



UNIVERSITY OF ROCHESTER CYSTIC FIBROSIS CENTER ADULT AND PEDIATRIC NEWS

INSPIRE

Spring 2016

IN THIS ISSUE

Complex Care Center Opens

University of Rochester Medicine Complex Care Center (CCC) celebrated its grand opening with a ribbon cutting ceremony



and open house on March 17, 2016. The CCC offers much needed services for adults who have been coping with serious health problems since childhood. The CCC is Rochester's first primary care practice dedicated to caring for adults with chronic childhood onset conditions such as Cystic Fibrosis, Sickle Cell Anemia, childhood cancers, Autism, and intellectual and developmental disabilities. Only a few such centers exist across the nation, but the demand for this type of care is rising as the patient population grows.

Tiffany Pulcino, MD, MPH is the medical director and developed the Complex Care Center model over the past several years by

listening to the needs of patients who often have multiple severe conditions requiring close management and face disparities in accessing health care. The 2,500 square foot space is designed as a primary care practice, but with key differences tailored to fit its patient population. Providers and care managers have fewer patients than in a traditional primary care practice, allowing adequate time to work with patients and develop care plans. The team is geared to help patients navigate the health care system to reduce preventable emergency department visits and hospital admissions.



Ribbon Cutting at the new Complex Care Center

FOR MORE INFORMATION

Phone: (585) 276-7900

Website: ccc.urmc.edu



COMPASSTM
CYSTIC FIBROSIS FOUNDATION

CF Foundation Compass Page 2

Learn about this program which helps patients and their families handle many of the hassles and burdens of navigating through insurance, financial, legal and many other issues related to living with CF.



Cloth Masks Page 6

Are cloth masks as good as disposable masks at preventing germs and microbes from entering your body?

CF Foundation *Compass*: With You through Insurance, Financial, Legal and Other Issues



For many people with Cystic Fibrosis and their families, financial burdens and insurance hassles are as much a part of living with the disease as nebulizers and vests.

As part of its commitment to helping people with CF live better today and at every stage of life, the Cystic Fibrosis Foundation offers assistance through *Compass*. CF Foundation *Compass* is a personalized service available to everyone, including family members and CF care providers.

“Our *Compass* case managers are knowledgeable and have many years of experience with CF issues. We listen closely, explain thoroughly, connect you with other resources when needed and work thorough issues with you from start to finish,” reports Anne Willis, Director of Patient Access Programs at the CF Foundation.

Life with CF can be hard, time-consuming and expensive. A recent study by the CF Foundation showed that 80 percent of adults with CF worry about having the financial support they need to live with the disease. Nearly 75 percent worry about getting or keeping their health insurance. Plus, understanding and dealing with insurance requirements can take many hours out of days that are already full trying to manage therapies and other aspects of life with CF.

People reach out to *Compass* for help with everyday concerns, and they often need more support during times of change, such as receiving an initial diagnosis, aging out of a parent’s health insurance or going on disability.

The good news: No one has to tackle these complicated issues alone. Working with *Compass* can help people with CF and their families resolve issues so they can have more

time for treatments and all other aspects of life.

A dedicated CF Foundation *Compass* case manager is ready to work one-on-one with anyone who needs help.

FOR MORE INFORMATION

Monday-Friday 8:30 a.m. to 5:30 p.m. ET

email: compass@cff.org
844-COMPASS (844-266-7277)

www.CFF.org/Compass

CF Compass

by Marcy Odell, LMSW

Compass, formally known as Patient Assistance Resource Library (PARC), is a personalized service to help with insurance, financial, legal and other issues patients are facing. It’s free, confidential and available to everyone.

Legal

Compass can help you connect with the CF Legal Information Hotline®, funded by the CF Foundation, for legal information about:

- Insurance
- Employment
- Education
- Government Benefits

Financial

Compass can help patients:

- **Connect to resources** that may pay for:
 - Drugs, vitamins and supplements
 - Some medical devices
 - Genetic testing
 - Co-pays, insurance premiums, deductibles and out-of-pocket expenses
- **Get the most out of financial assistance services**, including combining drug company programs and special CF care funds
- **Apply for benefits**, including social security and disability
- **Prior authorizations**
- **Getting guidance on appeals**

Other Issues Related to Life with CF

Compass can help with many issues related to life with CF. *Compass* has helped individuals find resources for:

- Receiving an initial diagnosis
- Life transitions
- Transplants
- Living and food expenses
- Transportation to and from care
- Housing
- Pregnancy and adoption
- Scholarships
- Funeral assistance
- Hospice
- Mold remediation
- Fitness programs

Staff Changes



Donna Germuga, RRT

With mixed emotion I would like to let the Rochester CF community know I will no longer be working in Pediatric CF clinic at Strong. I have been offered an opportunity to work at the new Complex Care Center which houses the Adult CF program.

