SPRING 2021

THE University of Vermont MEDICAL CENTER

THE University of Vermont Children's Hospital

CF CONNECTION

Newsletter of the Vermont Cystic Fibrosis Center Advisory Board

COVID-19 VACCINE

IN THIS ISSUE

By Kelly Cowan, MD

In December, 2020, two COVID-19 vaccines (made by Pfizer and Moderna) were approved by the U.S. Food and Drug Administration (FDA) for emergency use authorization. The Pfizer vaccine is approved for ages 16 and up and the Moderna vaccine for ages 18 and up. There are several other companies expected to submit vaccines for FDA approval in early 2021. This should help with the vaccine supply. There are currently studies being done for children and it will take some time before vaccines are available for younger children.

We are very excited to have these safe and effective COVID-19 vaccines approved. Both are close to 95% effective in preventing symptomatic illness with COVID-19 after two doses. The vaccines' studies included people with chronic stable medical conditions such as lung disease, high blood pressure, and diabetes. Although they were not studied in people who have CF specifically, we don't have any reason to think that people with CF would respond differently to the vaccine. You can discuss known benefits and risks/side effects with your doctor or care team. Some potential side effects of the vaccines (such as arm soreness, fatigue, muscle aches, chills, and fever) are common but tolerable and are a sign of the immune system working. Some people don't have side effects with the vaccine and that's ok too! It is too soon to know how long the immunity from the vaccine lasts, but it is expected to be longer lasting and more effective than infection with COVID-19.

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VERMONT CYSTIC FIBROSIS CENTER

PEDIATRIC PROGRAM
802-847-8600

Tom Lahiri, MD, Pediatric CF Program Director
Kelly Cowan, MD, Associate CF Program Director
Jillian Sullivan, MD, Associate CF Program Director
Lauren Elizabeth (L.E.) Faricy, MD, Pediatric Pulmonologist
Keith Robinson, MD, Pediatric Pulmonologist
Tara McCuin, PhD, Psychologist
Martine Antell, PharmD, Pharmacist
Emily DiSchino, RN, CF Nurse Coordinator
Melissa Barron, RN, Pulmonary Nurse Coordinator
Rylee Kilbride, RN, Pulmonary Nurse
Michael Bissonette, RT
Maryann Ludlow, RD, CDE
Christine Prior, LICSW
Ashley Mitchell-Ringuette, CCLS
Julie Sweet, BA, CF Research Coordinator
Diana Grinberg, Medical Assistant
Kendra Therrien, Practice Support Specialist

ADULT PROGRAM
802-847-1158

Charlotte Teneback, MD, Adult CF Program Director
Juan Pablo Perdomo Rodriquez, MD, Endocrinologist
Zachary Weintraub, MD, Pulmonologist
Abe Sender, PA-C
Tara McCuin, PhD, Psychologist
Martine Antell, PharmD, Pharmacist
Christine Prior, LICSW, Program Coordinator
Kaitlin Steiert, RN, CF Nurse
Kitty Brady, RT
Maryann Ludlow, RD, CDE
Julie Sweet, BA, CF Research Coordinator
Lisa Benoure, Medical Assistant
Jenna Carroll, Practice Support Specialist
Susan Heney, Operations Support Specialist

COVID-19 Vaccine (continued)

Initially, there is a limited supply of authorized vaccine. When, where, and how people access vaccine depends on state plans and guidance. We do not have access to this in CF clinic. The supply is distributed to states in phases, in small quantities. The first people to receive vaccine are those at greatest risk for virus exposure, including healthcare workers and people living in congregate settings such as long-term care facilities. Next, persons with high exposure risk and also higher risk of COVID-19 complications due to age or medical illness will be considered. People with CF who are age 16 and older should consult their doctor to determine if they meet the criteria for this high-risk group to receive vaccine earlier as defined by their state authorities. As more vaccine supply becomes available, we hope to be able to recommend the vaccine for everyone in the age group for which the vaccine is approved.

COVID-19 vaccines are a big part of preventing severe COVID illness and reducing infections. Because we don't know yet how well having a vaccine stops the spread of COVID from person to person, we will still recommend the same masking and physical distancing and hand washing as we do now - even for people who have had the vaccine. Eventually, when enough of the population has had the vaccine, we will know more about how well the vaccine works in preventing spread of COVID-19 and how much long term protection it provides.

