



THE
University of Vermont
 MEDICAL CENTER

THE
University of Vermont
 Children's Hospital

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CF CONNECTION

Newsletter of the Vermont Cystic Fibrosis Center Advisory Board

PATIENT PERSPECTIVE



Clinical Trial Participant Shares Her Experience

By Erin Evans

In October 2017, I had the incredible opportunity to participate in a clinical trial for a new triple combination CFTR modulator medication. After hearing of so many people with CF who were benefitting from Orkambi and Kalydeco, I was hopeful that a drug would become available for my more rare gene mutation, although I assumed it would be years before that happened. When I heard that the trial for a medication that may benefit me, and people like me, was in the works, I was really excited. After a month of screening (and not getting sick or having to go on antibiotics, which at that time was incredibly hard for me), I was informed that I had officially been accepted to be part of the study. I had been in clinical trials before, but the magnitude of this one felt very different. It was amazing to think that if this drug was eventually approved (along with the other CF medications already out there) up to 90% of people with CF would be able to benefit from one of these life-changing medicines.

I knew the chances I would be on the actual drug (rather than a placebo) were fairly good and in my favor. There was a more than 80% chance I would be on some dosage of the actual medication. Even with this information, I went into the study cautiously, trying not to get my hopes up.

(continued on page 3)

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
 Emily DiSchino, RN, CF Nurse Coordinator
 Martine Antell, PharmD, Pharmacist
 Christine Prior, LICSW
 Melissa Barron, RN, Pulmonary Nurse Coordinator
 Kelly Lagrow, RN, Pulmonary Nurse
 Michael Bissonette, RT
 Carlie Geer, RD, CD
 Maggie Holt, PT
 Julie Sweet, BA, CF Research Coordinator
 Tara McCuin, PhD, Psychologist
 Lauren Haskins, Medical Assistant
 Kendra Therrien, Practice Support Specialist

ADULT PROGRAM

802-847-1158

Charlotte Teneback, MD, Adult CF Program Director
 Juan Pablo Perdomo Rodriguez, MD, Endocrinologist
 Abe Sender, PA-C
 Connie Lotspeich, RN, CF Nurse Coordinator
 Martine Antell, PharmD, Pharmacist
 Christine Prior, LICSW
 Erick Duprey, RN
 Kitty Brady, RT
 Maryann Ludlow, RD, CDE
 Sasha Morey, PT
 Julie Sweet, BA, CF Research Coordinator
 Tara McCuin, PhD, Psychologist
 Lisa Benoure, Medical Assistant
 James Crane, Medical Assistant
 Brent Michale, Medical Assistant
 Jenna Carroll, Practice Support Specialist
 Susan Heney, Operations Support Specialist



ACC Opens New Outpatient Laboratory

A new outpatient laboratory opened last month on level two of the ACC. The new space provides four times more space than the old lab location. For the benefit of pediatric patients, there are two pediatric-friendly private draw rooms and a private waiting area designed for families with children. The new lab space has extended weekend hours and onsite registration.

This space positions the medical center to develop a robust Pediatric Lab Program. A key component to the new Pediatric Lab Program is the hiring of a dedicated Child Life Specialist and Pediatric RN to support pediatric patients in this new space. A workflow is being developed to determine which pediatric patients will continue to be seen in the Comfort Zone and which will be triaged to the new space.



Clinical Trial Participant Shares Her Experience *(continued from page 1)*

As lots of people with CF can relate to, things don't always go as planned. I remember taking the two pills while sitting in the room at the VT Lung Center and thinking how these pills could potentially change my life and the lives of so many others with CF. The rest of the day, I tried to not think about what they could be doing (or not doing) inside me. It was on the second and third day that I started to feel very "different." It was clear that something was happening. By the end of the third day and into the fourth day, I was starting to feel parts of my lungs that had been unknown to me. I could take a deep breath without pain or needing to cough. People who were close to me and knew I was in the study would ask what it felt like. The only way to adequately describe it was to say it felt like I didn't have CF anymore. Doing my airway clearance also started to be more effective than ever. I could feel the medicine actually reaching areas of my lungs that it hadn't in so long.

