INSPIRE

WELCOME

Welcome to the Fall/Winter edition of the Inspire Newsletter brought to you by the Cystic Fibrosis Center in Rochester!

We hope it has been a healthy winter so far; everyone has gotten their flu shots and is cruising through with minimal illness.

There are lots of exciting things going on in the Rochester CF community and inside you will find events sponsored by the local CF Foundation chapter and the CF Family Connection as well as being introduced to the newest members of both the adult and Pediatric CF teams at the care center.

We hope you find this newsletter interesting and informative. Please provide feedback if there are topics you think the community would like more information on! Stay healthy!

In This Issue:

A Note from The CFFC

By: Greg Smith

Cystic Fibrosis Family Connection is pleased to announce the date and venue for our annual education event. We will be holding the event on June 8, 2019 at Trio restaurant (3423 Winton Place at Brighton Henrietta Townline Rd).

After experimenting with a weekday evening event, we are returning to a Saturday morning format. The program has not yet been finalized but we are looking at morning sessions and ending with lunch.

Trio is located near expressway exits and has abundant free parking. Weather permitting some sessions will be held in Trio's patio area.

We will be providing updates as the program is developed. Details will be added to the CFFC calendar (https://www.cffamilyconnection.org/event/cffc-family-education-day-2019/) as they become available.

We look forward to seeing you on June 8th.

Cystic Fibrosis Family Connection

Cystic Fibrosis Family Connection (CFFC)

The Cystic Fibrosis Family Connection (CFFC) is a charitable, not-for-profit corporation established to assist cystic fibrosis patients and their families.
Dedicated to supporting CF patients and families in their daily struggle with cystic fibrosis.
https://www.cffamilyconnection.org/

A Note From The CFF President: Nicole DeBraal

Cystic Fibrosis Foundation: Until It's Done!

As your Rochester Cystic Fibrosis Foundation (CFF) Chapter President, I had the opportunity to sit in on a call for all the Chapter Presidents nationally. There is so much excitement for the profound impact CFTR modulators will have on everyone with CF -- and likely within the next couple years! It is striking how comprehensively the CFF is looking at the changing landscape of CF and how they can positively impact these changes.

Below is a summary of just some of what the CFF is doing to fight for you/your loved ones...

CFTR MODULATOR HIGHLIGHTS: There are currently three CFTR modulators FDA approved: Kalydeco (ivacaftor), Orkambi (lumacaftor + ivacaftor), and Symdeco (tezacaftor + ivacaftor). There are two more CFTR modulators in their final phase of trials. Both are tezacaftor + ivacaftor plus a third compound called 659 or 445. Both of these new drugs have extremely promising results to date. Vertex will seek FDA approval for the drug that has the best trial results. Once this drug becomes FDA approved for everyone from birth, 93% of those with CF will be eligible for a CFTR modulator! This process will take several more years - but it is in the foreseeable future. In addition, the CFF is actively working to find a CFTR modulator for the 7% of people with CF with rare and nonsense genes. They have already screened another 750,000 molecules and have had some "hits" that may move to clinical trials. In addition, they have invested another $11 million to screen another 2.25 million molecules. NO ONE WILL BE LEFT BEHIND.

OTHER RESEARCH HIGHLIGHTS: CFTR Modulators are only a fraction of the research that the CFF is funding. The CFF has committed to invest $100M for new antibiotics to kill the drug resistant bacteria that is prevalent in CF. In addition, they are significantly investing in anti-inflammatory drugs, mucus clearing drugs, and nutritional/GI drugs. See the full drug pipeline at https://www.cff.org/trials/pipeline.

THE CF COMMUNITY IS CHANGING: As CFTR modulators are approved for more and more folks with CF, the CFF anticipates that our community will change rapidly. The adult community continues to grow and represent a higher percentage of people with CF -- while the pediatric folks with CF will represent a smaller portion. It's hard to believe that the adult clinics only started 10-15 years ago! As the adult community grows, the CFF is anticipating an increase in CF related diabetes, bugs, complications, etc. They are very thoughtful about staying in front of this growing need and continue to fund research to improve and maintain a positive quality of life. The CFF has created new gatherings to connect our community with both virtual and in-person options. We hope you can join one of these gatherings. See other newsletter articles for complete details.