CFF.org has more information about the COVID-19 vaccine approval process and also the advocacy activities of the CF Foundation to support the CF community related to the COVID-19 vaccines.

https://www.cff.org/Life-With-CF/Daily-Life/Germs-and-Staying-Healthy/CF-and-Coronavirus/COVID-19-Community-Questions-and-Answers/

Patient Perspective

One Year Trikafta-versary

By Reid Jewett Smith

Jell-O® Chocolate Jell-O pudding. When I was coming of age in the 1990s, the most sophisticated science-based recommendation in CF nutrition was lots of Jell-O pudding. I remember coming home from school every day and making pudding with whole milk, waiting 15 minutes, and then eating the whole thing - all 660 calories of it. Even more vividly, I remember my mother explaining to my sister why she had to have *normal* snacks. For years, I ate and ate and ate. Whatever I wanted. Whenever I wanted. During hospital stays, I'd order strawberry and syrup covered waffles and eat them lying down with a full-fat yogurt on the side. As I aged into adulthood (I am now 34), I continued to do all the things that other adults dropped - I ate heavy breakfasts, I drank juice, I hammered bread, I treated myself to seconds. Eating recklessly was the one bright spot in an otherwise crummy disease.

Then I started Trikafta®. I started Trikafta when I was very sick and 30-weeks pregnant in March 2020, a week before the pandemic sent the United States into full lockdown. Within weeks, I felt better at 35-weeks pregnant than I ever had in the 35 years prior. It was a remarkable turnaround that came at a complicated time. I experienced life-saving relief from respiratory symptoms at a time when the world suffered deadly respiratory complications.

I spent March and April eating my way through the pandemic and end of my pregnancy. Then I spent May and June taking care of a newborn. I did telehealth appointments and never stepped on a scale. Then, in July, I started to realize that I hadn't really dropped any baby weight. I went to an in-person clinic visit and realized I was 15 pounds heavier than I'd ever been.

At the same time, I began to realize that my guts worked. I slowly cut back on Miralax. I didn't have days of miserable gassy-bloating or awful cramping. It started to occur to me that Trikafta was affecting my digestive health in an unforeseen way. On the one hand, my gut was absorbing food for the first time, and on the other hand, I wasn't burning so much energy doing basic stuff like breathing and digesting.

I was mad. This was *the one* silver lining that accompanied CF. I'd always been able to count on my figure looking decent regardless of the internal dysfunction I suffered. I'd never had to think about limiting my diet or using exercise as a weight-loss tool. But, suddenly, at 34 with a new baby, with the fear of surviving the pandemic and a slate of other family and professional commitments, I had to adjust my diet (and deprive myself of some beloved CF eating habits) to stabilize my weight. I took up a strict new exercise regimen, which is admittedly much easier than ever before because of my post-Trikafta lung function. While I struggle with appearance in a way I never have before, I always tell myself the same thing: *SMALL PRICE TO PAY.*

As I approach my Trikafta-versary and reflect on where I was a year ago, I realize things could have gone one of two ways. A serious decline during pregnancy could have unraveled into life-threatening danger if I caught COVID and wasn't on Trikafta. *OR* I could have experienced life-changing relief from symptoms with built-in resilience and a few extra pounds. Given the heightened fear that 2020 thrust upon the CF community, I'd take chubby resilience over life-threatening vulnerability any day. Now that I can plan into the future for the first time, I know that I can get fit, lose weight, and re-train myself to eat healthily in time, as I re-frame my future to include decades I didn't know I had.

TRIKAFTA®, One Year In

By Maryann Ludlow, RD, CD, CDE

Trikafta® is called "highly effective modulator therapy," and indeed, it is highly effective! For many people with CF, Trikafta has had a big impact on improving digestive symptoms and enhancing absorption. Because of that welcome improvement, calories, as well as vitamins, minerals and phytonutrients "stick" better than they ever have before. Therefore, weight gain is often much easier than it has ever been before.

