FALL 2018

THE University of Vermont MEDICAL CENTER

THE University of Vermont Children's Hospital

CF CONNECTION

Newsletter of the Vermont Cystic Fibrosis Center Advisory Board

FOOD INSECURITY SCREENING

Why we screen and how we can help

By Christine Prior, LICSW

People with cystic fibrosis require more energy to breathe normally, fight lung infections and compensate for fat malabsorption. For these reasons, they need more calories than people without CF. For some patients and families, the cost of these additional calorie needs is more than their household budget can allow.

In an effort to recognize and address this struggle for many of our patients and families, in March we began screening for food insecurity in both our pediatric and adult CF clinics. Simultaneously we developed a team including nutrition services, CF physicians and our CF social worker to build supportive interventions for those who screen positive for food insecurity. Our hope is to be able to offer families a variety of resources in recognition that one intervention may not work for everyone. Included in these may be grocery cards, help in signing up for food stamps, food vouchers for a hospital meal or the option to access food through our CF food pantry.

Our food pantry began with generous donations from nurses on Baird 5 and nutrition services at UVM Medical Center. Both donated a great deal of food to help push forward our effort. Since then, we have been fortunate enough to launch a pilot program in partnership with the VT Foodbank. Our goal of this project is to help alleviate the financial stress and emotional burden of food insecurity amongst patients with CF and their families. (continued on page 2)

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Lisa Benoure, Medical Assistant
Jenna Carroll, Practice Support Specialist
Susan Heney, Operations Support Specialist

Pulmonary Function Testing Lab

The Children's Specialty Center recently opened its own Pulmonary Function Testing (PFT) lab in February in an Around the World themed room. It is also equipped with a portable PFT machine that is frequently used on busy CF Clinic days. Having our own PFT lab allows patients and families to receive their care in one convenient location.

Food Insecurity (continued from page 1)

If you or your family are struggling to buy food, there is help and resources available at your clinic visits. Please do not hesitate to ask for help or email Christine Prior, LICSW to discuss your concerns at: chrisitne.prior@uvmhealth.org.

The CF Team is excited that they will present this project at the NACFC this year in Denver, CO. Dr. Keith Robinson and Christine Prior, LICSW have been asked to be members of the CF Foundation's Food Insecurity Committee. The group aims to look at how food insecurity affects CF patients nationally.

New Faces in CF Clinic

Alexis Szczypiorski, CCLS

Alexis Szczypiorski, CCLS is a Certified Child Life Specialist through the Association of Child Life Professionals. Alexis completed her Clinical Child Life Internship and Practicum at the UVM Children's Hospital. She received her undergraduate degree in Human Development and Family Studies through the University of Vermont. Alexis is a native Vermonter and she resides in Burlington with her husband and Cavalier King Charles pup Loulou. In her free time, she enjoys traveling, pottery, yoga, outdoor activities and spending time with family and friends. You can find Alexis working five days a week in the Children's Specialty Center.

Noelle Pavlovic, RN, Clinical Research Nurse

Noelle Pavlovic, RN is a Clinical Research Nurse at the Vermont Lung Center. She has been a nurse for 19 years at the UVM Medical Center. After graduating from nursing school at Harper College in Palatine, Illinois in 1999, she finished her BSN at UVM in 2015. She moved to Burlington, Vermont, for her first job as a nurse on Baird 4. The other reason she moved to Vermont was her other passion - snowboarding! She spends her winters snowboarding at Smuggs and surrounding ski areas with her husband George and son Cody, who is now 18 and just going off to college. After an amazing three years of working hard and learning tons on Baird 4, Noelle moved to Pre-op and worked there for 15 years. She loved the atmosphere around the O.R., working with patients of all ages, and she made life-long friends who will forever be her "pre-op family." She left in February of 2018 to discover new territory and joined Vermont Lung Center as a Clinical Research Nurse. She is enjoying her time here working with CF and learning a whole different side of nursing. Noelle is also active with NPG, and is super-passionate about the nursing profession, helping patients who are sick or hurting, and being of service to others.