“Courage doesn’t always roar. Sometimes courage is the quiet voice at the end of the day saying, ‘I will try again tomorrow.’” – Mary Anne Radmacher

THANK YOU ROCHESTER: Our events here in Rochester chapter have increased slightly in revenue over last year. Your participation and support has our Rochester Chapter ahead of other CFF chapters. A humble thank you to our Rochester and Finger Lakes friends for making this possible. But, our work isn't done. The CFF has vowed not to stop until we find a cure -- and neither can we! "Until It's Done!" Please join me at one of our fundraising events:

May 19: Rochester Great Strides Walk, Genesee Valley Park

June 8: Hornell Great Strides Walk, Steuben Trust

July 20: Cycle For Life, Mendon Ponds Park

October 10: Rochester's Finest Celebration Dinner, Locust Hill Country Club

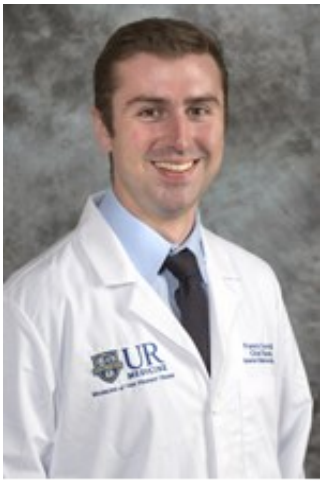
It is impossible to convey how proud I am to be a part of an organization that influences every individual with CF in such a profound way and how invigorating it is to support our local CF community and the CFF's efforts. My hope is that you feel the excitement and choose to join us in supporting CFF’s commitment to the Rochester community as well as the nation! Hope to see you there!

Nicole DeBraal
CF Mom
Your Rochester CFF Chapter President
https://www.cff.org

Introducing New Staff Members

Hello, my name is Shea Hill and I am new to the CF community. I started with the Pediatric Pulmonary Group as a Respiratory Therapist at Golisano Children's Hospital in November 2018. Prior to this, I worked in the homecare setting. I am looking forward to this new path in my career.

Shea Hill, RT



Francis Coyne, MD

Francis Coyne, MD, trained in internal medicine and pediatrics, is completing his chief resident year at URMC. He is a graduate of University of Buffalo School of Medicine and Biomedical Sciences and did his residency at the University of Rochester Medical Center in the Internal Medicine and Pediatrics Program. Dr. Coyne is interested in medical education and the transitional care of individuals with complex pediatric-onset conditions as they move from pediatrics into the adult health care system. He is a member of the Complex Care Center provider team. He brings with him a wealth of knowledge, as well as a fresh and energetic enthusiasm.

After finishing my med-peds residency training in Rochester, I spent 8 years in primary care in both rural and urban settings. While I did not have a lot of patients with CF, I had several patients with complex medical needs that required a lot of coordination with specialists. I understand and appreciate the challenges involved in caring for patients with cystic fibrosis and am excited to be a part of the CF center here at the complex care center. We (husband, 2 kids, 1 dog and 1 cat) moved to Rochester from Michigan and have enjoyed exploring the area and playing in the snow! I look forward to working with you and the rest of CF community!

Ariadne Lie, MD

Are you a teenager with CF or a parent of a teenager with CF who is starting to think about the transition to the adult CF center in the next few years?

Did you know that many people have anxiety about what will happen with their health when they become an adult and start to see new providers? It is normal to feel uneasy about the next steps in life, people with CF (or any type of chronic health care condition) often fear leaving their pediatric health care team to transition to adult care. We understand that this is difficult and want to make this process easier by inviting you to come visit the Complex Care Center (home of Rochester's adult CF center). Keep a look out for the Complex Care Center's next Health Care Transition Open House (spring/summer 2019). Open house welcomes any CF patients who are age 14 or older, family members, friends, and caregivers to tour the office, meet providers and clinical staff, and ask questions. We look forward to meeting you. If you have any questions, please contact Kristine Reinhardt by calling the Complex Care Center office at 276-7900.

Kristine Reinhardt, MSN FNP-BC

Nursing Discussion - Home Tune-Ups: The Good and The Bad

By: Andrea Roy, RN

As Cystic Fibrosis patients, family members, or caregivers you know the CF exacerbations can happen any time and put a wrench in all sorts of life plans. Tune ups require extensive airway clearance, IV antibiotics, breathing treatments and rest to put it lightly. Majority of the time patients are admitted to the local hospitals for a period of time ranging from 7-21 days to treat these exacerbations. Being away from family, friends, events, work, and school can often add more stress to an already stressful situation. This is why more recently doing a tune-up at home has become more popular among our patient population.