Within a week after starting the medication (or what I thought was the medication, rather than the placebo; I still don't know for sure), I had more energy and didn't always feel run down. The sensation of not being in pain, or discomfort, or short of breath, or on the verge of being sick, or just getting over being sick, was completely foreign to me. It felt like a weight had been lifted off my shoulders, literally. At a routine clinic visit about one week after starting the clinical trial, my lung function had gone up by 10%. I remember staring at the computer screen, almost in disbelief, seeing numbers I hadn't seen in years - numbers, I assumed before then, I would never see again.

The timing of starting the medication could not have been more perfect, as it was also around this time (about three weeks into the trial) that my son was born (through adoption). We drove to Maine on a Sunday, and he was born on Monday. We were able to be there when he was born and be the first ones to hold him. Because of some minor health complications with him, we had to stay in the hospital for almost a week. It was the first time I'd stayed overnight in a hospital and was not the patient. I was able to be there for my son in a way that may have been more stressful and taxing for me had I not been on the new medication. It would be months before my son even heard me cough for the first time.

When the trial ended, he was a month and a half old, and my lung function was more than 15% greater than it had been when I started the study. It took a week or so before my typical CF symptoms returned. Even on the good days, I had that all too familiar heaviness in my lungs that comes with having CF. I had almost forgotten in that short time what it felt like to experience those things and to have the anxiety of worrying about when I would get sick again. But knowing that this medication is out there and on its way to being available is what helps me stay as healthy as possible in the meantime. For the first time in my life, I feel genuinely hopeful and excited for the future, knowing that this medication exists. I'm also so incredibly grateful to have had the chance to participate in this clinical trial. I can say for sure it's definitely going to be worth the wait.

A NOTE FROM CLINIC ABOUT STUDY PARTICIPATION

As clinicians and researchers, we very much appreciate the willingness of individuals like Erin, and many others like her, to step forward and participate in studies for new treatments or new approaches to treatments. We would not be where we are today as a community without this. We will always work to ensure that those who participate in studies are safe and experience no ill effects. I do want to note, however, that each participant's experience is unique. Not everyone will have the same great results that are described in this article. If you have any questions about participating in a study, please don't hesitate to reach out.

Adult CF Center Updates

By Charlotte Teneback, MD

There have been recent staffing changes in the adult program, which many of you are already aware of:

- Dr. Laurie Leclair left at the end of December to move to the CF center in Salt Lake City, Utah. She is very much missed.
- Dr. Charlotte Teneback has taken over as the Adult Program Director.
- Dr. JP Perdomo is the new Associate Program Director. He is an endocrinologist who has been working closely with the adult CF program to provide support for patients with CFRD and other endocrine issues. We are thrilled to be able to increase Dr. Perdomo's involvement with our CF program in this way.
- Dr. Zac Weinstein is a pulmonologist currently completing his training in Philadelphia. He will join our program this summer as a second adult physician. More introduction to come as the time gets closer, but we are really looking forward to having Dr. Weinstein join our team.

There have also been changes to the inpatient side for adults:

- The inpatient CF service is now under the consult service, rather than directly under Abe Sender as it had been for many years. That means that the consult fellows will be the first line providers, with support from the consult attending physician. At least once a month, that physician will be Dr. Teneback. This is a temporary change, with the long-term goal that adult CF inpatients will be cared for by a hospitalist team, with medicine residents and attending physicians and consultation provided by Abe. This is the model used in many centers across the country with good success. It has a number of benefits, in terms of night and weekend coverage, among other things. We will update you when we know more details about when this transition will take place, but we are aiming for later this year—ideally late summer. The whole team will continue to do multidisciplinary rounds on Thursdays and will be available at other times if needed.

Please don't hesitate to reach out if you have questions or concerns. We are committed to providing the best possible in-hospital experience for everyone and know there are always some bumps in the road with changes. With your help, I am confident that we can make this work for everyone.

