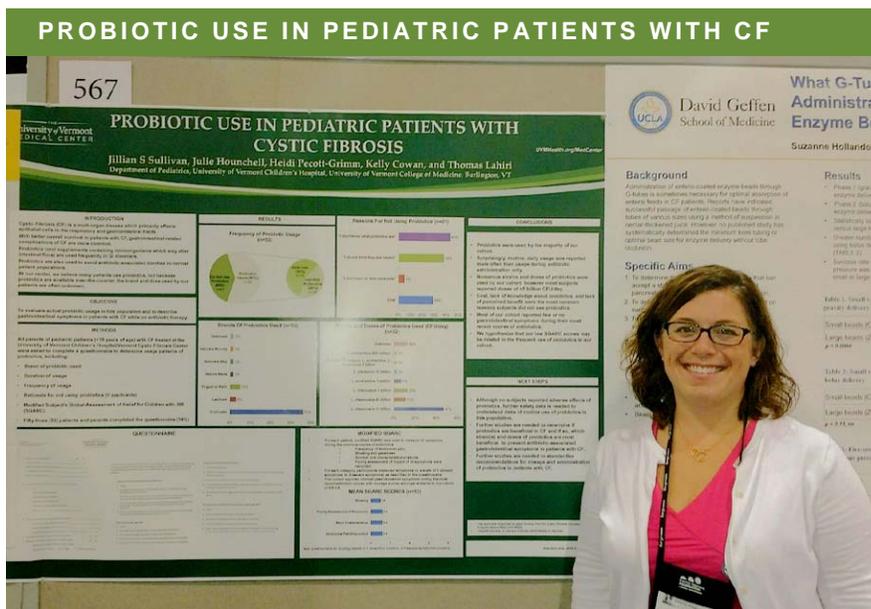


CF CONNECTION

Newsletter of the Vermont Cystic Fibrosis Center Advisory Board



Jill Sullivan, MD, presents probiotic use study results at the North American Cystic Fibrosis Conference in October (see article on page 12)

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Do you remember?

By Laurie Whittaker Leclair, MD

Likely you or your family can remember the day you heard the words “You/your child have/has CF.” You can probably remember the multiple questions it raised about the future and the types of treatment and care that might be available. Over 65 years ago, families affected by CF, likely with similar concerns, joined together to create the Cystic Fibrosis Foundation (CFF). Its central mission is proving a means to control and ultimately cure CF. To accomplish this mission, the group began fundraising. Since its inception in 1955, the CFF has contributed well over \$875 million to CF clinical and research efforts. As a result, the future of a child born in 2016 with CF looks very different than even 20 or 30 years ago. The success in improving the health of CF patients likely depends on multiple factors. One of these is the implementation of nationwide newborn screenings for early diagnosis before symptoms develop. Another factor is the standardization of “best care” through the CF clinical care center network. Importantly, a third factor is a robust therapeutics pipeline focused on the development of new treatments for patients with CF.

(continued on page 3)

VERMONT CYSTIC FIBROSIS CENTER

PEDIATRIC PROGRAM**PHONE 802-847-8600**

Tom Lahiri, MD, Pediatric CF Program Director
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 Jillian Sullivan, MD, Associate CF Program Director
 Keith Robinson, MD
 Julie Houchell, FNP
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 Melissa Barron, RN, Pulmonary Nurse Coordinator
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 Carlie Geer, RD, CD
 Christine Prior, LICSW
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 Charlotte Teneback, MD, Associate CF Program Director
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 Meg Costello, FNP, Diabetes Nurse Practitioner
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 Kristen Bolton, RD, CDE
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 Joan Lippman, Research
 Kathy Meehan, Medical Assistant
 Lisa Benoure, Medical Assistant
 Jenna Carroll, Practice Support Specialist
 Susan Heney, Operations Support Specialist

HealthWell Foundation

By Christine Prior, LICSW

You may or not be aware that the CF Foundation recently decided to hire the HealthWell Foundation to manage its patient assistance program. At the same time, they decided to modify their eligibility criteria and expand the medications covered to include some oral supplements and CF vitamins. They also want to expand their coverage to other common over-the-counter CF medications in the near future.