This is, of course, a good thing! But, we all know we can have too much of a good thing, and some kids and adults with CF are not so pleased when they find they've gained more weight than they are comfortable with. This may still be a "normal" weight for their height, but simply not what they're used to, and they may not be as comfortable in their new bodies. Or it could be a weight gain into the overweight or obese range, causing even more body image concerns. This is a difficult spot for people who have been told to "eat, eat, eat" for their whole lives, and who used to be able to eat anything they wanted; in fact, that was part of their CF therapy!

Eating in a new way means transitioning from eating for survival to eating for longevity. People who take highly effective modulators like Trikafta will likely live a longer life than previous generations with CF, and with that comes the luxury of looking into the future. We want to keep that future as healthy as possible. The standard high calorie American diet that we've historically taught in CF clinic was not one of chronic disease prevention, because it was focused on the immediate need of improving and preventing malnutrition. Now, people with CF are much more like everybody else (i.e., their non-CF friends and family). And, just like everybody else, they may need to focus more on the kind of healthful eating that will sustain them into their elder years.

If you feel that you or your child has gained too much weight on Trikafta, please don't hesitate to bring up your concerns in clinic or contact me if you'd like some help strategizing. If you're the parent, it's better to focus on everyone in the household eating healthfully than on weight. There may be some "low hanging fruit" that is easy to change, such as drinking fewer liquids with calories, taking a look at the snacks that are "grab-able" in the house, and piling on veggies that are made in a way that increases the yum-factor. And speaking of low hanging fruit, putting fruit out where everyone can see it, like on the counter, increases the odds that it will get snacked on. We are visual animals - that's why TV ads work so well.

Lastly, keep in mind that changing any habit is hard, and it's especially hard if the old habit used to be good for you! It's important to recognize your feelings around it and talk to us about them - we hear you! Everyone on the CF care team can be a sounding board to help you or your child to cope with the problems that come with the good that this medicine brings.

UPCOMING CFF VIRTUAL EVENTS

- **CF MiniCon: Transplant, February 27** - CF MiniCon: Transplant gives people with cystic fibrosis, their family, and caregivers an opportunity to explore all stages of the transplant process.
- **ResearchCon 2021, April 15** - ResearchCon is a virtual event dedicated to cystic fibrosis science and research. It is for anyone with a personal or professional connection to CF.
- **Virtual Great Strides Rutland, May 15** - The CF Foundation's annual walkathon, Great Strides, is an opportunity for families, friends, students, and colleagues to come together to make a difference in the lives of people with CF.
- **CF Foundation Cares, TBD** - As a family member or friend of someone living with CF, we invite you to join others to connect, encourage and share experiences.
- **Grampions, TBD** - A virtual gathering for grandparents of those with CF to meet other grandparents and hear the latest news.

New Faces in Clinic

Kaitlin Steiert, BSN, RN

Registered Nurse in the Adult Program

Kaitlin started working at the pulmonary clinic at UVM Medical Center in November of 2020. She joined the adult CF team a month later. She was born and raised in Littleton, Colorado and moved here to Vermont last November. Kaitlin went to The University of Alabama, The University of Colorado Boulder, and graduated from Denver College of Nursing. She worked in the NICU at Children's Hospital Colorado before joining our team. When she's not busy working as a nurse, Kaitlin enjoys spending her time outside. A few of her favorite hobbies are skiing, hiking, and boating.

Diana Grinberg

Medical Assistant in the Pediatric Program

Diana was born and raised in New York City. She graduated from the University of Vermont in 2019 with a degree in biology. After graduation she worked at the UVM Medical Center emergency department. Diana joined the Children's Specialty Center team as a medical assistant in November. When she's not at the hospital or on service with Milton Rescue, she enjoys photography, cooking, hanging out with her two adorable kitties Rafiki and Tyco, and traveling.

New Roles in Adult Program

By Charlotte Teneback, MD

The coordinator for the CF clinic has traditionally been the nurse on the team. In fact, in the past, the position was called "Nurse Coordinator." However, over the years it has become clear that many of the roles of the coordinator are not nursing roles. Many centers, like our Adult Program, have also struggled with maintaining someone in this position long-term.