Home tune-ups can remove a lot of the hassle of being stuck in the hospital during an exacerbation. The process will look a little bit different for each patient but generally speaking it has the same steps to get to the end goal of making our patients feel better. If a patient doesn't have a port, the first step is getting them scheduled for a PICC (peripherally inserted central catheter) line. Once the PICC line placement is scheduled, usually through interventional radiology at the hospital, the nurses will then set up a home care nursing agency to come to your house the day of the procedure. We like to do it that day so they can assess the catheter dressing, change it if need be, and at that time they will usually give your first dose of antibiotic. From there the homecare nurse will teach the patient, family members, care givers to administer the IV antibiotics from home, and all the steps that are involved in that. The nurse will come out usually once or twice a week for blood draws and dressing changes. The goal of this is for everything the patient needs done to be done in the home. Of course during this time the patient will also need to be doing increased airway clearance, be it vesting, breathing treatments, etc.

It sounds pretty simple and straight forward, right? That is always the goal, but of course there are instances where it gets a little tricky. If the home care nurse is unable to come out on a specific day for a lab draw the patient is then responsible to go to a Strong affiliated lab to get labs drawn. The patient is also responsible for arranging their schedule in a way that they can get all their medications on time as well as complete required airway clearance. While home care nursing and the Complex Care Center do a lot of the arranging and organizing, the patient/family/care givers are the ones truly responsible for making sure labs are drawn on time, medications are administered on time, and communicating with their home care nurse. It is a lot to take on for several weeks for some patients, and that is why an open and honest conversation with your CF provider is crucial before starting this process.

The Complex Care Center team is working on having a more seamless process for this. Our goal is to use one home care agency, one pharmacy, and have all labs be sent through Strong. This will ensure timely feedback on dose changes if needed, home care nurses being aware of our process and needs, and to ensure medications and supplies are sent when they are needed. This is still a work in progress, but in the meantime we have had great success with home tune ups for many of our patients. Our team wants our patients to feel the best that they can without major disruptions in their day-to-day life, and any way we can assist in that we will happily do so! It all starts with a visit at the Complex Care Center and a conversa-

CYSTIC FIBROSIS FOUNDATION

GREAT STRIDES: CFF WALK 2019

When: May 19, 2019

Where: Genesee Valley Park - Round House Pavilion, Rochester, NY

Check-In: 10:00AM

Walk starts: 11:00AM

Distance: 5K

Come out and support the walkers and help raise money for the CFF!

Life Transitions in CF Care

By: Angela M. da Silva, LCSW, URMC Adult CF Care Center Mental Health Coordinator

When many people close to CF think of transitions, what most likely comes to mind is the transition from Pediatric to Adult CF Care. While much of what is covered in this article will focus on this very type of transition, all people living with CF, in fact all of us experience many transitions throughout our lives, though they tend to be more complex for people living with Cystic Fibrosis and other chronic illnesses. Mention of those transitions will be made toward the end, but first, a few words on transitioning from Pediatric to Adult CF Care.

What is transition from Peds to Adult all about?

Defined as the "purposeful planned movement…from child-centered to adult-oriented health-care systems". Essentially, your caregiver(s) was/were in the driver's seat from the point of your diagnosis and transition puts you in the driver's seat. Your caregiver(s) had to learn all they know about CF care and now… it's your turn! Think of it as learning to drive a car. You wouldn't just take the wheel and get on the highway until you learn how to change lanes safely, learn basic traffic signs, practice driving, etc. would you? Transitioning from pediatrics to adult care is that process; that period of time when you are preparing to take the wheel and be in charge of your own CF care. Nationwide Children's in Ohio calls it "a developmental process of skill-building in self-management supported by the health system, which is important for the successful transfer to adult CF care." This is also when your relationship with your care team has the potential to grow into a true partnership. Transition can look different from one center to another and one individual to another but the general goals of the transition process are to:

- Promote self-management- encourage you to know your care plan and steps to take to manage your care (i.e.; calling for appointments, requesting refills of your medications, etc.)
- Promote self-motivation in adolescents- teach you how to "take over" your daily regimen
- Teach adolescents adult life skills- make sure you know how to advocate for yourself and your individual needs at school, work and appointments
- Teach caregivers of children with Cystic Fibrosis techniques in promoting self-management of care
- Help caregivers transition into a new supporting role with the patient in the lead role

What does transition mean for you?