- **Eligibility:** You have to have some form of insurance. Medicaid and Medicare patients are eligible in addition to those of you with private insurance.
- **Income limit:** You must be below 500 percent of the poverty level. To give you a sense of what this equates to, for a household of one this is about \$58,350. For a family of four, this is about \$119,250 a year.
- **Grant limit:** \$15,000/year
- **What the program offers:** In addition to co-pay assistance for CF medications, they will also reimburse for many oral supplements and CF vitamins. (Please email me directly for a list of the specific supplements and vitamins covered). They are currently building the list of other over-the-counter medications that they will reimburse for, so if there is something you feel should be reimbursed and is not on their list you can email them at Grants@HealthWellFoundation.org and they will seek out approval from the CF Foundation.

Below is the link for the program and the information for how to apply for a grant:

www.healthwellfoundation.org/diseases-and-medications

I hope this is helpful. Let me know how it is working for those of you who enroll: christine.prior@uvmhealth.org.

Do you remember? *(continued)*

In 2001, the CFF founded the nonprofit group CFF Therapeutics (CFFT) to support therapeutics development and clinical trials. Clinical trials, also called clinical studies, are research trials with human volunteers that seek to answer questions about new potential drugs or new ways of using already approved therapies to treat a disease or condition. Persons with CF and their families are often very interested to learn more about therapies in development. The CF drug pipeline is a resource for such information. Easily accessed from the CFF website, it outlines the therapies in development supported by the CFF or CFFT and their progress along the path to becoming widely available to patients.

<https://tools.cff.org/research/drugdevelopmentpipeline/>

While having a healthy drug development pipeline is a central part of the CFF mission, so is the capacity to perform clinical trials within its care center network. In 1998, the CFF created the Therapeutics Development Network. This network first included seven CF centers but was expanded in recent years to include over 70 centers nationwide. These sites, including the UVM Medical Center, are known as the Therapeutic Development Centers (TDC). The TDC are responsible for recruiting to and performing the majority of the clinical trials of therapeutics in the development pipeline. Participation in the TDC requires ongoing training of clinical research staff in best practice and quality improvement. This is similar to what takes place in the care centers.

Although an efficient clinical research infrastructure is required to perform clinical research, none of it would be possible without the participation of patients. In recent years, the CFF launched an “I am the key” campaign. This campaign highlights that the patient is central to the development of new treatments for CF. The willingness of CF patients to participate in clinical trials is remarkable, with over 1,000 patients participating during last year alone. Here at the UVM Medical Center, 24 patients participated in studies in 2015.

It is an exciting time in CF with an ongoing need for patient participation in clinical trials focused on the development of new therapies. Therapies remain central to the CFF’s original mission of controlling and ultimately curing this disease. Learning more about which clinical trials are currently active at the UVM Medical Center or in the region is easy! You can ask your CF provider or visit the CFF website for a list of all recent clinical trials. If a study is not being performed locally, your provider can make a referral to a participating center. www.cff.org/Our-ResearchClinicalTrials/

SUPPLEMENTAL FUNDING FOR MEDICALLY NECESSARY FAMILY SUPPORT

The Vermont Department of Health’s Children with Special Health Needs (CSHN) has provided The Vermont Family Network (VFN) with grant funding to assist families who cannot pay their child’s necessary medical expenses. The Vermont Family Network Medically Necessary Family Support Supplemental Fund is for families of children with special needs from birth to age 21. It is for the child’s medical expenses. The child’s medical expenses must be medically necessary and be within the fund’s requirements:

- The family income must be less than 500 percent of the federal poverty level
- There is a limit of \$1,000 per family, per 12-month period

The VFN Health Care Financing Specialist and the CSHN Social Work Supervisor review all grants. The VFN Health Care Financing Specialist will notify when funding applications are approved.

If you cannot pay for your child’s medically necessary medical expenses, and you fall within the project structures bulleted above, please contact Betty Morse, Health Care Financing Specialist, at Vermont Family Network: 1-800-800-4005 ext. 201 or Betty.Morse@vermont.gov.

Patient perspective: Participating in a clinical trial

By DeAnna Farnham

I joined my first clinical trial in 2007, and I have continued to be in a study of some kind every year since then. I have found that being in a study helps me to be more compliant with my medical treatments and aware of my health needs. It has been rewarding and educational. I have met wonderful clinicians who work diligently and quietly behind the scenes to bring new treatments for patients.

