FALL 2019

CF CONNECTION

Newsletter of the Vermont Cystic Fibrosis Center Advisory Board

THE University of Vermont MEDICAL CENTER

THE University of Vermont Children's Hospital

IN THIS ISSUE

Flu Season is Here

Although flu shots may not be your child's cup of tea or even your own, it is very important to get your annual flu shot. Vaccination from the flu has many benefits. It reduces the risk of flu illness, length of illness, hospitalizations, and even risk of death in children and vulnerable populations. Patients with a pulmonary medical diagnosis like CF should NOT get the quadrivalent live attenuated influenza nasal spray vaccine (LAIV4) made with attenuated (weakened) live flu virus. This vaccine has the possibility of causing some illness and triggering an exacerbation. So please ask to receive the standard quadrivalent flu shot that is available for people six months old and up. Be advised that if this is your child's first year receiving the flu shot, he or she will get two split doses spaced at least four weeks apart. Please speak with your provider if you have any questions or concerns.

BACK TO SCHOOL

Another School Year Begins

By Liz Hammel

Vermont Cystic Fibrosis Center Advisory Board

Parents of school–aged children have a lot of things to do as the year begins. There are the typical tasks that all parents must complete like buying the school supplies and clothing. We must fill out the stack of forms about everything from health to activities to emergency plans. We have to plan for the bus or carpool or make sure our student's car is ready to go. Did we toss last year's lunch box or can we get another year out of it?

When your child has cystic fibrosis, there are even more things parents need to consider and plan for with each new school year. For some, that means meeting with the school nurse to discuss having your child evaluated for creating a health plan, 504 plan or IEP. For others, it means reviewing the existing health or 504 plan or IEP before the yearly meeting at school to see if there are changes you think are appropriate for your child.

For all of us, it means meeting with the school nurse, either by phone or in person, to discuss communication within the school and with us parents. Some teachers have little or no knowledge of what CF is and what it means to have a child with CF in their classroom. That's understandable, as many will not have had a student with CF in their class before. It's the school nurse's job to make a medical alert for the student, informing the teachers about CF and what considerations should be in place for him or her.

(continued on page 5)

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Tooth Brushing and Your Health

By Michael Bissonette BS, RRT

Tooth brushing is the most common method of maintaining oral hygiene. Brushing teeth removes plaque and food particles from the teeth and stimulates blood circulation of the gums. Bacteria, blood, saliva and food particles could end up on toothbrushes if not cleaned and stored properly. The toothbrush can be contaminated with bacteria coming from both the oral cavity and the environment in which it is stored. The wet environment of the bathroom and contaminated hands can contribute to the colonization of bacteria on the toothbrush. Most families store their toothbrushes in common containers leading to the possibility of cross-infection.

It is interesting to note that children with Cystic Fibrosis have been reported to have fewer dental cavities due to their higher oral pH and increased buffering capacity of saliva. However, there is a tendency for a higher reported occurrence of minor enamel developmental defects or spotting. The long-term use of antibiotics is thought to influence the biofilm and reduce cavities. Nonetheless, this natural tendency for reduced dental cavities can be overwhelmed by high fat- high carbohydrate diets, sweetened medications and the lack of both good oral hygiene and exposure to fluoride.

Poor dental hygiene may contribute to poor pulmonary outcomes by transmission of oral bacteria to the lower airways. Further studies are needed to determine whether poor dental hygiene or other adverse factors (socioeconomic status, adherence) or even sugar containing medications given to children could contribute to poor pulmonary outcomes. The actual impact of toothbrush contamination on the lungs by *S. aureus* or *P. aeruginosa* seems to be very difficult to assess. This is because bacteria can grow from different sources and is highly dependent on an individual's lung status. Indeed, nebulizers, toilets and washbasins have been described as potential sources of airborne bacteria. *(continued on page 6)*

New Faces in Clinic

Dr. Zachary Weintraub
Pulmonologist, Adult CF Program

Zac is originally from Colorado. He first came to the East Coast when he enrolled at Skidmore College in upstate New York in 1996. He was awarded a bachelor's degree in 2000 and moved to Richmond, Vermont. For the better part of a decade he worked in construction and spent winters ski patrolling at Stowe Mountain Resort. He earned his MD degree St. Georges University College of Medicine in Grenada W.I. In 2019 he completed his postgraduate training in Internal Medicine, Pulmonary Critical Care and Cystic Fibrosis at Drexel University/Hahnemann University Hospital. In 2019 Zac returned to Vermont as a faculty member at UVM Medical center. In his spare time Zac enjoys spending time outdoors with his family.