Transition means something different for each person. Successful and meaningful transition to adult care can help build a foundation of skills for other difficult life transitions. Take a moment to reflect on which transition you may find particularly challenging, anxiety-provoking or intimidating and write down your thoughts.

- Growing from childhood to adolescence
- Growing from adolescence to adulthood
- Growing from adulthood to older adulthood
- Initially relying on others for care and then moving on to more independence with CF care
- Saying goodbye to your pediatric care team and hello to your adult care team
- Moving on from high school to work or further education
- Preparing for intimate partner relationships, marriage and children
- Returning to work after a long illness/hospitalization
- Changes in lifestyle with disease progression
- Changes in health requiring you to rely on others once again

Transition Challenges

What are your concerns about transition? Write them down and bring them to your next appointment with your CF care team. Trust me- your CF team cares about your thoughts on transition.

You are very likely familiar with your care team promoting healthy habits such as good sleep hygiene and the importance of adequate sleep, regular physical activity, avoiding drugs and alcohol abuse, and screening for and maintaining mental health and wellness. Engaging in these healthy habits also ties in with transition, so you will have the opportunity to speak with your care team about it at least at your annual screening visit.

However, you can start a conversation with your CF team at any time, even if they haven't brought it up to you, no matter your age. We hope that you feel empowered to initiate talks about your transitions after reading this article.

Respiratory Therapy Update

The adult CF program is currently working on a Quality Improvement (QI) project with the RT's on the inpatient units at Highland Hospital. We are trying to determine if patients and therapists have the same expectations from the time spent working on airway clearance in the hospital. We also want to know if the therapy is the most effective technique for the patient, resulting in the best outcomes.

For patients transitioning from the Children's Hospital, the changes on the adult unit are many. At Highland, Respiratory Therapists do all airway clearance and nebulized treatments unlike the Children's Hospital where this is a nursing responsibility. Some transitioning patients feel they are being watched as if they can't be trusted. In reality the RT's are trying to maximize airway clearance to promote the best clearance possible.

Inpatient RT's may think that patients are much more savvy about their treatments than they are. It's true that people are doing therapies regularly at home, but it also may be true that bad habits have formed over time and the RT's can help correct technique. RT's also may have other techniques patients can learn based on experience with many patients over time and can help patients tailor their therapies to be most effective.

We are in the process of gathering data and will review and make potential changes after enough patients have gone through the QI process. We will then try to implement small changes over time that will add up to more patient and staff satisfaction.

It's really exciting to me to work closely with my inpatient counterparts and hopefully improve care for all patients who are admitted to Highland Hospital!!

Donna Germuga, RRT

Nutrition & CF

By: Elle Woodworth, RD

Having CF presents many challenges. One of the challenges we don't often think about is the amount of food someone needs to consume to meet the increased demands of a body with CF. It turns out, the problem of affording the food needed to take the best care of yourself is much more common than we might think. In the general population, the greater Finger Lakes Region experiences food insecurity at an average of 12% of the population. Areas of Rochester have up to a 40% prevalence of food insecurity in their communities. These numbers don't take into account the extra amount of food a family with CF needs to obtain so you can imagine how much the financial burden of grocery shopping increases when meeting these high calorie needs diets. Food insecurity is a present problem in Rochester; if it is currently affecting you and your family ask your clinic social worker, dietitian, or physician how your CF clinic can help.

Collectively, as your healthcare team, we want to invite you to have an open and honest discussion about your food security while you are in clinic. As a person with Cystic Fibrosis you need a lot of calories and buying that much food can get expensive!

We are here to help, if you are feeling financial pressures around purchasing adequate food, vitamins, supplements, etc please bring it to our attention at your next appointment. There are many options we can help you explore for you and your family. Not all benefits have income minimums and there are a variety of available resources to meet both short and long term needs.

The CF Foundation also has many resources to help those in need. One of these resources is the COMPASS program from CFF, they can educate you on resources in your area as well as national resources available to people and families with CF.