VOLUNTEERS NEEDED FOR RESEARCH STUDY

Hello! 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 research team including a psychiatry resident, Dr. Karen Lewicki, and a medical student, Bailey Fay, working with Dr. Rabinowitz, Dr. Lahiri, and Christine Prior, hoping to better understand how kids and young adults between 11 and 22 are affected by this diagnosis. This study is being conducted by the University of Vermont Medical Center and the University of Vermont Children's Hospital. Starting this winter, we will be in the CF outpatient clinic, as well as visiting people in the hospital, offering a survey of less than 15 questions. There will be a \$15 Amazon Gift Card for your time. Please let us know if you'd be interested in taking part! We would love to hear from you. If you have any questions, please contact Dr. Rabinowitz at: 802-847-4727 or at: terry.rabinowitz@uvmhealth.org

Join the VT CF Center Advisory Board
for the 11th Annual

Cystic Fibrosis Education Night

Tuesday, May 7, 2019 5:30-9pm

UVM Alumni House,

**61 Summit St,
Burlington, VT**



Featured Guest Speaker

Emily Schaller

a heroine with one goal in mind,

To **Rock CF**

Agenda

- 5:30 – 6 pm Registration, mingle with other families, and visit vendor tables
- 6 – 7 pm Dinner and presentations including the most recent CF Center data by Tom Lahiri, MD and Charlotte Teneback, MD
- 7 – 7:30 pm Mingle with other families, and visit vendor tables
- 7:30 – 9 pm “Running Down a Dream” - Emily Schaller

Registration is required- go to [Registration Webform](#)

Deadline: Friday, April 26, 2019

Questions? Email VTCFAdvisory@gmail.com

This **free** event includes dinner and is open to caregivers, professionals, friends and relatives of those affected by CF. In keeping with the CFF Infection Prevention and Control Policy, only one person with cystic fibrosis may attend an indoor event sponsored by a CF Center. That person will be our guest speaker, Emily Schaller. We invite people with CF to view the recording of this event on our YouTube channel (video will be posted after the event)

Join us for complimentary dinner, conversation and community

CFF CARES



As a family member or friend of someone living with CF, we invite you to join others to connect, encourage, and share experiences.

“It was an event I didn’t know I needed. I no longer feel alone.”

– CFF Cares Participant



April 9, 2019

6:00-8:00 PM

Fire & Ice Restaurant

26 Seymour Street, Middlebury, VT

Space is limited, please RSVP by March 15th to no-new-eng@cff.org

Important Note on Attendance at Foundation Events: To reduce the risk of getting and spreading germs at CF Foundation-sponsored events, we ask that everyone follow basic best practices by regularly cleaning your hands with soap and water or with an alcohol-based hand gel, covering your cough or sneeze with a tissue or your inner elbow and maintaining a safe 6-foot distance from anyone with a cold or infection.

Medical evidence shows that germs may spread among people with CF through direct and indirect contact, as well as through droplets that travel short distances when a person coughs or sneezes. These germs can lead to worsening symptoms and speed decline in lung function. To further help reduce the risk of cross-infection, the Foundation’s attendance policy recommends inviting only one person with CF to an indoor Foundation-sponsored event at a specific time.

New Faces in CF Clinic



Connie Lotspeich, RN

Nurse Coordinator in Adult Program

Connie was born and raised in the state of Washington. She has lived in six states since leaving home. In 2007, she and her son relocated to Vermont from Portland, Oregon. They both love Vermont for all that it offers - outdoor activities, culinary selections, culture and proximity to other enjoyable cities. Connie worked in I.T. for 12 years before returning to school for a career in health care. She worked at UVMHC as a respiratory therapist for four years before deciding to pursue her dream of becoming a nurse. Following nursing school, she worked as an operating room nurse at North Country Hospital, then decided to return to UVMHC. She is very excited to join the Pulmonary Department. In her free time, she enjoys reading crime/suspense novels, gardening, hiking, traveling, and (although she doesn't do them frequently) she is a skier and a SCUBA diver.



Erick Duprey, RN, BSN, MS

Registered Nurse in Adult Program

Erick grew up in Michigan and earned his BSN and MS in South Carolina. He has been a registered nurse for 12 years and has worked in a variety of venues, including five years as an inpatient nurse. Recently, he and his family were overseas in a third world country, where Erick established and ran a medical clinic in an isolated mountain village. After working a total of seven years with an overseas mission agency, they relocated to Vermont. Erick became interested in pulmonary medicine when his mom battled lung cancer. He joined the UVMHC pulmonary team in November 2017. He has a heart for people who are hurting, and he desires to help people enjoy the gift of life to its fullest potential. His specific role in the CF clinic is overseeing the care and maintenance of those with ports and PICC lines. Outside of the hospital, Erick and his family enjoy exploring their new state. As an ordained Christian minister, he also teaches regularly at his church in Williston. Erick and his wife have three young children.