I have loved working with patients and families of all ages and this is a bittersweet transition for me.

Thank you all for your kind words and generosity in sharing your journey with Cystic Fibrosis with me and allowing me into your lives. I look forward to greeting each pediatric patient at the Adult Center when the time comes and I will still be very active in the local CF community through the CFF and CFFC. This opportunity will allow me to practice my clinical skills and also allows more time for teaching and coordination of care with an individual based on his/her particular skill set and needs assessment.

So, thank you again, I have been unbelievably lucky to have had the opportunity to work with you and the wonderful team in Pediatric Pulmonary who gave me room to spread my wings and the courage to try something new.

Until we meet again.



Holly Torkington-Wood

With the recent changes in the division, we would like to introduce you to a new member of our nursing team, Holly Torkington-Wood. Holly is an experienced pediatric registered nurse who has many years of inpatient experience in the children's hospital as a staff nurse on the former 4-1600 unit. Prior to joining our division, she spent the past year in the pediatric community as a nurse at Daystar for Medically Fragile Children, caring for pediatric patients at this community agency. We are delighted to have Holly join our nursing team!

Nurses' Nook

Spring 2016

One of our goals as partners in your health care is to help make communication with our division as easy as possible.

When you call our office with a medical concern about your child, one of the division's registered nurses (Mary Platt or Holly Torkington-Wood) will be returning your call. Very often Mary or Holly will be able to answer your questions or provide you with guidance when they call you back. If your concern needs to be reviewed with one of the medical providers or another member of our care team, they will gather information that will be shared with the appropriate team member. The nurses will call you back with recommendations or a plan of care from the appropriate provider.

MyChart is another way to reach our division with **non-urgent** medical concerns, prescription refill requests or request for appointments. If you have an urgent medical concern, please call the office to speak with one of the nurses during regular office hours or the on call provider after hours. Do not use MyChart for urgent concerns. Please do not use email to communicate medical concerns or questions with the staff. All MyChart messages that are sent to any member of our division are routed directly to a mailbox that is monitored by the nursing

staff. The nurses will triage the messages, taking care of the requests for prescription refills and often answering your non-urgent medical questions. Messages that require medical provider input will either be reviewed with the provider by the nurse or forwarded to the provider. It may take 2-3 days for the provider to respond to your **non-urgent** medical question. Please be aware that our providers are spending a majority of their day either in clinic or caring for inpatients. For most MyChart messages, a nurse will be responding so our providers can continue to care for our clinic patients and children that require hospitalization.

Please note the nurses monitor the MyChart messages during office hours Monday-Friday. Any messages sent after 4:30 pm during the week will be triaged the next morning. Messages sent any time after 4:30 pm on Friday through Monday morning at 8:30 am will be triaged when the office opens on Monday morning at 8:30 am.

If you have not had the opportunity to sign up for MyChart, we would be happy to assist you at your child's next clinic visit or visit <https://mychart.urmc.rochester.edu> and follow the link to sign up.



Sterile vs. Distilled Water

Here is a section from the 2003 publication *Infection Control Recommendations for Patients with Cystic Fibrosis: Microbiology, Important Pathogens, and Infection Control Practices to Prevent Patient-to-Patient Transmission*, "locally prepared distilled water may harbor pathogenic organisms. Sterile water can be prepared in the home by achieving a roiling boil for five minutes. Sterile water can become contaminated, but the rate at which this occurs is unknown.

Boiling water immediately before use minimizes this possibility.

Distilled water should not be used for cleaning or rinsing respiratory therapy equipment since contamination with *B. cepacia* complex can occur during the manufacturing process. The only manufacturing regulations for distilled water relate to preventing contamination with coliform bacteria, e.g., *E. coli*, *Klebsiella-*

Enterobacter spp. 70" (Mangram A, Jarvis WR. Nosocomial *Burkholderia cepacia* outbreaks and pseudo-outbreaks. *Infect Control Hosp Epidemiol.* 1996; 17:718-20.)