Rylee Kilbride
Pulmonary Nurse, Pediatric CF Program

Rylee is a Registered Nurse working at the Children's Specialty Center. She earned her nursing degree in Maine this past spring and decided to return to Vermont to continue her nursing career. She had worked at the UVM Surgical and Pediatric Intensive Care Unit for four years and left last September to begin her journey as an RN. A native Vermonter, in her free time Rylee enjoys "DIY" projects, boating, and exploring new places with her rescue pup, Charlie. She is very excited for this opportunity working with the Pediatric Pulmonary team.

Ashley Mitchell-Ringuette
Child Life Specialist, Pediatric CF Program

Ashley is a Certified Child Life Specialist (CCLS) through the Association of Child Life Professionals. She received her undergraduate degree in Communication Sciences and Disorders with a minor in Human Development from UVM. She received her Professional Certificate in Child Life from UCSB Extension. Ashley completed her Clinical Child Life Internship and Practicum at UVM Children's Hospital. Before becoming full-time in the Children's Specialty Center, she worked per diem. This allowed her to grow her skills in all areas where child life is present at UVM Children's Hospital. She loves spending time with her husband, daughter and pup. She looks forward to the fall for hiking and apple picking.

Lauren Haskins
Medical Assistant in Pediatric CF Program

Lauren is currently a Medical Assistant II in Pediatric Pulmonary at the Children's Specialty Center. She earned her Bachelor of Science in Human Development and Family Studies in 2015 from UVM while working as a nurse's assistant at a memory care facility. She worked in early intervention for the next several years through the Howard Center. During the summer of 2019 she obtained her EMT license and began once again working in healthcare, while returning to UVM for a Post-Baccalaureate Premedical Program. In her free time she likes to explore all that the Vermont mountains have to offers - snowboarding, splitboarding, hiking, mountain biking, and adventuring with her husky, Bauer.

CF Virtual Events

by Lara Govendo

For the past two years I have participated in several virtual events hosted by the Cystic Fibrosis Foundation. Last fall I had the opportunity to be a part of the planning committee for BreatheCon, the largest virtual event of the year. It was an eye-opening experience on multiple levels.

It was an honor to be a part of the decision making process regarding what would be most beneficial, fun, and include something for everyone to connect on. It was enlightening to collaborate with others living with CF where we could bring our ideas to the table, make choices based on high regard, and work for the betterment of those with CF.

Additionally, I have sat on a few panel discussions where I, along with other CFers, chatted candidly about our personal experiences with CF or transplant. Facilitating conversations is an important part of the event as well. It's essential to feel safe in an environment where sharing vulnerable details of our lives are discussed openly. There are guidelines and rules that channel an open place for discussion, which further enhances the experience for everyone involved.

The CF Foundation has created a platform to facilitate the conversations between those living with CF. They have established a place where CFers can organize dialogue around the things we deal with on a daily basis: the good, the bad, and the ugly. It's also an opportunity to find friends that we can connect with because we have CF, but also because we are human beings and have lives that exist outside of our disease.

It's easy to have mixed feelings regarding such events, but it depends on the lens that you're viewing the intention through. You get back what you put in, as it goes with anything that you experience in this life.

For me, I only started "meeting" other people with CF about five years ago. Previously, I never discussed having CF publicly. It was something that I dealt with on my own (with my support squad of course). I think this coincides with the generation I grew up in. Nobody knew what CF was and therefore we just didn't talk about it openly.

Beginning the evaluation for a double lung transplant four years ago, I knew that I needed to open the conversation up for my sanity. I needed to find support and to also educate others before they saw me with oxygen tubing shoved up my nostrils.

I found groups on Facebook and was immediately met with open arms (virtually). Others welcomed me when I disclosed my current health situation and I felt heard in a way I never knew existed. When others experience what you've lived, you connect on a different, more personal level.

Connecting with others who have CF has transformed my life in the best of ways. CF is an isolating disease, given that it is ill advised to hang out with CFers in person. To have the camaraderie of others who are fighting the same battle is a priceless gift.

Yes, CF brings us together. What binds us together, though, is our individualistic human element where we can laugh, cry, and grow together as people navigating daily life. These events leave me feeling validated as an individual living with a chronic condition. I'm able to verbalize all the weird eccentricities that come along with CF and ask questions to better understand my symptoms. I can discuss both the physicality of CF and the under-regarded mental/emotional health aspect that is drastically affected living with our disease. The greatest gift of connection is knowing that we are not alone in this fight.

Thank you to the CF Foundation for caring enough to find a special way for us Cfers to connect without risking infecting each other. I look forward to seeing you all at the next virtual event, coming up in November!