COMPASS 1-844-266-7277, compass@cff.org, CFF.org

2019 VIRTUAL EVENTS for the CF community

ResearchCon
Feb. 28 For people with CF and their families

CF FamilyCon
June 9 For people with CF and their families

BreatheCon
Sept. 20-21 For people with CF

CF MiniCon: Transplant
Nov. 14 For people with CF and their families

SAVE the DATE

Get more information and register:

CFF.org/VirtualEvents

Building a Virtual CF Community

Designed by and for adults with cystic fibrosis and their families, virtual events provide the opportunity to **connect**, **share**, and **learn** from peers **through open and honest dialogue**.

Virtual events feature **keynote panels**, **fun activities**, **group chats**, and **small group video breakouts** on issues that are unique to people living with CF and their families, from maintaining relationships to major life transitions. Discussions focus on overall well-being, not clinical care, and are not for clinicians.

CF CYCLE FOR LIFE
CYSTIC FIBROSIS FOUNDATION

Rochester CF Cycle for Life 2019

When: July 20, 2019

Where: Mendon Ponds Park, Rochester, NY

Check In: 7:00AM

Race States: 8:00AM

Route Mileages: 10-mile, 35-mile, and 65-mile options

Come together and ride in support of an amazing cause!

The Progress of the LLC Project: Lung Transplant Learning and Leadership Collaborative

The Adult Cystic Fibrosis Program has been involved for the last year in a Quality Improvement project sponsored by the CF Foundation. The projects' main purpose is to improve the process for people pursuing lung transplantation. 10 transplant centers around the country have partnered with 10 referral centers to try to come up with best practices where transplant is desired.

We (referral center) have partnered with the University of Pittsburgh (transplant center) in this process. We are focusing on level of lung function as a way to know when to begin conversations about what happens when disease progresses. As lung health declines to a point where changes in the support needed for daily activities may increase, we have begun having conversations outside of clinic time that include the patient and any support people they would like to bring to help navigate declining health. We call these Advanced Care Planning Visits and they aim to outline how health needs are changing and the goals of each patient and family. It also gives family and friends a chance to ask the questions on their minds and get an idea of the support their loved one may need.

We have also worked on the actual referral to a transplant center. We are streamlining the process, identifying the people we need to be able to get in touch with and arranging for our patients to get needed testing close to home when appropriate.

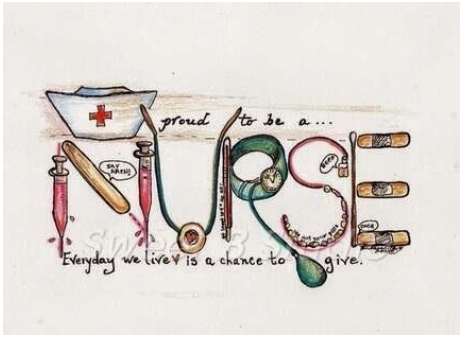
This project has been so successful that the CF Foundation has increased the time line another 6 months so we can concentrate on how communication happens once the transplanted patient returns home.

Our mission is always to improve the process and provide excellent care at all stages of illness .We want to help people make decisions that are right for them about increasing needs. We will honor the wishes of people who don't want to consider transplant as a treatment option for themselves. The Rochester Adult CF Program is very mindful of personal wishes and what is right for each person as an individual. We will work with patients and families to achieve their goals at every stage of life.

NURSES NOOK

The 32nd annual North American Cystic Fibrosis Conference was held in Denver, Colorado in October. Several members of the Pediatric Cystic Fibrosis care center had the privilege to attend this annual conference. Central to the annual conference are the plenary sessions. These sessions are designed to bring together clinicians, researchers, patients and families to explore topics that are of importance to the care of patients with Cystic Fibrosis.

One of this year's plenary sessions was entitled, Partnering: The Oldest New Idea to Improve CF Care. Fundamental to the management of cystic fibrosis are the relationships that people with CF and their families build with their clinical care teams. This plenary session brought together a multidisciplinary panel of clinicians, a patient and parent to explore partnering in CF care.



At the outset of the plenary, the concept of co-production was introduced as a vital component in the partnering of patients families and providers in CF care. Although not unique to the care of patients with cystic fibrosis, co-production is about patients and professionals making better use of each other's assets and contributions to achieve better outcomes or improved efficiency. As people with CF live longer, their disease increases in complexity, making coordination and individualized care ever more dependent upon the relationship between patient, family and their clinical care team.