A study visit usually involves a physical, blood work and general questions regarding your experience with or without the medication being studied. Appointments are generally not much different than a regular clinic visit with your doctor. Some studies have needed very little time and others require a large commitment over a year but all are important and equally necessary. Many studies will compensate your time and travel with a stipend for each visit completed in the study.

I was very excited to have my medical data from the Vertex 770 trial in 2009 put forward to the FDA approval of Kalydeco. I also recently participated in the extended trial that led to the approval of Orkambi. Although I currently don't take either of those medications, I feel proud to have been a part of such ground breaking discoveries in the fight against cystic fibrosis.

Participating in a clinical trial is easy. All of my visits have been worked into my life without any difficulty. I have been given excellent medical care throughout each trial that I have been in. I encourage any person, who is healthy enough, to become involved in a trial. Being in a clinical trial is a simple way to give back to the medical community and help advance science in your own area of need.



CF Connect dinner

By Carol Baker

On November 10, Allergan (formerly Actavis) sponsored the first CF Connect dinner at Fire and Ice restaurant in Middlebury. Jennifer Lloyd, our Allergan representative, set up a wonderful round table event that was attended by 26 people. These dinners are meant to give CF families and caregivers a chance to meet and discuss everything CF. Tables were set up with cards that had discussion ideas generated by advisory members who attended the North American Cystic Fibrosis Conference in October.

Those in attendance were very pleased with the evening. It was a relaxed environment, allowing families an unusual opportunity to talk about what works for them or ask questions of others. One couple had never met or spoken with other CF parents before. Families left feeling excited about attending the next dinner.

Ms. Lloyd would like to have these CF Connect dinners every few months. Allergan covers all costs and they will be located in different areas so hopefully anyone interested will be able to attend at least one. The next one is scheduled to be in Plattsburgh on a date to be determined.

If you have any further questions, contact the CF Family Advisory at vtcfadvisory@gmail.com.

NACFC: Making sure that people with CF have the opportunity to live more tomorrows and better today's

By Laurie Eddy

In October 2015, I joined more than 4,600 people from 42 countries at the North American Cystic Fibrosis Conference (NACFC) in Phoenix, Arizona. NACFC is an annual meeting that brings together scientists, clinicians and caregivers from around the world to share ideas on the latest advances in cystic fibrosis research and care.

Although this was the twenty-ninth year of the NACFC, it was only the fifth year that advisory board members were welcome to attend and the first year that we were encouraged to attend the full conference. Bruce

Marshall, Senior Vice President of Clinical Affairs at the CF Foundation, explained the reason for this change: "People with CF and families are at the heart of all that we do in the CF community, and now, more than ever, we are engaging them on a national level, modeling the partnership that many of you have developed at your care center."

The NACFC was also live-streamed to enable anyone interested to watch the three plenary sessions and over 20 other sessions online. More than 400 people watched live. If you missed the live-stream, you can register to watch the free video archive that is available at this link: <https://arc.nacfcconference.org/cff/live/14>.

What is it like to attend NACFC?

NACFC is a scientific conference intended for research and medical professionals and the content is not targeted to a general audience. I imagine that the NACFC is like most scientific conferences. It is physically and intellectually draining. My head was spinning trying to navigate the schedule of more than 60 concurrent sessions held over three days in the huge convention center. The content of the sessions covered topics related to basic science, clinical research and clinical care. Although I was able to follow most of the material presented, my brain had trouble keeping up in some of the sessions. I needed Google's help with sessions like "Transepithelial Migration Is Impaired in Peripheral Blood Neutrophils Isolated from Cystic Fibrosis Patients."

What does it mean to be a scientific conference?

All of the workshops, symposiums, and posters presented at NACFC are first submitted and judged against very specific criteria, such as scientific merit and originality. To have a chance for acceptance, abstracts must address an important question. Attending the NACFC, I learned very quickly that there are more questions than there are answers. I eagerly anticipated answers to the questions posed in the sessions I attended. For example, the research question in one session was, "Are there gaps in care during transfer from pediatric to adult care centers?" The research showed that the majority of patients transfer between age 18-25, and most do not have a gap. Those with the largest gap in visits, however, had greater decline in lung function. This, of course, leads to more questions and more opportunities for research.