Staff Changes

Christine Prior, LICSW is the social worker in both the pediatric and adult CF clinics. Starting in August her role expanded. She also assumed the role of the inpatient case manager for CF patients.

CF FamilyCon co-chairs Linda Bowman and Laurie Eddy close out the first-annual event

CF FamilyCon 2018

By Laurie Eddy

This year, the Cystic Fibrosis Foundation is supporting six virtual events created by and for adults with CF and their families to connect and share their experiences. In 2016, a group of adults with CF created BreatheCon. It was a two-day virtual event that had a powerful effect in connecting community members. BreatheCon was an event open only to adults with CF. For the first time in CF history, adults made up more than 50% of the CF population. BreatheCon gave adults an opportunity to have a larger voice in the community and in working with the Foundation. Since the CFF Infection Prevention and Control Policy was put into place, this was the first time for many adults to be able to be "with each other" in a real and vulnerable way.

The success of BreatheCon led to the CFF hosting several MiniCons. These are shorter, topic-specific virtual events that have been wildly popular with adults. Family members like me heard about BreatheCon and we also wanted to connect with others and build a larger community. So, when I learned that the CFF was looking for volunteers to help plan the first FamilyCon, I jumped at the opportunity!

The first CF FamilyCon was held on June 3rd. I was honored to co-chair FamilyCon with Linda Bowman, an energetic and funny woman with 57 years of experience living with CF. We worked with an amazing group of volunteers from around the country, including adults with CF, parents, siblings and spouses. We used video conferencing to meet and plan FamilyCon. The event featured a keynote panel, group chats and small group video breakouts on issues that are unique to people living with CF and their families. Topics included maintaining relationships and major life transitions. Nearly 400 people registered to participate in CF Family Con.

For me, the best part of FamilyCon was connecting with more members of the CF community. I would encourage you to get involved - you can do as much or as little as you want. This is a collaboration of volunteers working with the CFF staff; everything and anything is appreciated. It's an incredible community and our hope is to grow this network bigger and bigger.

There are two more virtual events in 2018:

- The third-annual BreatheCon on September 28 and 29
- A new, casual event called CF Adults Connect on November 7

New virtual events are also being planned for 2019, including the first ever ResearchCon. This is a virtual event for the CF community where participants will learn and discuss with experts in the field about a research topic.

For more information about all of these events visit www.cff.org/virtualevents. If you have any questions regarding virtual event volunteer opportunities, please contact communityvoice@cff.org.

Staying on TRACK for activity and exercise

By Maggie Holt PT

It's not easy to get and stay motivated to exercise - but it's super helpful if you do it! Exercise helps every system in your body, including the three systems that CF patients need to think about a lot: the respiratory system, digestive system, and endocrine system. It even helps your mood! You just have to get over the inertia and get started.

Tracking your exercise or activity can help you stay motivated, and it's easy. One type of tracker is an app on your phone that counts your steps. There are a lot of different apps out there for this, and many of them are free. Apple users can find the built-in Health app or download the Activity Tracker and see what their hourly, daily, weekly and monthly step count is. Android users can use apps such as Google Fit, Samsung Health, or Pedometer to get basic step-counting features. Tracking apps can get fancy, with calorie counting features and gym workout monitors, so be prepared to be dazzled by many options if you go to the app store to look them over.

Another type of tracker is a wearable one. Most of them are worn on the wrist like a watch. Wearable trackers are great especially for kids or hold outs who don't carry smart phones. You can see your current step count from the day on your display and you can see trends and stats when you sync the wearable with a website on your computer. Garmin, FitBit, and Moov Now are among the brands that make wearable activity monitors.

Once you decide to use a tracker, you will probably start to notice that on days when your step count is low, you don't feel as well as on days when your step count is high. Once you notice what your average step count is for a week or so, challenge yourself to meet or exceed that average every day. Then, once you have done that for a month, you can make you next goal 10% higher, and keep making your activity habits more regular.