In October, the CFF sent out an updated overview of the responsibilities of the CF Program Coordinator. It suggested considering team members other than the nurse for this role. We realized that the coordinator position has a significant amount of overlap with social work-related responsibilities. We talked with other teams who have been successful with having a social worker as their Program Coordinator. After consideration, we decided to use that model for our team as well. Kindly, Christine Prior has offered to be the Program Coordinator for the Adult Program. She will maintain her responsibilities as social worker and case manager for both the adult and pediatric teams. Kitty Brady will continue to be in charge of the Registry, as she has for the past five or so years. Our new nurse Kaitlin will take on all the nursing specific responsibilities (like blood draws, port flushes, medication questions, etc.). We hope this approach will better meet the needs of our patients by providing a consistent contact person for all coordinator related issues. Christine is perfect for this role, as she already has extensive CF experience and is not planning on going anywhere!

Understanding Cystic Fibrosis Foundation Accreditation

By Charlotte Teneback, MD

You may have heard members of your CF care team reference CF Foundation Accreditation. Or you may have heard us talk about how we need to meet certain criteria or quality measures for this purpose. The University of Vermont CF Care Center (the Pediatric and Adult programs combined) is one of over 130 nationally accredited centers in the US. These centers represent both academic and community-based hospitals. The care centers are carefully reviewed by the CFF to ensure they adhere to all treatment guidelines and are following the highest standards. As a patient or a family member, you can rest assured that an accredited center provides an elevated level of specialized, comprehensive care.

Care center accreditation is an ongoing process. Each center undergoes an annual program review. Also each has periodic re-accreditation in-person site visits. During these visits, physicians from other sites visit and meet with members of the team. They review our protocols and practices. This ranges from visiting the microbiology lab to meeting with patients, families, and hospital administrators. Our Center was last re-accredited in 2019. We were given a 5-year approval period, which is the longest option. Based on this site visit, both the Pediatric and Adult teams received the Quality of Care Awards (see photos).

Patients and family benefit from accreditation. Care teams benefit as well. Each Center also has access to education resources for team members, up-to-date guidelines, as well as some financial support for the team. This money is used to help the team travel to annual conferences. It also provides salary support to multi-disciplinary team members. In addition, it opens up doors for participation in research. We could not do what we do without this official support from the CF Foundation.

UVMCH Pediatric CF Program: (L-R) Kendra Arnold, Lauren Haskins, Martine Antell, Kelly Cowen, Mike Bissonette, Emily DiSchino, LE Faricy, Keith Robinson, Christine Prior, Tom Lahiri, Rylee Kilbride, Maggie Holt, Carlie Geer, Maryann Ludlow

UVMMC Adult CF Program : (L-R) Martine Antell, Christine Prior, Zac Weintraub, Maryann Ludlow, Abe Sender, Kitty Brady, Connie Lotspeich, Charlotte Teneback

Adult CF Clinic: What to Expect and Why

By Christine Prior, LICSW

The UVM Medical Center is an accredited CF Center. It is accredited by the Cystic Fibrosis Foundation (CFF). The CFF is an organization committed to creating a model of medical care that improves the health and extends the lives of people with cystic fibrosis. To ensure that people with CF experience steady gains in length and quality of life, the CFF helps its accredited care centers provide a standard of CF care. They base guidelines on the latest research, medical evidence, and consultation with experts on best practices.

Use the following link for full guidelines: https://www.cff.org/Care/Clinical-Care-Guidelines/.

What does this mean for you during your clinic visits in the adult CF program? Below is what you can expect over the course of the year as a standard of care. If you get sick or require hospitalization, your acute care will be in addition to the care outlined below.

Annual requirements

- At least one complete evaluation by each team member: social work, respiratory therapist, pharmacist, registered dietician
- Depression and anxiety screening
- Flu vaccination

Clinic visits

- Quarterly clinic visits
- Lung function monitoring by assessing symptoms, physical exam, and on most visits, spirometry
- Liver and spleen exam
- Medication review to assess ability to manage and sustain daily CF therapies. Discuss potential side effects of medications.