NEW RESEARCH STUDY

Are you ready to become more confident in managing your health care? The UVM Children's Hospital is working with the Vermont Child Health Improvement Program and hiCOLab (UVM Medical Center's design and innovation lab) on a program to support patients like you as you grow up and become more independent. We created a text messaging chatbot that helps adolescent patients transition more confidently to an adult specialty healthcare clinic when they reach adulthood. Patients seen at the Children's Specialty Center in the UVM Children's Hospital who are between 13 and 17 years old (and their parent/guardian) are invited to participate in this research study focused on improving the transition from pediatric to adult specialty care.

For more information: <http://uvmhealth.org/medcenter/txt4toc>



The Cystic Fibrosis Food Pantry at UVMHC

By MaryAnn Ludlow, RD

Food insecurity, the inability to consistently have access to all the food you need, is more common among people with CF than in the general population, simply because so much more food is required to fuel a person with CF. People with CF need up to double the calories that their peers without CF need, which can translate into a considerably higher bill at the grocery store!

In response to this need, we have launched a food pantry at UVMHC. Most of the foods in the food pantry are currently being donated by the Vermont Food Bank, and we are approaching other sources for donations. The foods that are available were chosen for their overall nutrition, calories and, just as importantly, their popularity with our CF patients.

At present all of the pantry items are canned or dry goods. Some examples of the foods that we have in the pantry are mac and cheese, spaghetti, spaghetti sauce, chili, beef stew, tuna, applesauce, and cooking oil.

How do I access the food pantry? At most clinic visits you will receive a food insecurity screening which allows you the opportunity to tell us about any challenges you are having affording food for you and your family. Those who indicate challenges in this area will be offered use of the food pantry. If you come to clinic and are not screened but feel you could benefit from the food pantry, you do not need to wait. Just ask! Christine Prior, our social worker, Carlie Geer, pediatric CF dietitian, and Maryann Ludlow, adult CF dietitian, can all help you choose from our list of food pantry items. We'll then retrieve your chosen items and send you home with your choices!

CF Scholarships and Financial Aid

Young men and women with cystic fibrosis who want to pursue higher education have many options for scholarships and financial aid.

Locally, The University of Vermont Medical Center is happy to offer **The Vermont Cystic Fibrosis Scholarship**. This \$500 scholarship is donated by a Vermont family. Applications are due by May 1, 2019. To apply, email Christine Prior, LICSW, a letter stating your interest at Christine.prior@uvmhealth.org. The recipient's name will be drawn from qualified 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.

The Cystic Fibrosis Foundation has great information about finding scholarships, grants, and financial aid available for students with CF. Go to <https://www.cff.org/Life-With-CF/Transitions/Managing-My-CF-in-College/Scholarships-and-Financial-Aid/> to make use of the sources of aid the Foundation has compiled.

If you would like help finding scholarships, call Cystic Fibrosis Foundation *Compass* (a personalized service to help you with the insurance, financial, legal, and other issues you are facing) at **844-COMPASS** (844-266-7277) Monday through Friday, 9 am until 7 pm ET, or email compass@cff.org.



Great Strides Walks for CF

By Jenny Eddy, CCLS

CF walks are the backbone to funding that supports many programs the Cystic Fibrosis Foundation runs, including research. Several years ago, the CFF put out a research findings document stating recommended safety guidelines for patients, families and care teams to follow. The expansion of the three-foot rule to six feet for patient-to-patient contact was among them. Another involved limiting the number of patients with CF at indoor events, such as education nights, to one.

Outdoor CF walks have always been, and will continue to be, very popular around the world as they bring people together for a common goal. The walks allow many people with CF, their families, and their friends the opportunity to be together for fundraising, supporting/bringing attention to an important cause and for camaraderie. This is done in a safe way, as long as the six-foot rule is followed. Organizers are very aware of this rule and plan with it in mind. We have put together a list of creative ways to enjoy outdoor CF walks with your children while still following the CFF's health safety guidelines.

