**CAMP KINDRED:**

Camp Kindred is a special camp for children (ages 7-18) that have an immediate family member with cystic fibrosis (usually their sibling or parent). Camp Kindred will be held the weekend of April 21-23, 2017 at Camp John Marc in Meridian, TX (Transportation Provided from Cook Children’s Medical Center). We will be partnering with Dell Children’s Medical Center and Texas Children’s in Houston. Through subsidization and generous grants, we are happy to announce that this weekend is **completely free** of charge! Activities at Camp John Marc are designed to build confidence in children and provide an opportunity to have new life experiences. These activities can include ropes course, star gazing and fishing. Part of the focus of this weekend is to provide a safe place for children to express and share their own personal experiences about having a family member with CF. If you’re interested in having your child attend Camp Kindred please contact Heather Bayers at 682-885-4181 or heather.bayers@cookchildrens.org by April 3, 2017.

“I have sent my daughter to Camp Kindred for 3 years. She loves it! She gets to meet new people, has a blast, and enjoys being the focus of attention. I highly recommend this opportunity!”

*Darla Eaken* (mom to CF son and nonCF daughter)
MAKE A WISH - ABIGAIL’S STORY

ABIGAIL’S WISH

“Thank you, God, for telling me that I needed a sister.”

- Abigail

Abigail, 16
Cystic Fibrosis
I wish for my family to adopt my best friend from the Bulgarian Orphanage

At first, Abigail may seem much like an everyday teenager, full of bubbly energy with dreams of Hollywood and movie stars. Her story is, however, anything but typical.

Abigail was adopted from a Bulgarian orphanage by her parents Dorcas and Tony in 2013. She was 13 years old at the time, and while she was elated to join her new family in the United States, it was also bittersweet as she had to leave Caroline, her roommate and closest friend in the world, behind.

But the story does not end there. Diagnosed with Cystic Fibrosis, Abigail was granted a wish by Make-A-Wish North Texas. She deliberated only briefly. Would it be a trip to Hollywood or something else – something she had in mind with deep personal meaning? With her parents’ blessing, Abigail wished to adopt Caroline, still dreaming to build a family. Make-A-Wish North Texas agreed to help facilitate and manage the logistics surrounding this most unusual wish.

It was a wish nearly two years in the making, but the Grubaugh family was recently made complete -- just in time for the holidays. How truly wonderful, for everyone involved, to be able to grant Abigail’s wish, while simultaneously making a dream come true for Caroline as well.

Since they’ve officially become sisters, Abigail and Caroline are both in school together. Caroline is learning English and absolutely loves her new biker! The Grubaugh’s are settling into life together as one happy family. Abigail has definitely not lost sight of her Hollywood dreams. But for now, her idol, Demi Lovato, will just have to wait to meet Abigail.

Read more North Texas wish stories at ntx.wish.org.
We Need Your Feedback!
Patient and Family Experience of Care Survey Reminder

Our CF Center is participating in a national Experience of Care survey and we want to hear from you!

By participating, you will help us learn what is working well and where we can improve—your voice can make a difference!

As a CF Center, we have the unique opportunity to learn about your experience of care with a special survey created just for people with CF and their families—15 minutes of your time can make a difference for you and everyone at our center!

If you are contacted by Quality Data Management (QDM), an Ohio-based company in the 440 area code, please take some time to share your experience! You will not be asked to take more than two surveys per year.

Thank you for your help!
Your CF Care Team

For general information, contact your CF care center. This Quality Improvement Initiative is supported by the Cystic Fibrosis Foundation. Confidentiality will be observed with all participants and responses.
One of the many challenges faced by the cystic fibrosis community is meeting their high-calorie diet requirements. Fortunately, there are resources to help meet this need. Paul O’Neil is a Dietitian who works with patients who have Cystic Fibrosis at Sir Charles Gairdner Hospital in Australia. He recommends the website www.cfcooking.org

“CF Cooking is six episodes of professionally filmed cooking demonstrations that are uploaded on the YouTube platform & embedded into their own website.

All the recipes have been tried, demonstrated & should be reliable if you follow the demonstration.

It was specifically aimed at people with cystic fibrosis, however the recipes were selected to promote a healthy version of the high fat diet using olive oil etc, so that they could be shared with their family & friends. The person with CF could add the extras at the table, or as snacks & homemade supplements in between meals.

I worked as a chef in another life & am pleased to incorporate these skills with my dietetic role.

I was also mindful of the lethargy that comes with a chronic disease & tried to make most of the recipes simple & easy to reproduce.