Generally, a good step count is considered to be 10,000 steps per day. Below 5,000 is considered low, and above 20,000 is high.

Let us know when you come to clinic what your activity monitoring is showing and what you've been doing to get your step count up. It's a very aTRACKtive (get it, attractive?) thing to do!

Monitoring CF with Folia Health

By Samantha Ambrose

About three months ago I started using Folia, a tracking service that helps parents and kids track their daily treatments and monitor their health and meds. It sounded like a tool that would be very beneficial in tracking my daughter's treatments and health over time. Day to day we often forget exactly when that little sniffle that turned into a cough began, or when a dosage of medication may have changed. Setup was easy and I added a medication to my daughter's list through a simple message to Folia.

We are currently looking at moving from one dose to another of a medicine. I have been using Folia to track number of pills and quantities so that the next time we go to clinic we will have more information and be able to pick the level and amount that is right for my daughter.

Folia is good with reminders to input the values and medications you give, but it really does work best if you are vigilant and input the information daily. There are Apps available (iPad, iPhone) that can help with that consistency. There are also free giveaways and swag for using the system.

Overall, I am very excited about the potential of Folia in tracking Matilda's health. The next step is to use the charts and graphs for appointments to give the team a more in-depth look into Matilda's daily health. Who doesn't love swag, graphs, and information that helps keep children healthy?

For more information, please go to www.foliahealth.com/.

The current invite code for Folia is (UVMCF).

10TH ANNUAL EDUCATION NIGHT A SUCCESS

Gunnar takes a selfie at the Education Night

In May, the Vermont CF Center Advisory Board hosted its 10th annual Education Night. You can view the keynote speech by Gunnar Esiason entitled *Successful Life with Cystic Fibrosis* on the advisory's YouTube channel at:

youtu.be/WjtI_t-d9Fk

Also available is the Folia Health presentation at:

youtu.be/MqjJVeyjMNM

Please see advisory member Samantha Ambrose's article above about using Folia to track her daughter's medications and symptoms.

CFTR Modulator Therapy

By Tom Lahiri, MD

We all are excited about the recent development of new therapies that target the basic defect in CF. There are now three different drugs available to patients which allow CFTR to function more normally. CFTR is a channel in the cells of the respiratory and digestive tracts. It allows the normal passage of electrolytes and water across the cells. When this doesn't work correctly, mucus and secretions in the bronchial tubes, gut and other organs become thicker and stickier. This may lead to many of the typical complications in CF.

Here is an update of the available drugs:

Ivacaftor (Kalydeco): First approved in 2012 and now available for people with CF over age one with the G551D or one of several gating mutations, including R117H. This accounts for about 4-5% of the CF population.

Lumacaftor-ivacaftor (Orkambi): Approved in 2015 for people with two copies of the most common CFTR mutation, F508del (also called delta F 508). This drug is now approved for individuals two years and older.

Tezacaftor-ivacaftor (Symdeko): This is the newest compound. Like Orkambi, it can be prescribed for people with two copies of F508del or for people with one of 26 "residual function" mutations. It has only been approved for ages 12 years or older. For the time being, we are prioritizing this drug for people who did not tolerate Orkambi or did not experience a benefit. Once insurances have this medication on their formularies, we may prescribe it more widely.

There are a number of new drug compounds that are currently in clinical trials that may help people with only one copy of F508del and other types of CFTR mutations. If you are not sure about your CF mutations, please ask at your next clinic visit.

Stay tuned for updates!

Seeking Survey Participants

By Dr. Karen Lewicki

Would you be interested in talking with us about your emotional and physical health and how you think about these things while managing cystic fibrosis? We are a small team of resident Dr. Karen Lewicki and medical student Bailey Fay working with psychiatrist Dr. Rabinowitz, Dr. Lahiri, and Christine Prior. We hope to better understand how kids and young adults between 11 and 22 are affected by this diagnosis.

Starting this fall we will be in the CF outpatient clinic, as well as visiting people in the hospital, offering a brief 11 question survey. Please let us know if you'd be interested in taking part! We would love to hear from you.