1. Make team t-shirts to identify yourselves.
2. Designate a table or section of grass for your team.
3. Stay with your group instead of walking or running ahead.
4. Bring a stroller or wagon to pull your toddler or preschooler who might be apt to stray from your group.
5. Let your preschooler take turns having shoulder rides on each adult team member.
6. Encourage your team to do warm up exercises together.
7. Bring a football, soccer ball or Frisbee to toss around with team members before the walk begins.
8. Bring a backpack with a few books, coloring pages, and toys that will help with distraction during speeches, photos and staggered start times.
9. Try this printable nature scavenger hunt to do during the walk:
<https://pin.it/ozcvmhJOR4vYU2>
10. Begin a team game of "Would you rather?"
11. Write down words ahead of time for team members to choose and act out among one another, or play charades. This could bring lots of laughs to your school age child!

The University of Vermont Medical Center Patient/Family Advisors

By Liz Hammel

If you've ever been on hold when calling the CF clinic or another office at the medical center, you have heard the recording that talks about the Patient/Family Advisors. With the help of these advisors, the UVM Medical Center is improving how they deliver care by using the knowledge and experience of the patients and families it serves.

I reached out to Amy Cohen, Director of Patient and Family Experience, to find out more about the advisors. Amy describes the role of the advisor and some of the ways they contribute:

"The commitment for the advisor is very flexible. It depends on the kind of activities advisors volunteer for. We have some advisors who are mostly e-advisors. That means they don't attend regular meetings on site. Instead, they advise electronically by reviewing and offering feedback on documents intended for patients and families. Examples include patient education materials, brochures, and changes to the After Visit Summaries or discharge paperwork, consent forms, etc. They also give feedback to shorter questions by email.

Some advisors join specific projects or committees where the medical center is including patients or family members as part of the teams. A team might meet once a month, bi-weekly, or in rare cases weekly. Weekly meetings are usually for short-term projects. So the involvement depends on which committees or projects advisors volunteer for and whether they are participating on one committee or more than one. We have lots of examples of committees or projects. An example of a population-specific group is the group that worked on young adult CF inpatient services and supporting the transition from Baird 5 to adult care units. There are many examples of broader groups that impact a lot of different patients and families. Some current examples are work going on right now to redesign the Emergency Department, a group that worked to build a new lab with a pediatric focus, and a project to help design the patient technology in the new Miller Building.

Finally, we do have some patient and family advisory councils. One is for the medical center broadly, and one for the children's hospital specifically. Those groups tend to meet once a month for two hours in the early evening. Right now, both happen to meet on Tuesdays. Not all advisors (probably not even most) participate on a council. The councils provide consultation to groups looking for broad patient and family input, and the councils sometimes engage in specific project work.

There is great flexibility in how and where advisors participate. Once on-boarded, advisors are added to an email distribution list where they receive about one email a week summarizing the different opportunities available to get involved in. Advisors are encouraged to volunteer for things they are excited about or interested in. They should unapologetically pass on opportunities which don't feel like a good fit."

The Patient/Family Advisors serve the broader UVM Medical Center community in the same way our members on the VT CF Center Advisory Board serve the cystic fibrosis community. Both are collaborations meant to help the UVM Medical Center provide better care and services to its patients and families. Sharing information between the two groups, and working together when given the opportunity, make both more effective.

If you would like to become involved as an advisor to the medical center, please email Amy Cohen at Amy.Cohen@uvmhealth.org. Your service as an advisor can be a helpful link between the larger medical center and the CF centers. If you would like more information about becoming involved as a member of the VT CF Center Advisory, please email vtcfadvisory@gmail.com.

Resources from the 2018 NACFC

By Laurie Eddy

Last October, 5,000 members of the CF community gathered in Denver, Colorado for the 32nd annual North American Cystic Fibrosis Conference (NACFC). NACFC is a scientific conference intended for researchers and our CF care team members to discuss the latest in cystic fibrosis research, care, infection, treatment and drug development.

Although this is a conference focused on the care and treatment of people with CF, risk of cross-infection prevents people with CF from attending in person. This year, the CFF made it easier for adults with CF, CF family members, or caregivers of those with CF to virtually attend NACFC from the comfort of home by live-streaming the plenaries and a variety of workshops and symposiums. If you missed the live-streamed sessions, they are now available to view online:

1. **Improving Outcomes of Infections in the Age of CFTR Modulators**
2. **Anti-inflammatories and Mucociliary Clearance Therapies in the Age of CFTR Modulators**
3. **Partnering: The Oldest New Idea to Improve CF Care**

These three plenary sessions are available from the [CFF](https://www.cff.org) website:

<https://www.cff.org/Research/Researcher-Resources/North-American-CF-Conference/2018-NACFC/>.