The videos & website are optimised for smartphone, or tablet so that you can watch it anywhere in the world where there is Wi-Fi access. There are links to the PDF recipes on each episode with nutrient analysis & you can read them straight off your device in the kitchen, or print it & use it that way.

The recipes are free & would be suitable for people with CF, their family, friends, or to show people who are new to CF. I have been recommending these recipes to individuals in clinic & it has been well received by many patients. Children might learn some of these recipes under the supervision of their parents.”

Additional recipes can also be found at https://www.chef4cf.com/recipes
The 30th annual North American Cystic Fibrosis Conference was held on October 26-29, 2016. You may access archived videos of the presentations through https://arc.nacfconference.org/cff/live/16 Please note that you will need to register for free to view the archived presentations. Among the numerous and informative presentations, we will take a look at staff summaries relating to mental health and exercise. More summaries will be included in future newsletters.

**MENTAL HEALTH**
At NACFC 2015, the mental health guidelines for screening patients with CF and their caregivers were revealed. The screening of CF patients was quickly and successfully implemented in many CF centers; however, the screening of parents/caregivers have not been as simple. One of the sessions I attended at NACFC 2016 tackled the challenges of screening parents and caregivers of CF patients. Some of the challenges were: where to document the parents’ results and referrals, where to keep the screener documents of caregivers, what to do if there is a suicidal parent, and how to refer parents to counseling, psychiatrists, etc. One solution was to keep a locked binder with results of caregivers’ screeners and it was documented that caregiver completed anxiety and depression screeners without scores. Another solution was to provide parents with a screening packet which included anxiety and depression screeners as well as resources in the community for mental health. It was documented that parent/caregiver was given mental health screening packet. These two CF centers have adult hospitals with whom they work and would take the parent there is there were any suicidal concerns. The screening of parents and caregivers can be tricky but it is very important to recognize the possibility for anxiety and depression of an individual who is taking care of someone with CF.

Aditi Prabhakar, LMSW, MBA
Pulmonary Social Worker
Cook Children’s Medical Center

**EXERCISE**

This session gave some great ideas for exercise in patients with CF. The presenters really stressed that exercise is important for patients, and staying active is one thing they can do and have control of to increase their lifespan. A lot of patients don’t realize this from an early age because it is not reinforced at home, and in the past exercise was actually not recommended. That is not the case, and exercise is healthy. Research showed that devices such as Fitbits are great motivators because the patient is only competing against themselves, and can set a reachable goal every day. Physical therapists can give patients exercise programs before patients leave the hospital, yoga or tai chi classes are beneficial, or with younger patients running outside, playing on a playground, or staying active indoors will also help. Patients as young as 4 can benefit from increased exercise 4-5 times per week for 30 minutes. Examples of some exercises are: running, walking, biking, weightlifting, yoga, playing approved sports, jump rope, or even interactive video games like the Wii or Xbox Kinect.

Ceci Gonzalez, PT, DPT
Physical Therapist
Cook Children’s Medical Center
CF Tips - Travel

Summer season is quickly approaching! It's that time of year when we start daydreaming about travels and adventures. If you are planning a trip that includes air travel, check out these airline travel tips. I was inspired by this article from Cystic Fibrosis News Today by Reid D'Amico: https://cysticfibrosisnewstoday.com/2017/03/01/five-tips-flying-cystic-fibrosis/ I have included his suggestions as well as some ideas of my own.

1. Stock up on your medications at least a week beforehand to make sure you have enough for your trip. This will allow for hiccups with filling your medication that we all know happens from time to time! Part of stocking up means bringing extra in case you experience any travel delays.

2. Have emergency medication available in case of an exacerbation. Let your doctor know your travel plans. It’s possible that they will provide you with some medicines for use if they are needed (steroid, antibiotic). This is especially helpful if you are on a cruise or out of the country and a pharmacy isn't close at hand that can fill a prescription for you.

3. Pre-board the plane. Let them know your medical situation and they may allow you to pre board to allow time for wiping down seats and storing your carry on bags.

4. Allow extra time at the airport for security screening. Typically we get stopped when we bring our vest machine so they can look at it more closely. It doesn’t usually cause any significant delay, but every experience can be different.

5. Speaking of carry on bags - ALWAYS carry your medications and equipment on the plane with you. These things are your lifeline and you can't risk anything getting misdirected.

6. Try to keep your meds with their proper prescription labels. I put my refrigerated medications in a small insulated bag with a small frozen pack. For long trips you can get ice inside the airport or once on plane to keep chilled.