Like most scientific conferences, the proceedings of the NACFC are published in a scientific journal. If you would like to read all of the abstracts that were accepted for the NACFC, they are available in a special issue of the scientific journal *Pediatric Pulmonary*. Here is the reference to the NACFC issue and a link to view it online:

Pediatric Pulmonary Special Issue: The 29th Annual North American Cystic Fibrosis Conference October 8-10, 2015, Volume 50, Issue S41, Pages S1-S473 <http://onlinelibrary.wiley.com/doi/10.1002/ppul.v50.S41/issuetoc>



Christine Prior, LICSW, medical social worker, on the big screens at the NACFC discussing the importance of mental health screening.

(continued on page 6)

NACFC *(continued)*

The best part of NACFC was the three plenary sessions. As a CF parent and advisory board member, my experience at the NACFC each day was an emotional rollercoaster, with both uplifting sessions on scientific advances and frightening sessions on the challenge of fighting airway infection. The highlight of each day was the plenary session. It was awe inspiring just being in a room surrounded by 4,000 people who are passionate about and dedicated to improving the health and quality of life for people with CF. These are some of my thoughts about the three plenary sessions:

Session One: “The Future of Personalized Medicine”

Robert Beall, PhD, opened the first plenary session by highlighting the incredible success of the CF Foundation over the past 60 years. He spoke about the passion and dedication of the people working on the front lines of care, at the research benches, and as volunteer fundraisers who have all played a role in changing the lives of those with cystic fibrosis. But the work is not done, and there are 23 new clinical trials expected in 2016. Beall characterized the incredible momentum of the CF Foundation as a train that is moving very fast, although not fast enough for the patients and families. He explained that, although he has stepped down as president and CEO, he would continue to be involved because “You can’t step off this train. It is moving too fast.”

Session Two: “Opening Doors to CF Clinical Research, Change Is Coming”

George Retsch-Bogart, MD, said that more new CF studies are getting off the ground than ever before, along with a growing demand for patient participation. He stressed that, in order to meet the demand, the CFF needs to listen to the CF community and make clinical research very personal. Retsch-Bogart shared results from a survey of people with CF and their families about their interest and preferences around participating in clinical trials. Seventy percent want to hear directly from their doctor about whether a clinical trial is right for them. Seventy-eight percent of people who have not participated in a clinical trial have never been asked.

It was very clear to me that the CF Foundation is the fast train that Beall described. It was also clear that the leadership of the CFF is devoted to the patients and families. Retsch-Bogart became choked up while sharing a story about one of his patients, a young boy who told him, “There’s a cure you know, they just haven’t found it yet.” Later that same day, Bruce Marshall, MD, spoke about the efforts the CFF is taking to improve care. Marshall became choked up with emotion as he spoke about the relationships that develop between families and care teams and the shift from including the patient’s voice to creating a partnership for care. The emotional response of both of these leaders in the CF community warmed my heart with the knowledge that the CF Foundation tagline “Adding Tomorrows and Better Lives Today” is more than just words on paper: they truly care about the patients and families.

Session Three: “There Is No Health Without Mental Health”

I am proud of the CF Foundation for recognizing the impact that CF can have on the mental health of patients and caregivers. The CFF not only announced the publication of guidelines for screening and treating depression and anxiety, but they are also providing clinics the resources and funding they need to better support families. The best part of session three was seeing our very own Vermont CF Care Team on the big screen. Our medical social worker, Christine Prior, described how the Vermont CF Center has already integrated high quality mental health screening for all of the patients within our care center. Although the new guidelines are not a mandate for CF centers, the Vermont Cystic Fibrosis Center has already instituted the change and is being held up as an example of how care centers can make it work. Kudos to our fabulous CF care team!

My most important take away from NACFC 2015

Attending NACFC solidified my opinion that the Vermont Cystic Fibrosis Center is one of the best CF care centers in the country. Our care team works hard to build and maintain relationships with the CF families. We are ahead of the curve when it comes to initiatives that not only add more tomorrows but also opportunities for better lives today.