Commonly Prescribed Oral Antibiotics

By Martine Antell, PharmD

There are some commonly prescribed oral antibiotics that are worth reviewing in regards to their side effect and drug interaction profiles.

Quinolones are a class of drugs that include levofloxacin (Levaquin) and ciprofloxacin (Cipro). These target MRSA and Pseudomonas infections. When either is taken orally, it should be separated from vitamins, antacids or dairy containing calcium, iron, zinc, selenium, or magnesium. For the best absorption, the antibiotic should be taken two hours before or six hours after any product containing these.

Sulfamethoxazole/Trimethoprim (Bactrim) is another antibiotic that is fairly well tolerated except at high doses. You should be aware that it could cause nausea. Also, it is very important to stay hydrated to avoid kidney injury. If Orkambi is also on the medication list, the levels of Bactrim could be decreased in the blood due to a drug interaction. In this case higher doses of Bactrim are necessary.

If **Doxycycline** is prescribed, you should be cautioned especially in the summer. It could cause extreme photosensitivity reactions with sun exposure. Wear sunscreen, sunglasses and protective clothing when spending time outside.

Cephalexin (Keflex) could be prescribed for Staph infections. Keflex is dosed 3-4 times per day. This makes timing tricky because it should not be given with any zinc containing food or vitamin. All multivitamins including CF vitamins usually have zinc in them. It is recommended to give Keflex first and only give the vitamin (containing zinc) three hours after. The vitamin should not be given before Keflex.

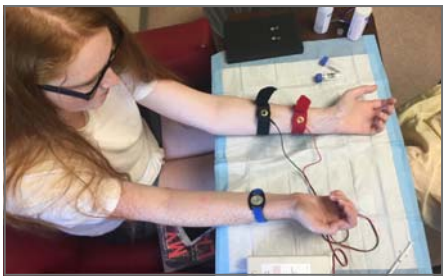
Cefdinir has an interesting drug interaction with iron that is worth mentioning. Iron could decrease blood levels of cefdinir. Also red, non-bloody stools could develop due to the formation of insoluble iron-cefdinir complexes. Avoid this combination altogether, or at least separate the administration by three hours to reduce the risk of this happening.

Lastly, when an antifungal is started, it is usually one in the azole class. These include fluconazole, itraconazole, or voriconazole. All of this type are tricky in that they affect other medications that you could be taking because they inhibit liver enzymes. These enzymes help metabolize drugs, which could cause increased or toxic levels of other medications you are taking with the antifungal. For example, a decreased dose of Kalydeco might be recommended when Fluconazole is started. Another challenge is with itraconazole and the need for the belly to be acidic for the medication to be absorbed into the bloodstream. Any stomach acid reducer like ranitidine, famotidine, omeprazole, pantoprazole, or lansoprazole could significantly reduce the absorption of itraconazole. This could make it ineffective. Sometimes, a cola drink can be given with the itraconazole to help restore acidity in the stomach to help with this.

The bottom line is that your medications can be extremely tricky to keep straight and manage appropriately. Please ask if there are concerns or questions. Someone from our team would be happy to help sort things out.

Research Studies Open for Enrollment

By Julie Sweet, Clinical Research Coordinator



Kelly Eddy doing a sweat test.

This is a very exciting time in Cystic Fibrosis clinical research! There are many promising opportunities for people with CF to help develop new treatments. These include therapies to improve quality of life by treating the symptoms of CF. Also, treatments that target the very cause of CF. In addition to helping advance our understanding of CF, participation in a clinical trial can have direct benefits. One way is helping people with CF take an active role in managing their CF care. Another is gaining access to new treatments before they are more widely available. Although there are many benefits to participating in a clinical trial, there are also possible risks that can be serious. Risks include side effects of the treatments being studied, unwanted events during the trial that may or may not be related to the study treatment, and failure of a treatment to work. The decision to join a clinical trial is personal. It is important to consider the benefits, risks, and time commitment required. We strongly encourage having conversations with family, friends, and your doctors and study coordinators to decide if a trial is a good fit.