To access recordings of the workshop and symposium sessions, along with abstracts, handouts, and other key materials, simply sign up for a free online account at:

<https://arc.nacfconference.org/cff/login>.

In addition, CFF hosted three Facebook Live events to allow the CF community to ask researchers follow-up questions about the topics presented. They are available at the following links:

- **Infection Research: Mission Possible:**
<https://www.facebook.com/cysticfibrosisfoundation/videos/569251990195926/>
- **Glad You Brought It Up: Mucus and Inflammation:**
<https://www.facebook.com/cysticfibrosisfoundation/videos/2133386736989878/>
- **Howdy, Partner! A Live Q & A:**
<https://www.facebook.com/cysticfibrosisfoundation/videos/255775475132890/>

If you only have time to watch one of these sessions, I highly recommend the plenary called “Improving Outcomes of Infections in the Age of CFTR Modulators.” Fighting infections is of special concern to me and to most CF families, so I was thrilled to learn that the CFF is investing \$100 million dollars over the next five years to improve detection, diagnosis, treatment and outcomes of infections for people with CF.

Infections strike fear in the lives of people with CF. The CFF Infection Research Initiative gives me hope that progress will be made soon to reduce the physical and mental burden of infection. There are more than 120 different projects being funded, but the one that I found most exciting is the development of a rapid diagnostic test that could detect bacteria types in a patient’s breath. Not only would this improve earlier identification and management of exacerbations, but also it would mean no more throat swabs! This would greatly improve my daughter’s visits to the CF care team - for both my daughter and the team!

I know that this is an overwhelming amount of information. The information presented at NACFC was head spinning, and I learned more than I can capture in this article. Much of the information is heavily scientific, but knowledge is power! The NACFC is a great resource for everything from the impact of health care reform to managing invisible symptoms of CF, such as CF-related pain. If you are looking for more information on topics of daily care, nutrition, and even palliative care, you will find it in the resource links for NACFC.

Clinical Research Update

By Julie Sweet

This is a very exciting time in cystic fibrosis clinical research! There are many promising opportunities for people with CF to help in the development of new treatments, from therapies to improve quality of life by treating the symptoms of CF to treatments that are even targeting the very cause of CF. In addition to helping advance our understanding of CF, participation in a clinical trial can have direct benefits, such as helping people with CF take an active role in managing their CF care and gain 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, 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, and it is important to consider the benefits, risks, and time commitment required. We strongly encourage having conversations with trusted family, friends, and doctors and study coordinators to decide if a trial is a good fit.

At the Vermont Lung Center at UVMMC, we are currently involved in studies focusing on the development of 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 gastrointestinal symptoms in CF, and the development of 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 typically received permission to enroll only a small number of participants, and at this point we have filled our available spots. 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 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 so long that they are exposed to unnecessary risks. This research study is for people with CF who experience a pulmonary exacerbation and are planning to receive IV antibiotic treatment. This study will look at the safety and effectiveness of three different lengths of IV antibiotic treatment for pulmonary exacerbations. 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 is provided up to \$210.

This research study requires:

- Diagnosis of cystic fibrosis
- Age of 18 years or older
- Doctor's confirmed plan to start 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 length determined by initial response to antibiotic treatment and then randomization

(continued on page 13)

Clinical Research Update *(continued from page 12)*

Savara AVAIL

This research study will look at the effectiveness of the inhaled drug vancomycin in adults and children 6 years and older with cystic fibrosis and positive cultures for methicillin-resistant staphylococcus aureus. This study is in two parts. The first part is placebo-controlled, meaning that some participants will receive inhaled vancomycin and others will receive placebo. The second part is open-label, meaning that all participants will 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 children ages 6 and older with CF who have positive cultures for methicillin-resistant staphylococcus aureus. 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
- Age of 6 years or older
- FEV1 % predicted to be between 30 to 90%
- Willing to participate in 13 fixed study visits over one year

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 catheter (PICC) is put in place to deliver the antibiotics. But complications from the PICC can occur, including blood clots and infection. Specific risk factors that lead to the complications can be broken down into three types. First are catheter-related factors. Second are patient factors. Third are 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 6 years and older with cystic fibrosis 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 to be drawn from the PICC line. Length of study participation is about 14-21 days. Financial compensation provided up to \$60.