Annual labs

- Serum vitamin levels (Retinol, Vitamin E, Vitamin D)
- 2 hour oral glucose tolerance test for cystic fibrosis related diabetes
- Panel of liver function tests (AST, ALT, Bilirubin, ALP, GGT)
- Complete blood count, electrolytes, and kidney function
- IgE level

Cultures

- Sputum culture, including antibiotic resistance testing, at least once per year. Four times a year is preferred.
- Throat cultures in those with CF who cannot produce a sputum sample. This is to determine if they are infected with *P. aeruginosa*.
- Non-tuberculous mycobacteria (NTM) culture if you have a stable clinical course and are able to produce a sputum sample.

Routinely

- BMI assessment and nutrition education
- Discussion of disease course and treatment options, including lung transplantation

Every 2-4 Years

- Chest X-rays (posterior, anterior, and lateral) in individuals with stable clinical status

Every 5 Years

- DEXA scan for bone health
- Colorectal cancer screening beginning at age 40

Recommendations for Pediatric CF Care
What to expect at your visits

By Emily DiSchino, RN

The CF Foundation recommends that pediatric patients are seen a minimum of every month for infants under 12 months of age. Children from one year to adulthood are seen at least every three months. There are important standards of care that need to be fit into the core quarterly visits to ensure the best care for yourself or your loved one.

Respiratory cultures are taken at every visit. These establish a baseline of microorganism growth found in the respiratory system. This allows the doctors to target antibiotic therapy during times of illness. To best understand what the lower airways may hold, the ideal sample is coughed-up sputum. A throat swab can be used for those unable to produce sputum. If a patient is unable to produce sputum and has recurrent respiratory illness that can't be managed by oral antibiotics, a bronchoscopy may be done to better sample the lungs for microorganisms.

Bloodwork is checked annually and as clinically indicated. Baseline bloodwork for CF involves fat soluble vitamins. This is because those with CF are often found to be deficient due to malabsorption. Also checked is a complete blood count to monitor for anemia. Recurrent infection or nutritional deficiency can cause anemia. A complete metabolic panel or hepatic function panel is drawn to monitor liver health. This is particularly important for patients on modulator therapy. Also, igE (immunoglobin that can suggest *aspergillus fumigatus* infection) is checked. After the age of 10 years, patients will partake in a two-hour glucose test to ensure they are not at risk for cystic fibrosis related diabetes (CFRD).

Pulmonary function tests (PFTs) are the most valuable in detecting small changes in the airways that otherwise would not be noted. Symptoms often surface when those small changes accumulate and there is larger damage to the lungs. Having lung function checked at least every three months enables a baseline value. This way, subtle changes in lung health are detected early on. Therapy can be adjusted before essential lung function is lost. Thankfully, the CF Foundation has provided everyone with a home spirometer so we can have even more opportunity to monitor your lung health if we are unable to see you in clinic.

A CT scan or x-ray of the chest is recommended yearly to monitor signs of disease progression.

The CF Foundation requires an annual review by nutrition, respiratory therapy, social work, the pharmacist, and the mental health coordinator. These team members will also pop in to visits as needed.

It is also best practice for every family to be introduced to our psychology team and genetic counselors at the time of diagnosis. They can be seen as needed at the preference of the family.

To ensure that you are always informed about the latest opportunities for your care, the Vermont lung center research team works very closely with our clinic to offer research studies that you may participate in to optimize your health.

The CF Registry

By Kitty Brady, RT

The Cystic Fibrosis Registry, also known as PORT CF (the portal to the registry), has been in use since the 1960's. The Cystic Fibrosis Foundation (CFF) understood that following the lives of people with CF would help them look at the whole picture of a person with CF. It has grown over time into collecting data on the different therapies used, clinical outcomes, and complications. Having all this information to guide treatments and research has helped produce consistent approaches to CF and successful results. Because the CF Registry was the first of its kind and so successful, many other chronic diseases have started their own.