Vermont Cystic Fibrosis Center Advisory Board
invites you to

The 8th Annual
Patient & Family Education Night
Cystic Fibrosis Research

Monday, April 11, 2016

5:30 – 9 pm

DoubleTree Hotel
South Burlington, VT

“Change is happening now. We don’t have time to waste.”

There have never been as many new CF drugs in development as there are today. Laurie Leclair, MD, will present the historical role of research in cystic fibrosis, the road ahead, and the changes needed to make it all possible.

AGENDA

- | | |
|-------------|---|
| 5:30 - 6 pm | Registration and visit vendor tables |
| 6 - 7 pm | Dinner and presentations by Tom Lahiri, MD and Laurie Leclair, MD |
| 7 - 7:30 pm | Visit vendor tables |
| 7:30 - 9 pm | Panel discussion by CF patients and parents |

In keeping with the CFF Infection Prevention & Control Policy, we invite people with CF and those who are unable to attend in person to view the live-streamed presentation online. A link and instructions will be provided upon registration.

Registration is required.

To register, please go to:

www.surveymonkey.com/r/CFEducationNight

Deadline: Monday, April 4, 2016

This free event includes dinner and is open to caregivers, professionals, friends and relatives of those affected by cystic fibrosis.

New faces in clinic



Evelyn Alexander, RN

Evelyn Alexander recently joined the pediatric team as its CF nurse coordinator. She was born and raised in Germany in the town of Solingen. She received a degree in clothing design before she decided to work as an *au pair* in Maryland for one year. The family wanted to extend her stay and sponsored her for a green card. She eventually moved to New York City, where she worked as a nanny and took acting classes with Lee Strasberg. She met her ex-husband in New York City and they moved to Vermont, where he attended graduate school at UVM. They had two fabulous boys, now 23 and 25 years old. While living in Vermont, Evelyn owned her own clothing business for over 20 years. In 2007, she enrolled in the nursing program at Vermont Technical College, since she had always been drawn to the medical field and has a sister who is a registered nurse and an aunt who is a veterinarian. In 2012, she simultaneously started a BSN program and a position on the cardiology unit at UVM. Evelyn worked on the cardiology unit for over three and a half years and decided that she wanted to look into something different. She has always enjoyed working with children and felt lucky that this position became available.



Maryann Ludlow, RD, CDE

Maryann is a registered/certified dietitian-nutritionist who has recently joined the team to work as the dietitian for the adult CF clinic. Maryann has worked in the field of nutrition for over thirty years and has had a rich variety of work experience in New York City, Long Island and Vermont. She has been a certified diabetes educator since 1997 and has worked at the UVM Medical Center since 2000. While she is new to the CF team, she has had a wealth of experience working with adults living with chronic diseases and with a multi-disciplinary team approach to health care. She is inspired by seeing people manage what life brings them, each in his or her own unique way. Maryann is an avid veggie gardener and co-leads a class for beginner gardeners at the UVM Medical Center. She also loves cross-country skiing, hiking, kayaking, and making meals that are both simple and healthy.



Rose Bergeron, Research Coordinator

Rose has been working at UVM for roughly 15 years. She started as a medical assistant and changed her role to a research coordinator. Prior to that she was an emergency medical technician for 30 years. In her spare time, she is a running coach who has completed 38 marathons and four half Ironman triathlons.



Kathleen Grazier, Practice Support Specialist

Kathleen, the new practice support specialist in the pediatric CF program, has her associate's degree in business and is a certified medical assistant. Prior to working at the UVM Medical Center, she worked for FairPoint Communication for 15 years. She appreciates being in a nice warm building, since last winter she was on the picket line from October to February due to a union strike. Kathleen grew up in Maine. She enjoys spending time with her husband, Rob and son, Joshua. They usually can be found either at the hockey rink in the winter or the soccer field during warm weather. Last summer, they traveled with their extended family of 16 to Turkey, Greece, and Italy. It was an amazing trip. Kathleen's New Year's resolution is to de-clutter her basement.

Patient- and Family-Centered Care

By Charlotte Safran

Greetings! My name is Charlotte Safran, and I am the patient- and family-centered care coordinator at The University of Vermont Children's Hospital. I am honored to share information regarding this new strategic initiative with the Vermont CF community.