Kathy Sabadosa, a parent of a young adult with CF and Melanie Abdelnour, an adult living with CF shared their personal stories of the importance their relationships with their CF care teams had in their lives. Rounding out the panel was Cindy George, the Sr. Director for Partnerships for Sustaining Daily Care from the CF Foundation. Cindy reviewed that the CF Foundation has several initiatives to support partnering to improve CF Care. Several of the initiatives that were presented are currently being implemented at our CF care center including collaborative pre-visit planning, patient registry smart reports, integrating mental health in CF care (screening) and use of clinical care guidelines.

Clinic visits with the CF care team are your (your child's) visits. Your care team wants to continue to help tailor your (your child's) visit so that the things that are important to you are addressed during your visit with us. We invite you to use My Chart in advance of an upcoming clinic visit to communicate with the team any questions or concerns that you would like addressed during the visit. Sending a brief My Chart message to one of the members of your care team in advance of your (your child's) visit is most welcome. Our team meets every Tuesday morning for pre-visit planning to review and plan for the patient visits that week. The CF care team will be able to review any questions in advance of your (your child's visit). If you or your child do not have an active My Chart account, we can assist you in setting up a My Chart account at your child's next visit.

As a reminder, the Family Advisory Board created a Pediatric CF Clinic Pre-Clinic Questionnaire that is also available to you on the Pediatric Cystic Fibrosis Center website. You can print the questionnaire from the center's website and fill it out prior to your visit. It can help you help us tailor your child's clinic visit to those concerns that are most important to you. The link to the Cystic Fibrosis Center webpage is : https://www.urmc.rochester.edu/childrens-hospital/pulmonology/cystic-fibrosis.aspx.

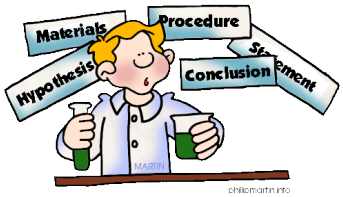
If you would like to view the conference plenary session in its entirety, it is available on YouTube at https://www.youtube.com/watch?v=bC-Lq2LWQcM. The presentation starts at the 7:25 minute mark.

Just Breathe Foundation

Our mission is to make the lives of individuals and their families battling cystic fibrosis (CF) more manageable. We provide funds to applicants in Western New York strug-gling with the financial hardships the disease causes. We strive to improve the quality of life and to inspire others to show their support for the individuals and their families who struggle with cystic fibrosis on a daily basis.

http://justbreathecf.org/

Research News - What's Going On In CF Research? By: Barb Johnson



(The studies listed below are funded by the Cystic Fibrosis Foundation – CFF)

STOP2

This study is looking at patients with CF who are experiencing a pulmonary exacerbation and will be treated with antibiotics by their doctor. Doctors and CF patients have questioned about the best way to treat pulmonary exacerbations and to make sure the antibiotics given are taken long enough to get better, but not taken for too long which expose patients to unnecessary risks. This study is evaluating the optimal length of IV antibiotics (between 10 and 21 days) for a patient with an exacerbation. This study is currently enrolling patients. Study visits are during the time you are being treated for your pulmonary exacerbation. If you are interested in participating, please speak to your provider for more information.

TEACH

People with CF commonly get chronic infections in their lungs. Certain bacteria or germs found in the lungs are normally treated with antibiotics, azithromycin and inhaled tobramycin. This study is evaluating if the routine azithromycin taken as an anti-inflammatory and inhaled tobramycin work well if they are taken at the same time. Researchers want to find out if azithromycin reduces the benefit of inhaled tobramycin or not. This study is currently enrolling patients. Study visits are scheduled once a month for up to 5 months. If you are interested in participating in this study, please speak to your provider for more information.

EPIC

This study evaluated why some people with CF develop lung infections earlier than others, why more antibiotics are given to some than others, what happens to the health of people who have CF after lung infections develop and what role do genes, other than the CF gene play in lung infections, lung health and overall health in people who have CF. These important questions were being studied over a number of years (up to 15 years) in those who underwent certain study measures. This study currently ended on December 31, 2018. The CF community is very interested in hearing the results. More to come....