At the Vermont Lung Center at UVMMC, we are involved in several studies focused on:

- Developing new chronic antibiotics to treat lung infections
- Improving our understanding of the use of acute IV antibiotics to treat CF exacerbations
- Improving our understanding of nutrition and growth in children with CF
- Developing new CFTR modulator therapies

We recognize that there is particular excitement about the development of new CFTR modulators, and we share this excitement! We feel fortunate to have been selected by Vertex for participation in several key trials as part of this development. In these studies, each research site received permission to enroll only a small number of participants. At this point we have filled our available spots. However, if you are interested in finding out about future CFTR modulator trials, please contact one of the coordinators for more information at (802) 847-2193.

At this time, the studies below are open for enrollment:

STOP2

Pulmonary exacerbations are treated with varying antibiotics for varying time periods. These are based on individual needs determined by patients, their families and care providers. Both doctors and CF patients have questions about the best way to treat pulmonary exacerbations. Doctors and CF patients want to make sure the patient gets antibiotics long enough to get better but not treat too long and expose the patient to unnecessary risks. This research study is for people with CF who experience a pulmonary exacerbation and will receive IV antibiotic treatment. This study will look at the safety and effectiveness of three different lengths of IV antibiotic treatment. Participants who respond early to IV treatment will receive antibiotics for 10 or 14 days. Those who do not respond early will receive antibiotics for 14 or 21 days. Researchers will study the effectiveness of the different IV treatment lengths by measuring changes in lung function. This study requires lung function tests and/or other measurements. Length of study participation is about 1 month. Financial compensation provided up to $210.

This research study requires:

- Diagnosis of cystic fibrosis
- Ages 18 years or older

(continued om page 10)

Research Studies: STOP2 (continued from page 9)

- Actively enrolled in the Cystic Fibrosis Foundation registry
- Doctor's confirmed plan to initiate IV antibiotics for a pulmonary exacerbation
- Willing to participate in three fixed visits at the beginning, middle, and end of the study
- Willing to follow a specific treatment duration determined by initial response to antibiotic treatment and then randomization

Savara AVAIL

This research study will look at the effectiveness of the inhaled drug vancomycin in adults and children six years and older with CF and positive cultures for methicillin-resistant Staphylococcus aureus (MRSA). This study is in two parts. The first part is placebo-controlled. This means that some participants receive inhaled vancomycin and others receive placebo. The second part is open-label, meaning that all participants receive inhaled vancomycin. In this study, researchers will test the effectiveness of inhaled vancomycin by measuring lung function. They will also monitor time to next treatment for pulmonary infection. This study is for adults and children ages six and older with CF who have positive cultures for MRSA. This study may require lung function tests, sputum samples, and/or other measures. Length of study participation is about one year. Financial compensation provided up to $2,000.

This research study requires:

- Diagnosis of cystic fibrosis
- Ages six years or older
- FEV1 % predicted between 30 to 90%
- Willing to participate in 13 fixed study visits over one year

RARE

There are over 1,900 mutations in the gene for the cystic fibrosis transmembrane conductance regulator (CFTR) protein that play a role in cystic fibrosis (CF). New, important clinical trials are evaluating potential therapies that directly target defective CFTR protein. But, most of these target the most common CFTR mutation, F508del. Many patients with rare CFTR mutations are not able to participate in those studies. The RARE study is specifically designed for people with CF over age two who have two nonsense mutations (also known as "x" or "stop" mutations). These cause the production of CFTR protein to stop prematurely. This is a single visit specimen collection research study conducted at six regional sites. Researchers will collect blood and nasal cell specimens from each study participant. Some may also choose to participate in an optional sub-study to collect intestinal cells. Cells from all of these specimens will be used to test future CFTR modulators to see if they might work for people with two nonsense mutations. Having cells to test in the lab is an important first step in identifying potential new therapies for people with these mutations. Participants may travel to any of the regional study sites to participate. They will need to talk with the research coordinator at the site of their choice to get all of the study details before they make a decision to participate. This study is for people with CF over the age of two who have two pre-mature stop codon mutations. This study may require the collection of nasal cells, a blood draw and/or other methods of cell collection. Length of participation is one day.