Patient- and family-centered care is an approach to health care that actively engages patients and families as partners. We work together to shape policies, programs, facility design and day-to-day care interactions. This patient, family and provider partnership is based on equality. Patient and family advisors provide their views and ideas for improving the health care experience. At the same time, health care providers and administrators listen with care and seek to understand the viewpoints and needs of patients and families.

The University of Vermont Medical Center and the UVM Children's Hospital recognize that patients and their families have valuable wisdom, advice and experience. These can be used to improve the delivery, quality and safety of health care. This is one reason that our institutional leaders, health care providers and staff are dedicated to working in active partnership with patients and families to implement the core principles of patient- and family-centered care:

Dignity and Respect: Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care. Those views and choices are listened to and honored in all phases of care.

Information Sharing: Patients and families receive timely and accurate information to effectively participate in their care. Health care providers communicate and share complete and unbiased information with patients and families in ways that are affirming and useful.

Participation: Patients and families are encouraged and supported to participate as integral members of their health care team.

Collaboration: Patients and families are included on an institution-wide basis. Health care leaders work together with patients and families in policy and program development, implementation and evaluation. They also work together on health care facility design, professional education and in the delivery of care.

I am privileged to have the opportunity to share this valuable information with patients and their families. I am also happy to answer any questions you may have regarding how to become a patient/family advisor for the UVM Medical Center and/or the UVM Children's Hospital. Please contact me anytime at: 802-999-9731 or charlotte.safran@uvmhealth.org.



Scholarships and Financial Aid

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

The Cystic Fibrosis Scholarship Foundation: The Cystic Fibrosis Scholarship Foundation (CFSF) awards scholarships to students with CF who are enrolling in an undergraduate college program or a vocational school in the fall. CFSF was founded by a parent of a young adult with CF and is neither part of nor funded by the Cystic Fibrosis Foundation.

Scholarships of \$1,000 each are awarded and may be used for tuition, books, and room and board for up to one year of study. Students may reapply the following year for an additional award but are not guaranteed future awards. Awards are sent directly to the institution that the student is attending. Scholarships are awarded based on a combination of financial need, academic achievement and leadership. For application forms, deadlines and other information, visit www.cfscholarship.org or call 847-328-0127.

AbbVie CF Scholarship: Applicants must be US citizens with CF who are enrolled in or are awaiting acceptance from an accredited institution in the fall. Awards are based on applicants' creativity, academic excellence, community involvement and ability to serve as a positive role model for the CF community. Forty scholars will be selected based on their academic record and extracurricular activities, essay and creative presentation. Each selected student will receive a \$2,500 scholarship. Of these forty recipients, one undergraduate and one graduate student will receive a Thriving Student Scholarship of more than \$20,000. The application and additional information about the scholarship can be found at www.AbbVieCFScholarship.com/apply. (Note: The 2016 application period has ended)

The Elizabeth Nash Foundation Scholarship Program: The Elizabeth Nash Foundation Scholarship Program awards scholarships to assist persons with CF to pursue undergraduate and graduate degrees. Scholarships are awarded on the basis of demonstrated need and accomplishment, both academic and other. Grants are made each year to people with CF who exhibit clear academic goals and a commitment to participate in activities outside the classroom. Grants are made directly to the academic institution to assist in covering the cost of tuition and fees. For application deadlines and more information, visit www.elizabethnashfoundation.org.

Other Resources

For other options, contact the George Washington University HEATH Resource Center for a publication entitled "Creating Options: Financial Aid for Students with Disabilities," which provides contact information and background about financial assistance opportunities. To order a copy, please contact:

The George Washington University HEATH Resource Center

2121 K Street, NW, Suite 220

Washington, D.C. 20037

Phone: 202-973-0904

Fax: 202-994-3365

E-mail: askheath@gwu.edu

www.heath.gwu.edu

Federal Student Aid Information Center at the U.S. Department of Education provides a publication entitled "The Student Guide" which lists many financial assistance programs:

Federal Student Aid Information Center

P.O. Box 84

Washington, DC 20044-0084

Phone: 800-4-FED-AID (800-433-3243)

www.studentaid.ed.gov

Enzyme Company Assistance

BycMaryann Ludlow, RD, CDE

If you are on enzymes, consult the table below to see what assistance and benefits the enzyme makers offer to patients who use their products. Some of them now are offering assistance with your medical plan deductible, which is helpful.