This research study requires:

- Diagnosis of cystic fibrosis
- Ages 6 years or older
- Doctors confirmed plan to start IV antibiotics for a pulmonary exacerbation using PICC line
- Less than 11 historical PICCs

(continued on page 14)

Clinical Research Update *(continued from page 13)*

GALAXY

Digestive symptoms are very common in people with CF and may include poor appetite, abdominal pain, constipation and nausea/bloating. These symptoms can be troublesome and can negatively affect a person's quality of life. The goal of this study is to understand more about what digestive symptoms people with CF have. The information collected from this study will help the researchers design future studies to improve these symptoms. This research study is for adults and children 2 years and older with cystic fibrosis. This study will require a single visit where participants will enroll in the study and take four questionnaires. After this visit, participants will be asked to complete the same questionnaires outside the clinic three additional times on a mobile device (such as a cell phone or tablet). Length of study participation is about one month. Financial compensation provided up to \$105.

This research study requires:

- Diagnosis of cystic fibrosis
- Ages 2 years or older
- Willing to complete questionnaires at one study visit and three additional times on a mobile device

A NOTE FROM THE ADVISORY BOARD

We want to benefit from the ideas, strengths, and interests of our community members and continue to help the VT Cystic Fibrosis Center provide exceptional care. If you are a parent, caregiver, significant other, or adult with CF and are interested in learning more about the mission of the VT CF Center Advisory Board and how you can get involved, please email vtcfadvisory@gmail.com or Christine Prior at Christine.Prior@uvmhealth.org.



Northern New England Calendar of Events 2019

February

February 16th Rangeley World Record Snowmobile Ride
Rangeley, ME

July

July 26 - 28
The Three Day Stampede
Bristol, VT



March

March 8-10
Omni Mount Washington Resort
Bretton Woods, NH

September

GREAT STRIDES
CYSTIC FIBROSIS FOUNDATION



September 15th
Burlington, VT

September 21st
Bar Harbor, ME

April

April 11th Taste for a Cure
Executive Court Banquet Facility
Manchester, NH



May

Saturday, May 4th
Hanover, NH

Saturday, May 18th

Nashua, NH	Manchester, NH	Rutland, VT
Lancaster, NH	Wolfeboro, NH	Portland, ME
Bangor, ME		

Sunday, May 19th

Seabrook, NH	York, ME	Augusta, ME
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October

October 7th
Breakfast Hill Golf Club

October 25th
Barrett's Halloween Benefit

November

TBD
Take a Breath Social
Portland, ME



June

June 7 - 9th
New England Classic Charity Trail Ride
NH Motor Speedway
Loudon, NH

Individual Giving Opportunities

Cystic Fibrosis Foundation
Annual Fund

65 ROSES CLUB
CYSTIC FIBROSIS FOUNDATION



For more information on these opportunities:
Email: jgilbert@cff.org



July

July 13th
CF Cycle for Life
Kittery, ME

Cystic Fibrosis Foundation

114 Perimeter Road, Units G & H, Nashua NH 03063
(800) 757-0203 — no-new-eng@cff.org
<http://newengland.cff.org>



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CF CONNECTION NEWSLETTER

The CF Connection Newsletter is produced twice yearly by the Vermont Cystic Fibrosis Center Advisory Board.

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Online Resources

CF Community Blog

The Cystic Fibrosis Foundation's website includes this blog with short posts from people with all sorts of connections to CF. Two recent additions to the blog include:

- Thoughts from a CF Nurse Practitioner about *Five Feet Apart*, the movie released this month about two fictional teens with CF. Check out her post at: <https://www.cff.org/CF-Community-Blog/Posts/2019/A-CF-Nurse-Practitioner-Talks-IPC-and-Five-Feet-Apart/>
- A CF mom's post about learning of her daughter's CF after the newborn screening and deciding how she would approach the diagnosis. View her post at: <https://www.cff.org/CF-Community-Blog/Posts/2018/Choosing-How-I-Approach-My-Daughters-Diagnosis/>