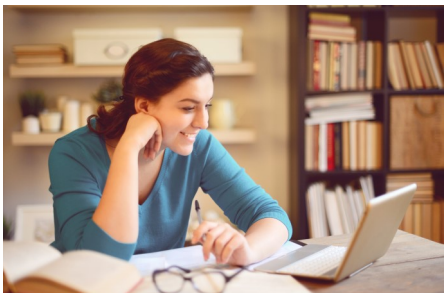
The Registry protects your privacy by assigning an ID number to all participants. Names are not shared with anyone except your own CF care team. The Registry collects information like date of birth, date of diagnosis, reason for diagnosis (ex. failure to thrive or grow, multiple lung infections, newborn screening), sweat test values, genetics, the date and reason of death. It also collects information on treatments used, weight, height, lab values, chest imaging, and other complications. These may include liver disease, CF related diabetes, bone loss, and asthma. Sputum sample results and pulmonary function test (PFT) results are also collected. The Registry asks us to capture all clinic visits (virtual or in-person), hospital admissions, home IV courses and any other reason for antibiotic use. Recently, COVID-19 testing information has been added. This allows the Registry to see how many CF patients have been tested and their outcomes.

Because we know that CF affects more organs than just the lungs, the CFF has recommended a combined team approach. Over the years, different team members have been added based on need. One example of this has been the addition of a clinical pharmacist to the team as medications have become more complex. With this in mind, the Registry requests data on how often someone is seen by a respiratory therapist, social worker, mental health care worker, nutritionist, pharmacist, and physical therapist.

By gathering all of this information, scientists have been able to put together studies that look at more and more successful treatments. The Registry has also helped show how important it is to be consistent with treatments. These treatments have improved the quality of life of people with CF and have allowed them to experience more normal lives.

In its own words, "The CF Foundation Patient Registry collects information on the health status of people with cystic fibrosis who receive care in CF Foundation-accredited care centers and agree to participate in the Registry. This information is used to create CF care guidelines, assist care teams providing care to individuals with CF, and guide quality improvement initiatives at care centers. Researchers also use the Patient Registry to study CF treatments and outcomes and to design CF clinical trials."

Cystic Fibrosis Registry: https://www.cff.org/Research/Researcher-Resources/Patient-Registry/



CF Scholarships and Financial Aid 2021

By Christine Prior, LICSW

Many scholarships and financial aid options are available for students with cystic fibrosis who want to pursue higher education.

There are many types of scholarships available based on different criteria. For example, scholarships might be based on being involved in athletics, being in a military family, having a skill or ability, having cystic fibrosis, or having a chronic disease in general. When you start your search, it might be helpful to think about different types of scholarships for which you might be eligible.

A good place to start looking for scholarships specifically for people with CF is Cystic Fibrosis Research Inc., which maintains a list of about 20 scholarships and their eligibility criteria. You can find that list here:

https://cfri.org/wp-content/uploads/2018/04/CF_Scholarship_Programs.pdf. NeedyMeds also maintains a list of CF-specific scholarships.

The Federal Student Aid Information Center at the U.S. Department of Education provides information about finding grants and scholarships, including tips on where to look for them.

The National Association of Student Financial Aid Administrators has a database of financial aid options that you can search for by state.

Vermont Cystic Fibrosis Scholarship

In addition to these state and national scholarships, UVM Medical Center is happy to offer The Vermont Cystic Fibrosis Scholarship. This $500 scholarship is provided by a Vermont family. Applications are due by **March 15, 2021**. To apply, email Christine Prior, LICSW a letter stating your interest at Christine.prior@uvmhealth.org. Recipient's name will be chosen from qualifying candidates at random. Eligible patients are those students who have not received this scholarship previously and are enrolled in a college program for the fall.

If you would like help finding scholarships, call Cystic Fibrosis Foundation Compass at 844-COMPASS (844-266-7277) Monday through Friday, 9 a.m. until 7 p.m. ET, or email compass@cff.org.

Research Update

By Julie Sweet

This is a very exciting time in cystic fibrosis clinical research! There are many opportunities for people with CF to help improve our understanding about CF and the development of new treatments. For the first time, researchers are trying to understand whether people who are able to take highly effective therapies like Trikafta®, that treat the underlying cause of CF, can safely stop taking some of their longstanding therapies. For people with CF who are unable to take these new therapies, we are deeply committed to research aimed at closing the gap and providing highly effective treatments targeting the root cause of CF to all. In addition to helping advance our understanding of CF, participation in a clinical trial can have direct benefits. These include helping people with CF take an active role in managing their CF care and 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. These risks include side effects of the treatments being studied, failure of a treatment to work, and unwanted events during the trial. Such events may or may not be related to the study treatment. The decision to join a clinical trial is personal. It is important to consider the benefits, risks, and time commitment required. We strongly encourage patients to have conversations with trusted family, friends, doctors and study coordinators to decide if a clinical trial is a good fit.