Enzyme Brand	Program Name	What's Available	How to sign up
Creon® (AbbVie)	CF Care Forward	<p>Vitamins (choose one):</p> <p>MVW Complete Chewable MVW Complete Softgel MVW Complete Softgel D3000 MVW Complete Pediatric Drops Libertas Chewable Libertas Softgel Libertas Pediatric Drops</p> <p>Nutritionals</p> <p>Supplements: Ensure®, Ensure Clear®, Ensure Plus®, Ensure Complete, AdvantEDGE Carb Control, Pediasure®, Pediasure® 1.5, Pediasure Peptide 1.5, Similac Advance Powder Bars: ZonePerfect® Bars, Myoplex® Bars</p>	<p>Online:</p> <p>www.creon.com/CFPatients/EnrollInCFCareForward</p>
Creon® (AbbVie)	Deductible & Co-Pay Assistance	<p>Enzymes completely covered until deductible is met. After deductible is met, enzymes completely covered when prescription cost is \$50 or less. Co-pay applies when enzyme prescription cost is over \$50.</p>	<p>Ask at CF clinic for a co-pay card</p>
Zenpep® (Aptalis)	Live2Thrive	<p>Vitamins (receive both):</p> <p>AquADEK: liquid, chewable, and softgel</p> <p>Carlson Vitamin D softgels: 2000 IU or Super Daily D for Kids drops: 400 IU with added Vitamin E</p> <p>Nutritionals</p> <p>Supplements: Scandishake®, Scandical®, Boost® VHC, Boost Plus®, Boost® Kid Essentials 1.5</p> <p>Bars: Clif Bar®, Clif Kid Zbar™</p> <p>Deductible/Co-pay Assistance</p> <p>Enzymes completely covered from January-March 2016 (no monthly limit) to help with deductibles.</p> <p>After March 31, enzymes completely covered if co-pay is \$40 or under</p> <p>Co-pay applies, up to \$40. For co-pays over \$40, up to a co-pay yearly savings limit of \$1500 a month.</p> <p>Rewards Program</p> <p>Earn points by taking nutrition-related quizzes, watching educational videos, filling enzyme prescriptions</p> <p>Points can be redeemed on the website for a variety of items</p>	<p>Sign up to receive the benefits and a card at:</p> <p>www.Live2Thrive.org</p>
Pertzye® (Chiesi)	Chiesi Care Direct	<p>Co-Pay Assistance</p> <p>\$0 out-of-pocket cost for enzymes up to a co-pay yearly savings limit of \$1440 a month.</p> <p>Nutritional Rebate ProgramSM</p> <p>Provides up to \$75 rebate on vitamin supplements, high-calorie drinks, or other nutritional food sources for each 30-day prescription filled or up to \$225 for each 90-day prescription filled.</p>	<p>Download assistance form from:</p> <p>www.pertzyecf.com/patient/free-support-and-savings/</p> <p>The form needs to be completed by both the patient and the physician.</p> <p>Call 1-888-865-1222 or ask at office for the nutritional rebate form (must be sent in with receipts for nutritional products that were purchased).</p>



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The University of Vermont Children's Hospital
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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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Probiotic use in our CF population

Jill Sullivan, MD MSCS

You may have been asked recently to take part in a survey on probiotic use. With this survey, we hoped to understand more about why patients and families chose to use probiotics or not. We were able to survey 75 percent of our patients. Our research was accepted for a poster presentation at this fall's North American Cystic Fibrosis Conference and was well-received. Of the families surveyed, 60 percent reported using probiotics. About half used probiotics on a regular basis, while others used with antibiotics only. Culturelle® was the most common probiotic used, although many other types were also used. In the group of our patients using probiotics, minimal intestinal symptoms (abdominal pain, bloating and diarrhea) were experienced while on antibiotics. Thus, we believe that probiotics likely help prevent intestinal symptoms while on antibiotics. Given the design of this study, we cannot tell for certain that GI symptoms improve because of probiotics. We also looked carefully at the 40 percent of patients who did not use probiotics. Many reported that limited knowledge of probiotics and cost were reasons they did not use them. Approximately one-third of parents also noted that probiotics did not seem to help their children. Thank you to those who participated! Please feel free to contact me if you have any other questions about our results.