It is important to understand distilled water is **NOT** sterile. Distilled and/or tap water can be sterilized if it is boiled for 5 minutes, **NOT** 15 seconds.

Can I Make my Own Hypertonic Saline to Inhale?

To help prevent any germs from getting into your or your child's lungs, and to make sure the solution contains the right amount of salt, we strongly recommend you only use hypertonic saline prepared by a pharmacy. Ask your CF care center team which

pharmacy in your area can fill a prescription for inhaled hypertonic saline.

The CF Services Pharmacy, a national mail order pharmacy, also can supply hypertonic saline with a doctor's prescription. Also, do

not forget to clean and disinfect your nebulizer. If you have any questions about nebulizer care, ask your CF care team or read *Respiratory: Stopping the Spread of Germs*.

36th Annual Kit Taylor Memorial Lecture

Patrick Sosnay, MD, from John Hopkins was the guest lecturer at this year's Annual Kit Taylor Memorial Lecture held April 5-6, the topic was "CF Genetics: How much does a patient need to know?"

Dr. Sosnay was well-received at Family Night on Tuesday, Grand Rounds, and the case presentations for hospital staff on Wednesday.

Thank you to those of you who attended and those of you who viewed the webinar online. The total number of online views this year is 13 to date, with live views totaling 7 and on demand views 6. This is the largest number of online views yet! Hopefully the larger community will become more familiar with the technology and each year we will reach even more people who would like to attend but cannot.

The responses we received regarding the lecture have all been fantastic. People

appreciated what Dr. Sosnay had to share and found the information he provided very useful. We specifically appreciated your feedback and suggestions on how to improve the lecture for next year. We will try to address your recommendations, particularly to find a way for those who are watching the webinar to interact or ask questions by calling or writing in at the time of the lecture.

Please contact us if you have any further thoughts about upcoming events. For those who did not have a chance to watch or those who would like to watch again, please go to the accompanying website.

The Rochester Cystic Fibrosis Center is grateful to the Taylor family for keeping this valuable educational opportunity viable for so many years. There is always so much to learn!



Patrick Sosnay, MD, from John Hopkins was the guest speaker at this year's Kit Taylor Memorial lecture

TO WATCH ONLINE

<https://www.urmc.rochester.edu/Childrens-Hospital/Pulmonology.aspx>

Research Update

We are happy to welcome our new research coordinator, Judy Sroka, who joined our team in December, 2015!

On July 2, 2015, the Food and Drug Administration approved Orkambi® (lumacaftor/ivacaftor) for Cystic Fibrosis patients 12 and older who have two copies of the F508 mutation. This drug is taken twice a day by mouth and partially corrects the chloride channel defect that is malfunctioning in people with CF.

The FDA approval of this drug was based on a study of almost 1,000 patients with CF. There were three groups of patients in the study: (1) a group that received a placebo, an inactive pill with no medication (these patients eventually had the opportunity to receive the active drug), (2) a group that received 400 mg of lumacaftor plus 250 mg of ivacaftor, and (3) a group that received 600 mg of lumacaftor plus 250 mg of ivacaftor. There was an overall improvement of lung function of 2-3 percent; although this was statistically significant, the improvement is small. The accompanying graph shows the proportion of patients who had a greater than 5 percent improvement in lung function and the proportion of patients who had a greater than 10 percent improvement.

When evaluating the results, the people who were on either dose of the active medication had a better increase in lung function and fewer pulmonary exacerbations compared to the people not getting the active medication.

For those of you who have younger children (below 12 years old), our center participated in a multi-center study of Orkambi® in children who are 6 to 11 years of age. We are waiting for results now. If this study shows the same type of improvements without detrimental side effects, we look forward to a day when the FDA will allow Vertex

Pharmaceuticals to change their package label to down to 6 years of age.

