thriving and optimistic about life.

Wilson acknowledges that public awareness has a long way to go before people truly understand the challenges of cystic fibrosis. However, with the continued community efforts, she sees that positive changes are coming very soon. "These advances have been amazing," she says, exuding both faith and confidence. With these continued efforts, soon everyone within the cystic fibrosis community will be able to take a breath in, and let a breath out, just like everyone else.