CF-FC (Cystic Fibrosis – Fibrosing Colonopathy)

This is an observational study looking at patients with CF who are treated with pancreatic enzyme replacement therapy. Fibrosing colonopathy (FC) is a health problem that affects the colon and is seen almost only in patients with Cystic Fibrosis. FC is a painful swelling, shortening and fibrosis (scarring) of the colon. Patients with FC may have abdominal pain, diarrhea, rectal bleeding and in some cases, partial or complete blockage of their colon. It is not known exactly what causes FC. The purpose of this study is to determine the number of patients affected by FC and to learn more about what might cause it, including use of pancreatic enzyme supplements.

Cystic Foundation Patient Registry

The goal of the Patient Registry is to collect health information on individuals with cystic fibrosis (CF) or with a CF-related disorder to better understand the illness and ultimately improve the care and survival of those with CF. The Patient Registry has played an important role in helping us know the best clinical care and in the design of clinical research studies. Each year, the data in the Patient Registry is analyzed and an annual report of CF health trends is created. Using this information, CF clinicians can look at nutritional status, infection control, pulmonary treatment and metabolic issues quickly.

CFF: COMPASS

Cystic Fibrosis Foundation Compass is a personalized service to help you with insurance, financial, legal, or other issues you are facing.

A dedicated, knowledgeable CF Foundation case manager is ready to work with you, one-on-one. This expert guidance is free and confidential. Call us at 844-COMPASS (844-266-7277) Monday through Friday, 9:00am until 7:00pm ET, or email us at compass@cff.org.

Compass is available to anyone with CF, their family, and their care team, regardless of income or insurance status.

COMPASS®
CYSTIC FIBROSIS FOUNDATION

ROCHESTER CYSTIC FIBROSIS CENTERS

PEDIATRIC PROVIDERS AT STRONG MEMORIAL HOSPITAL:

Karen Voter, MD; Matthew McGraw, MD; Augusto Litonjua, MD

Clinic Scheduling ..... (585) 275-2464

Clinic and Prescription Refill .... (585) 275-8706

Tammy Cheney……..(585) 275-2464

Debbie Longbine, Administrative Assistant…….(585) 275-2464

Megan Schlindwein, Physician Support Specialist…….(585) 275-2464

Bridget Platania, Nurse Coordinator ..... (585) 275-2464

Pat Lamarche, Nurse Practitioner ..... (585) 275-2464

Holly Torkington-Wood, RN ..... (585) 275-2464

Barb Johnson, Research Coordinator ..... (585) 275-2464

Laurie Johnson, NP ..... (585) 275-2464

Kim Bordeaux, Respiratory Therapist…….(585) 275-2464

Shea Hill, Respiratory Therapist……..(585) 275-2464

Marie Bieber, Nutritionist/Dietitian ..... (585) 275-2464

Marcy Odell, Social Work ..... (585) 275-9105

Karen Voter, Newborn Screening Coordinator..... (585) 275-2464

For Urgent Issues:

Call the office at (585) 275-2464. If after-hours, the answering system will provide instructions for your needs.

ADULT PROVIDERS AT COMPLEX CARE CENTER:

Tiffany Pulcino, MD; Steven Scofield, MD; Heather Busick, MD; Ariadne Lie, MD; Francis Coyne, MD

Clinic Scheduling ..... (585) 276-7900, FAX (585) 288-1381

Donna Germuga, Clinic Coordinator/ RT ..... (585) 276-7900

Elle Woodworth, Dietitian ..... (585) 276-7900

Angela DaSilva, Licensed Clinical Social Worker ..... (585) 276-7900

Kristen Davidson, Psychologist ..... (585) 276-7900

Jeffrey Iler, Psychiatrist..... (585) 276-7900

Kristine Reinhardt, Nurse Practitioner ..... (585) 276-7900

Jennifer Coglitore, Nurse Manager ..... (585) 276-7900

Sarah Creek, RN ..... (585) 276-7900

Andrea Roy, RN ..... (585) 276-7900

Barb Johnson, Research Coordinator ..... (585) 275-2464

Shandell Moreno, Patient Support Specialist ..... (585) 276-7900

Kristie Cowens, Prior-Autorization Specialist..... (585) 276-7900

Julie Buerger, Physical Therapist ..... (585) 276-7900

Nancy Dukelow, Occupational Therapist..... (585) 276-7900

Adela Planerova, Director of Dental Services ..... (585) 276-7900

For Urgent Issues:

Call the office at (585) 276-7900. If after-hours, the answering system will provide instructions for your needs.

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