This research study requires:

- Diagnosis of cystic fibrosis with two nonsense (x) mutations
- Ages two years or older
- Willing to travel to a regional site for one study visit

RESOURCES INCLUDE:

- Welcome Bag
- Medication Bag
- Weekly Pill Organizer
- Patient and Family Checklist
- “Beginning CF Care” Handbook
- “Who I Am” Book
- “Milestones in CF Care: Newly Diagnosed/Early Childhood” book 1 of 3
- Child Life Specialist Flyer
- My Health Online Brochure
- CFLifeLessons.com Video Clip
- Living with CF Series
- Huxi: A Coloring Adventure
- An Adult Coloring Activity
- Parenting with Love & Logic Handbook
- 9 tips for Teaching Kids Responsibility
- CF Voice.com
- Team Impact
- **The Big Trip to the Beach**
- **Jeremy Bishop Explains CF**
- **Therapeutic Video Game Recommendations**
- **Living Extreme: Beyond Cystic Fibrosis**

CF Resource Corner

By Jennifer Eddy, CCLS

Welcome back to the CF Resource Corner! We work hard to ensure that patients and families are up-to-date on current age-appropriate educational materials and generally helpful resources. Watch as the list grows over time. The newest resources are **bolded**. How many do you have? How many have you browsed or used recently? Please feel free to reach out if you are missing one or more. They are meant to be tools for caregivers, siblings, teachers, nurses, etc. We can provide extra copies if needed.

The Big Trip to the Beach (preschool-early school age) - A no-mess paint storybook that focuses on the importance of working together with your team members to make plans of care that meet your healthcare needs and lifestyle. The story has been made possible by Pulmozyme.

Jeremy Bishop Explains CF (school age) - An interactive workbook that provides educational information, conversation starters (for both children and parents and children and peers about CF) and fun games to engage in.

Therapeutic Video Game Recommendations (school age +) - A quick reference guide tailored to helping to alleviate symptoms of pain, boredom during inpatient stays, anxiety/hyperactivity, sadness and cognitive impairment. The games are broken down by video game system as well as symptom. The guide was curated by researchers at EEDAR (the largest specialty video game research firm in the world) and mental health researchers at UCSD (University of California, San Diego). Child’s Play non-profit organization has helped to make the guides accessible to children and families.

Living Extreme: Beyond Cystic Fibrosis (school age +) - A short film (co-produced by Cystic Life, Cystic Fibrosis Lifestyle Foundation and Essential Image Source Foundation) about how exciting, active and rich a life with CF can be. The film highlights the lives and stories of people with CF that engage in extreme activities and physical lifestyles. Check out the trailer on the website livingxtreme.org/.

POSTAGE HERE

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Online Resources

Get Involved!

- **BreatheCon 2018 - September 28-29**
  The third annual BreatheCon is a two-day virtual event designed by and for adults with cystic fibrosis. It will provide the opportunity to connect, share, and learn from others with CF through open and honest dialogue. Learn more and register at www.cff.org/Get-Involved/Participate/Participate-in-an-Event/Virtual-Events/BreatheCon/.

- **CF Peer Connect** is a peer-mentoring program run by the CFF. It is for people with cystic fibrosis and their family members age 16 and older. Talk with and learn from someone who is also affected by CF and has gone through similar experiences. Learn more at www.cff.org/Get-Involved/Community/CF-Peer-Connect/.

- The CFF created **Community Voice** in 2014. The group provides opportunities for people with CF and their family members to take an active role in shaping the initiatives and resources that are developed for them and the rest of the CF community. Each person's experience is valuable, and every perspective should be heard. Visit www.cff.org/Get-Involved/Community/Community-Voice/ for more information.