7. Portable nebulizer compressor systems are convenient when traveling.

8. Backup plan - Sometimes our equipment fails while traveling (we’ve had it happen). So if your therapy machine has a failure, plan an alternative for airway clearance (like manual CPT, huff coughing). Our compressor broke once while on a cruise - fortunately the medic on board had one they could loan to us . It wouldn’t hurt to bring an extra if you have a backup (and room).
Mental Health Screening

A Letter From Your CF Care Team

To Our Patients and Families:

As we continue to strive to provide the best possible care for our CF families, we will be implementing new recommendations of the International Committee on Mental Health in CF beginning January 1, 2017. In 2013, the Cystic Fibrosis Foundation (CF Foundation) and the European Cystic Fibrosis Society put together a team of experts to form this Committee, established to help CF Centers address anxiety and depression in individuals with CF and their parents/caregivers. The CF Foundation is now recommending that each CF Center offer screening for anxiety and depression to all patients ages 12 and over and to parents/caregivers of children from birth to age 17 at least once per year.

Research shows that individuals with CF experience anxiety and depression at a rate that is 2-3 times higher than those in the general population1. This is also true for their caregivers. People experiencing anxiety and/or depression may have a harder time getting treatments done, their health tends to be poorer, and they are more likely to experience struggles in school, work and relationships. Though we all experience some worried or sad feelings at times, anxiety and depression that doesn’t go away can interfere with daily activities and worsen overall quality of life.

What does screening mean for you?

• At an upcoming clinic visit, patients 12 years and older and parents/caregivers of all pediatric patients will be offered the opportunity to complete two simple screening tools called the Patient Health Questionnaire and the Generalized Anxiety Disorder Screener. The questionnaires consist of 9 and 7 questions and should take no more than 3-5 minutes total to complete.

• A qualified staff member will share the results with you and/or your child. If there are concerns based on the results, the medical team will work with you and your family to find the best solution to address these concerns.

These questionnaires are optional, but we hope that by identifying symptoms of anxiety and depression early through screening, then providing supportive education and linkage to helpful services, we can work to improve health and quality of life for all of our patients and their families. Please see information sheet for details on CF mental health research and the process for mental health screening in clinic.

We are glad to answer any questions you may have about these new guidelines. Please do not hesitate to contact us, as we value your input. You may contact your CF coordinators Janet Garbarz, or Carrie Stradley or clinical therapist, Mariah Snapp for more information or discuss this with the team in clinic.

We look forward to seeing you at your next visit!

Sincerely,

Your CF Care Team

Mental Health Screening

Information Sheet:

CF Mental Health Research

A recent international study was conducted exploring depression and anxiety symptoms in individuals with CF and their caregivers. Study participants were recruited from 45 CF care centers in the US and CF centers in eight European countries. Participants completed reliable questionnaires designed to identify symptoms of anxiety and depression.

Research Results

¬ Teens and adults with CF were 2-3 times more likely to experience symptoms of depression and anxiety than people who do not have CF.

¬ Rates were similar for parents/caregivers (including both mothers and fathers) of people with CF.

¬ Adolescents were more likely to have elevated depression and anxiety scores, if they have a caregiver experiencing significant symptoms.

Table 1. Depression
Table 2. Anxiety


Mental Health Screening for Children/Teens with CF

¬ At least once a year, patients 12 and over will be asked to complete two simple validated screening tools. Questionnaires take about 5 minutes to complete.

¬ Screening results will be shared with you and your child during the course of a routine clinic visit.

¬ If there are concerns based on screening results, our staff will work with your child/family to provide individualized education on coping techniques and/or coordination of referrals to address your child’s specific needs.

Mental Health Screening for Caregivers

¬ If your child is 17 years or younger, you will be offered the opportunity to complete two simple screening tools. Questionnaires take about 5 minutes to complete.

¬ If there are concerns based on screening results, our clinic staff will share these with you privately and provide supportive education, information on coping techniques and referral information.
Staff Spotlight

Mariah Snapp, LCSW

Mariah was born in Wisconsin and moved to Kentucky where she attended Morehead State University and received a bachelor’s degree in social work. She continued on in her education at the University of Kentucky obtaining a master’s degree in mental health social work. She is a Licensed Clinical Social Worker (LCSW). She has spent her career working with children and their families in different aspects regarding their mental health. Mariah joined Cook Children’s psychiatry team in November 2015 as the Clinical Therapist for the pulmonary department. She is passionate about helping patients and their families learn to cope with the stressors of having a chronic health condition and allowing them to see hope and joy in their lives. In her free time, she loves to spend time with her husband and 2 children. She enjoys running, camping, and reading.

WANT MORE?

For more support and information please visit http://www.cookchildrens.org/SpecialtyServices/Pulmonology/Services/cystic-fibrosis/Pages/default.aspx