Another School Year Begins (continued from page 1)

It is also very important for the school nurse to answer some basic questions:

- How many students in the school have CF?
- If the answer to the first question is two or more, what classes are they assigned to and when?
- What lunch times do they have (if students eat together in a cafeteria)?
- What extra-curricular activities and sports are they signed up for?

As the parents of children with CF we have a right to know the answers to these questions. Because of privacy issues, we may not know *who* the other students with CF are, but we must know *how many* there are. Also, we must be confident that the school has answered these questions before the school year starts. Before schedules are sent home to students and parents, the school must make sure students with CF are assigned to separate classes and lunch times whenever possible. If the size or configuration of the school means that it is unavoidable that more than one student with CF will share indoor space, the parents must be informed.

We parents can then meet with the school nurse and administrators to determine how to protect our students with CF from cross-infection. Or, we can make alternate plans for our child. In order to make the best decisions for and with our children, we have to be fully informed about the situation.

The Cystic Fibrosis Foundation has comprehensive information on its website under the heading *Daily Life: CF and School*. There is a teacher's guide to CF and recommendations for "When There's More Than One Person With CF in the Same School." This is good information for your child's school to have. Bringing it with you to a meeting can make it easier to talk about the school's responsibility to minimize cross-infection and protect your child's health.

It is also important for us to communicate well with the school about any changes to our child with CF's medications or health status since the last school year. Many school nurses request a letter from clinic regarding the students carrying their enzymes with them and self-administering them at lunch and snack times. Our clinic's nurse coordinator Emily DiSchino is very responsive when parents make these requests either on My Health Online or by phone and will fax the necessary information directly to the school.

Each new school year is an exciting time for kids and parents alike. Planning ahead for a new year is a lot of work, but it is time well spent when your child with CF sets out for a school that is prepared to meet his or her unique needs.

IMPORTANT INFORMATION WHEN CHOOSING A PRIVATE INSURANCE PLAN

Christine Prior recently received an alert from the Cystic Fibrosis Foundation. Kim Reno, Manager of Policy and Advocacy, wrote about a trend they have noticed with private insurers. Some have started "using copay 'accumulator programs' to control spending." These programs stop things like copay assistance programs from counting towards a person's deductible and out-of-pocket maximum. People with CF and their families rely on these programs from the drug companies to help make medications affordable.

The CF Foundation *Compass* is available to help people and families with CF during open enrollment. Kim writes, "*Compass* case managers will work one-on-one with people with CF and their families to review coverage options… Case managers will try to identify whether a plan has an accumulator program."

***Compass* case managers are available to work with Christine Prior or directly with patients and parents. Call 844-COMPASS (844-266-7277), Monday through Friday, 9 a.m. until 7 p.m. ET, or email them at compass@cff.org.**

Tooth Brushing and Your Health (continued from page 2)

What should you do as a parent or adult with CF?

1. Routine mouth cleaning should begin as soon as the teeth appear. This can be in the form of wiping the teeth with a face cloth on a daily basis. This gets infants used to having their mouth gently wiped clean. Introduce tooth brushing as soon as the first teeth have appeared.
2. Start with a small toothbrush. The parent must clean the teeth even if there is a great desire to “do it myself.” In fact, parents should supervise brushing even up to age eight to 10, until the child develops the necessary manual dexterity to clean his or her own teeth.
3. An appropriate strength fluoride toothpaste needs to be used beginning around age one. Guidelines suggest a low fluoride toothpaste and to spit, not rinse. Given the background of oral health issues children with Cystic Fibrosis can be exposed to, it is probably a good idea to provide good dental care early.
4. Encourage water to be drunk as the main between-meal refreshment.
5. Limit between-meal sweet snacks and make sweet snacks a post main-meal treat. Try to finish meals with a “chewing food” to stimulate salivary flow.
6. After the use of metered dose inhalers, rinse the mouth with water. This lessens the direct effect of the low pH of the medication on the dental tissues. It also reduces the likelihood of oral thrush in long-term users of inhaled steroids. It is easy to tie in twice daily preventative asthma medications to brushing teeth after breakfast & dinner.
7. Use a daily fluoride mouthwash as prescribed by your dental clinician. Prior to bedtime, children six years and older can rinse for 1 minute and then spit out.
8. Use daily a plaque (biofilm) reducing rinse such as Biotene to help maintain oral health.
9. At around the age of 6 introduce dental floss to clean the back teeth. Look for the molars to have come in.
10. Avoid putting infants to bed with a bottle of sweetened liquid or placing honey on a pacifier to get a child to sleep.

