
COOK CHILDREN'S CF NEWSLETTER

Winter 2018



The Cook Children's Cystic Fibrosis Family Advisory Council and your CF care team wish you and your family a Happy New Year!

We hope you make many memories, find joy in the season, and celebrate life!

Together in 2018 and beyond, we will strive to make CF stand for Cure Found!

Sincerely,

Your CF-FAC

WE WANT YOU!

To take charge of your Cystic Fibrosis Care with Co-Production

PRE-VISIT PLANNING

Your clinic wants you involved in your child's care every step of the way.

You should have received a letter in the mail about pre-visit planning.

We are now sending emails to you prior to your clinic visits inviting you to help us make your visits more beneficial and efficient. Please check your email!

POST-VISIT SURVEY

The CF Foundation wants to hear from you! Tell us about your experience at Cook Children's Pulmonary Clinic.

It's easy to do. You will get a survey at your clinic check in. After your visit, before you leave, turn it in at check out and you're done!

Your answers will be kept confidential, and will help us improve patient care and your clinic visits.

FAMILY ADVISORY COUNCIL

Cook Children's Cystic Fibrosis Families

Cook Children's believes in a family-centered approach to healthcare, and the Family Advisory Council (FAC) is an important part of the family-centered care initiative. The Family Advisory Council is a partnership between families and staff who volunteer their time, meeting once a month to make the clinic and hospital experience the best it can be for all CF patients and families.

The FAC shares ideas and family perspectives with the clinic team to ensure that our parents and families experience the highest quality care possible.

Interested in joining FAC? Talk to the CF care team at your next visit or email today at parents@cookchildrens.org



Ready for College?

Whether you're letting your child spread their wings, or you are finally ready go back and get that degree, college can be a major expense. Before you start taking out student loans, check out these great scholarship opportunities for people living with CF.

<https://www.cookchildrens.org/SiteCollectionDocuments/specialties/pulmonology/scholarship-list.pdf>

With opportunities from pharmaceuticals, Boomer Esaison Foundation, private donors and more, there is a scholarship option for everybody.

Stronger and Longer

1,000 strong #STROLO

Recently, the Cystic Fibrosis Lifestyle Foundation helped its 1,000th person with cystic fibrosis (CF) live stronger and longer.

The CFLF understands that some people cannot afford to prioritize fitness along with medical expenses. That is why it has given over half a million dollars in the form of Recreation Grants to help pay for gym memberships, sports camps and more for 1,000 individuals with CF all over the United States ranging in age from 6 months to 80 years.

The 1000th Recreation Grant was awarded to 44-year-old Kiley Lyon from Rock Island, Illinois. Diagnosed with CF at the age of 12, after years of misdiagnosed respiratory infections, he received his diagnosis at the University of Iowa. "When I was told I had Cystic Fibrosis, despite the fact that the average life span at the time was 18 years, I was relieved. I finally knew why I always felt terrible." Kiley used his Recreation Grant for a 12-month gym membership, something he feels has been critical to his CF health. "Working out is what has helped me control my CF, and not let my CF control or dictate my life." Kiley believes that the support of his wife, exercise and his "never give up" attitude have allowed him to live a full, productive life.



*To Donate to the
#STROLO campaign
[http://www.cflf.org/
donate-now](http://www.cflf.org/donate-now)*

STAFF SPOTLIGHT

Child Life Specialist

Sarah is a Certified Child Life Specialist that covers the Pulmonary clinic. She has been at Cook Children's for seven years as a CCLS and loves getting to support patients and families through their healthcare experiences! Sarah grew up in Abilene and went to Abilene Christian University. She moved to Fort Worth after graduating college and absolutely loves this area! Sarah is a HUGE Texas Rangers fan and goes to games as often as possible. She loves to cook, try new restaurants, and spend time relaxing at home! Sarah also loves to travel! Sarah is excited to be a part of the Pulmonary team!



CF Peer Connect

Are you or someone you know living with Cystic Fibrosis and facing a life transition or milestone? CF Peer Connect is a peer mentoring program for people with CF age 16 and older. You can get connected with a trained mentor who is also living with CF and has gone through similar experiences. CF Peer Connect matches you with a Peer Mentor based on a variety of topics including:

Going to college, dating and relationships, work decisions, going on disability, starting a family, infertility, parenting, getting a CF diagnosis as a teen or adult, CF-related diabetes, getting a G-tube, considering lung transplant, post-lung transplant issues.

Life with CF can be challenging; you don't have to go through it alone. Contact peerconnect@cff.org

Upcoming Events



Great Strides May 20, 2018-

For 30 years, Great Strides – the Cystic Fibrosis Foundation’s largest national fundraising event – has supported the Foundation’s mission to cure cystic fibrosis and raise awareness for this rare, genetic, life-shortening disease that makes it difficult to breathe and shortens lives.

Great Strides provides a fantastic opportunity for family, friends, students, and colleagues to come together and make a difference in the lives of people with CF. The event harnesses the power of people with a shared vision and encourages collaboration, team building, and leadership, as we collectively take steps to find a cure.

Registration is free, but walkers are encouraged to raise funds. Your support will help accelerate innovative research and drug development, as well as advance care and advocacy. Nearly every CF drug was made possible by the Foundation and because of funds raised from Great Strides, people with CF are living longer, healthier lives and pursuing their dreams.

We are working every day to build on this incredible momentum, and we won’t stop until there is a cure for all people living with CF.

Sign up to walk in Great Strides today and join us as we take steps towards a cure.

The time is now. Together, we can cross the finish line. Let’s LACE UP. WALK. CURE CYSTIC FIBROSIS.

Walk Details

Date: 5/20/18

Check-in: 8:00 AM

Walk: 9:00 AM

Distance: 5k

Chapter: Northeast Texas - Ft. Worth, ftworth-ne-texas@cff.org, 817-249-7744

Event Location: Panther Island, Ft. Worth, TX

Help the CF Foundation learn more about the challenges people with CF face with health care coverage by participating in this survey. They will use the results of the survey to advocate for the needs of people with CF and help the *Compass* program better meet your needs.

HEALTH CARE IS COMPLICATED

Access to care, health insurance coverage, and cost can be challenging for people with cystic fibrosis.

TAKE OUR SURVEY



- ✓ Visit cff.org/survey on your smartphone or computer.
- ✓ Complete a 20-minute survey.
- ✓ Receive \$10 to Target or Amazon.



Questions?
Contact 202-994-7368
or cffcoverage@gwu.edu

Calling Campers for Camp Kindred Weekend Camp

For Siblings of Cystic Fibrosis. Patients/ Families

When: April 20 to 22, 2018

Where: Camp John Marc in Meridian, Texas

Activities: ropes course, archery, fishing and s'mores

Camp Kindred is a weekend camp that provides an opportunity for siblings of Cystic Fibrosis patients to build therapeutic relationships with other siblings experiencing similar stressors. Camp Kindred allows siblings to gain support beyond the medical setting. This camp is free to all who attend.



Camper Application due March 23rd

Please contact Heather Bayers for further questions either
by email

heather.bayers@cookchildrens or 682-885-4181