If you are interested in finding out more about current or future research studies, please contact the Vermont Lung Center for more information at (802) 847-2193. At this time, the studies below are open for enrollment. The descriptions here are very brief; please contact the Vermont Lung Center for more information.

SIMPLIFY:

The SIMPLIFY study is being done to test if it is safe to stop taking inhaled hypertonic saline or Pulmozyme® (dornase alfa) in people with cystic fibrosis (CF) that are also taking Trikafta™. SIMPLIFY will study if there is a change in lung function in people who are assigned to stop one of the two inhaled therapies compared to people who keep taking them while on Trikafta. Participants who join the study will be randomly assigned to one of the following groups:

- Study A to keep taking hypertonic saline
- Study A to stop taking hypertonic saline
- Study B to keep taking Pulmozyme
- Study B to stop taking Pulmozyme

This research study is for adults and children ages 12 years and older with CF who are also taking Trikafta. Participants must be willing to comply with the randomly assigned study treatment to either keep taking or stop taking hypertonic saline or dornase alfa. This study will involve 4 visits over about 8 weeks. Study visits may involve physical exams, measurement of lung function using spirometry, and paper and electronic questionnaires (done on your phone or tablet). Financial compensation provided up to $447.

BEGIN:

The BEGIN study looks at growth in infants and young children that have CF. Many infants and young children with CF have trouble gaining weight and achieving normal growth. Yet, our understanding about the effects of CF throughout the body during infancy and early childhood is still limited. The BEGIN study will collect health information about early changes in infants and children up to 5 years old. It includes information about growth hormones and changes in lung, digestive, liver, and pancreatic function. The study will also collect information on lung and gut

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Research Update (continued)

microbiology and inflammation. There are two parts to the BEGIN study. The goal of Part A, which is currently open to enrollment, is to collect health information on infants and young children before starting treatment with highly effective modulator therapies containing the drug ivacaftor, such as Kalydeco™ and Trikafta™. Part B of the study will collect health information about growth and symptoms related to CF after starting treatment with one of these highly effective modulator therapies. Part B will start if Trikafta becomes approved by the FDA for use in children under 6 years old. This research study is for children up to 5 years old. This study will involve up to 6 visits over 36 months. The study visits will be at the same time as regularly scheduled CF clinical care visits at the UVMMC. Study visits may involve measurement of height and weight, collection of urine, stool, blood, and throat swab samples, and completion of questionnaires asking about the child's health and quality of life. We will also ask to test lung function using spirometry in children three years of age and older. Financial compensation provided up to $450.

Calithera Biosciences CX-280-202:

This is a research study to learn more about the safety of a drug called CB-280 in people with CF. CB-280 is an investigational drug that is taken by mouth and blocks an enzyme called arginase. Arginase is thought to play an important role in promoting lung infection in CF. This study hopes to identify which CB-280 doses are safe to take without causing too many side effects. Participants who meet all of the study requirements will receive either CB-280 or placebo to be taken by mouth twice daily for 14 days. This research study is for adults ages 18 years and older who have positive cultures of *Pseudomonas aeruginosa* in the lungs. Participants' FEV1 % predicted must be between 40 to 90%. The study will include a total of six visits over an eight week period, with two of the visits lasting about 15 hours each. Study visits will include blood draws, physical exams, lung function testing such as spirometry, electrocardiograms, and sputum induction (collection of mucus/phlegm that is coughed up after breathing in saline). Financial compensation provided up to $1320.