In regards to bacterial growth on a toothbrush, there has been some research regarding concerns associated with bacterial cultures present on the toothbrush following brushing. Most of the research indicates that the bacterial numbers become insignificant after 24 hours. This creates a dilemma as dentists recommended brushing two times a day, morning and night, or every 12 hours. One solution is to recommend utilizing two toothbrushes - 1 for morning use and 1 for evening use - that results in 24 hours between each use and allowing adequate time for the brush to dry out.

Dentists recommended that toothbrushes get changed at least every three months or even more often for the most vulnerable subjects. Since the frequent changing of the toothbrush increases the cost of maintaining oral hygiene, a cheaper alternative might be to sterilize the toothbrush. Individuals with Cystic Fibrosis should sterilize their toothbrush every two to three days (more frequently if they are sick or having an exacerbation) using the same process as they clean their nebulizers and *always washing your hands with soap and water before you* start.

- Submerging in boiling water for 10 minutes.
- Soaking in a solution of 2 teaspoons household bleach and 2 cups water for 30 minutes.
- Soaking in 70% isopropyl alcohol for 5 minutes.
- Soaking in 3% hydrogen peroxide for 30 minutes.
- Washing in the dishwasher with a water temp 158 degrees
- Toothbrush sanitizer devices are available.

Rinse with sterile water and air dry on a clean dry surface (remember bacteria grow on things that stay damp and wet).

Good dental care is associated with transplant-free survival. Therefore, it is encouraged to develop good oral hygiene as part of daily routine and decrease the chance of lung infection.

What Kind of Exercise Should I Do?

Maggie Holt PT

This is a question that people ask a physical therapist quite a lot. It does not have an easy answer. A lot depends on specific goals you have, your schedule, where you live, who you have to exercise with, and your starting point.

So the best answer is: do the exercise that you like best! Pick something to do every day and stick with it. It is helpful if you exercise with other people, but some people can keep up a habit alone.

There are many types of exercises that help the body in different ways. I have created a chart to help you understand different types of exercise. You can focus on one type, or create a schedule where you do different types.

Please ask for help and advice on exercise during a CF clinic appointment if you need it! We are glad to help!

Type of Exercise	Examples	Benefits	Notes
Cardiovascular	Vigorous walking, running, swimming, cross country skiing, continuous cycling, hiking, dancing	Helps with airway clearance, burns calories, reduces shortness of breath during everyday life, makes your heart and your lungs work better. Improves mood and mental health. Helps regulate blood sugar.	Any amount is good, but best benefits happen when your heart and breathing rate go up and stay up for at least 10 minutes at a time.
Strength	Weight lifting, bodyweight resistance training (like push-ups, sit ups, dips, planks, squats). Pilates works on core strengthening specifically. Yoga can work on strength.	Improves muscle performance. Decreases the work load on your heart and lungs because your muscles are more efficient.	When you work at a high intensity, muscles need a day to recover. Yoga has a strength component when done mindfully.
Flexibility	Static or dynamic stretching, yoga, posture exercises	Can improve comfort in tight muscles and joints. Can improve posture and alignment.	A balance of flexibility and strength is important. A thoughtful approach to yoga is important.
Agility	Obstacle courses, cutting and dodging, playing sports, dancing, boxing, martial arts	Confidence for moving under tricky conditions	It helps to have strength and flexibility before doing higher-level agility training.
Balance	Tai Chi, yoga, sports such as skiing, snowboarding, skating, boxing, martial arts	Better balance, confidence, fall prevention	Balance requires concentration and awareness as well.
Breathing exercise	Huff cough, active cycle of breathing, autogenic drainage, yoga breathing	Improved awareness of breathing pattern, options for spontaneous airway clearance	Ask at clinic if you want to learn breathing exercises. There are some on line resources as well.

POSTAGE HERE

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Online Resources

Family Education Night Videos Available

By: Laurie Eddy, Vermont Cystic Fibrosis Center Advisory Board

The 11th annual Vermont Cystic Fibrosis Family Education Night was held on May 7, 2019 at the UVM Alumni House in Burlington, VT. Dr. Lewis First, Chief of Pediatrics at the UVM Children's Hospital, was the Master of Ceremonies. The video of this event is posted in two parts. Part 1 includes Dr. Thomas Lahiri presenting the most recent data from the VT CF Center, and Dr. Charlotte Teneback presenting an update on CF research. Part 2 is the keynote speaker, Emily Schaller of the Rock CF Foundation, presenting "Running Down a Dream."

The link for Part 1:

https://youtu.be/eFquypEI0lQ

The link for Part 2:

https://youtu.be/gPVAYzSUGqk