PICC-CF:

Cystic fibrosis often causes lung infections that need to be treated with intravenous (IV) antibiotics. When you are admitted to the hospital for IV antibiotic treatment to treat lung flare-ups, a peripherally inserted central catheters (PICC) is put in place. Important complications from the PICC can occur like blood clots and infection. Risk factors which lead to the complications can be broken down into three types: catheter-related factors; patient factors; catheter-management factors. The main purpose of this study is to see whether we can identify important factors in each of these three categories that are linked to blood clotting complications. This study is for adults and children six years and older with CF who are experiencing a pulmonary exacerbation and planning to receive IV antibiotics. This study may require pictures be taken of the PICC insertion site, measurement of the arm, and blood samples drawn from the PICC line. Length of study participation is about 14-21 days. Financial compensation provided up to $60.

LIMIT-NTM:

This research study is being done to learn more about chronic lung infections involving non-tuberculous mycobacteria (NTM) and other lung microbes in people with CF. It will examine samples of sputum (mucus). Researchers are working to better understand what is happening in the lungs of people with CF who are chronically infected with NTM. They also want to know how NTM infection interacts with other lung infection microbes. The information collected from this study may also help the researchers develop better treatments for lung infections involving NTM. This research study is for adults ages 18 years and older with CF who have had at least one positive culture for NTM in the lungs. The study will include a single study visit during a CF clinical care visit at UVMMC where participants will enroll in the study and provide a sputum sample.

COVID-Related Resources and Community Supports

By Christine Prior, LICSW

Financial Support

COVID-19 economic impact payments / stimulus checks

Learn more about the economic impact payments / stimulus checks from the federal government.

Financial Grants

Compass: Compass provides 1-on-1 case management services to patients with CF and their families and can help research grants and financial resources for you locally and nationally based on your individual needs.

https://www.cff.org/Assistance-Services/About-Compass/What-Is-Compass/

Food Assistance

The following list will help you access food and programs that best fit your needs in Vermont including school meals, 3squares, WIC, local food shelves, Veggie Van Go and more.

https://www.vtfoodbank.org/coronavirus-services-for-individuals

The following link will help access food programs that best fit your needs in New York including school meals, pop up pantries, Just Say Yes to Fruits and Vegetables and more.

https://regionalfoodbank.net/agency-list-by-county/clinton/

Unemployment

If you lost your job or had your hours cut due to the COVID-19 coronavirus, you probably can get some help. You can apply for benefits even if your employer says not to. If you are self-employed, an independent contractor or freelancer, you could be eligible if you meet the other criteria.

Learn about unemployment benefits in response to the coronavirus crisis.

Find out how turning down a job offer can affect unemployment compensation.

Mental health and wellness supports

COVID Support VT is a grant-funded program offering mental health and wellness supports for Vermonters during the pandemic. Call 2-1-1 and talk to support counselors Monday - Friday from 8 a.m. - 8 p.m. for emotional support, connections to community resources and to have a listening ear. Join an online Weekly Wellness Group to learn self-care strategies for coping and relaxing. Download wellness resources available in many languages. Services are confidential and free.

Please reach out if you are in need of additional resources and I am happy to help identify those for you.

POSTAGE HERE

The University of Vermont Medical Center
The University of Vermont Children's Hospital
111 Colchester Avenue
Burlington, VT 05401

CF CONNECTION NEWSLETTER

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NEWSLETTER EDITORS
Liz Hammel
Erin Evans

NEWSLETTER PRODUCTION
Susan Hayward

PEDIATRIC PROGRAM
Children's Specialty Center
East Pavilion, Level 4
111 Colchester Avenue
Burlington, VT 05401
PHONE: (802) 847-8600
FAX: (802) 847-5805

ADULT PROGRAM
Gartman Center for Medicine
East Pavilion, Level 5
111 Colchester Avenue
Burlington, VT 05401
PHONE: (802) 847-1158
FAX: (802) 847-7244

Online Resources

Coronavirus Information

Many of you have reached out to us looking for guidance around how to best protect yourselves from exposure to Coronavirus (COVID-19). Websites from the CF Foundation, CDC and VT Department of Health are below and contain the most up to date information and current recommendations:

CF Foundation:

https://www.cff.org/Life-With-CF/Daily-Life/Germs-and-Staying-Healthy/

CDC:

https://www.cdc.gov/coronavirus/2019-nCoV/summary.html#anchor_1580064337377

VT Department of Health:

https://www.healthvermont.gov/response/infectious-disease/2019-novel-coronavirus