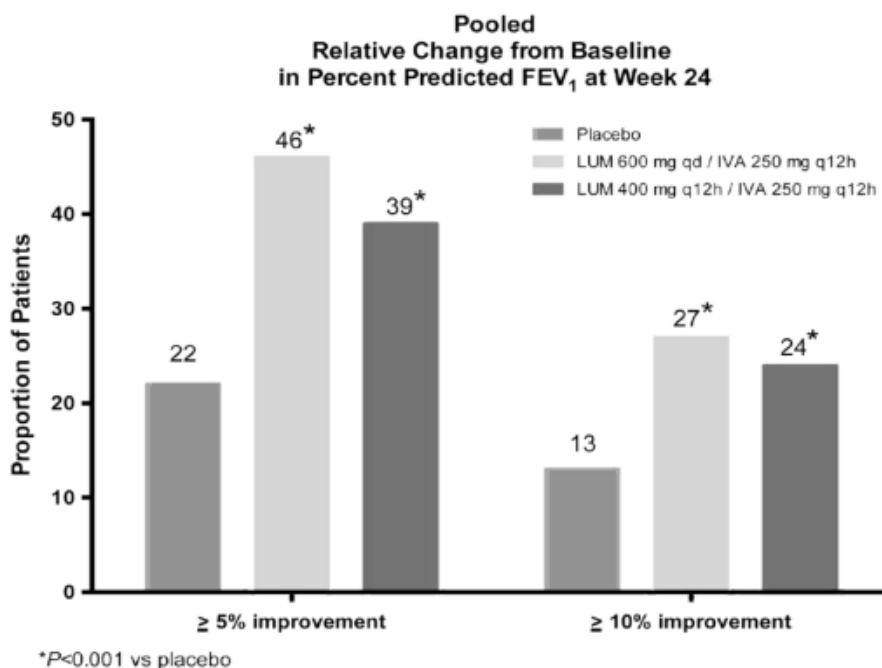
Sometimes the science of Cystic Fibrosis can be very confusing, if you have any questions about this or any other CF study or treatments please bring those questions to clinic and let your practitioners help you make sense of the information or call either Judy Sroka or Mary Platt.

As always, we are grateful to our past, present, and future patients for their participation in research studies. Without you, these advances in CF medications and treatments would not be possible.

CONTACT

Judy Sroka
(585) 275-8580

Mary Platt
(585) 276-4123



The graph shows the proportion of patients who had lung function improvement

Cloth Masks

by Melissa Bronstein, RN, MPA, BSN, CIC

Everyone wants to look their best when out and about. Now that many people with CF are advised to wear a mask when in the hospital, many are taking the opportunity to make a fashion statement by wearing stylish cloth masks in place of the basic clinical face masks provided by the hospital. Unfortunately, these stylish cloth masks may put the wearer at an even greater risk for acquiring pathogens.

There are two ways pathogens in the environment enter the mouth and nose: either breathing pathogens in or hand delivery. Delivery by hand is the most frequent way organisms find their way into our mouths and noses. The average person touches their face at least four times an hour, and each touch provides an opportunity to potentially inoculate

your mouth or nose. Wearing a mask helps keep hands away from the mouth and nose, but of course the potential to touch the

mask several times a day still exists. Could the mask itself be a potential source of pathogens? In some circumstances, yes it can.

Both the exterior and interior of a mask are at risk of becoming contaminated. The exterior of the mask, the side outside of the wearer, is there to “catch” microbes that might be floating in the air. If someone coughs within a few feet, the aerosols will be captured on the surface of the mask. If the mask is doing its job, they will be prevented from entering the mouth and nose of the wearer; however, if the wearer touches the surface of the mask, those microbes can still be picked up on the hands and potentially find their way into the wearer’s body by touching the nose, mouth or eyes. Disposable masks are intended to be worn for brief periods of time and have less chance of accumulating high levels of

contamination. Cloth masks are less likely to be cleaned frequently, so the mask itself becomes a source of contamination.

The effectiveness of a mask is decreased when the mask becomes wet. Wearers are advised to change masks when they become damp. Since every exhale contains moisture, it is common for masks to become damp after about 30 minutes of continuous wear. While it is easy to throw away a paper clinical mask and grab a new one, this may be more difficult with a cloth mask. Wearing a cloth mask while it is damp will not provide the level of protection needed.

Cloth masks are attractive and can

make the wearer feel better about themselves; however, unless special attention is paid to the condition of the cloth mask, it might actually hurt the wearer more than it helps. When considering

which mask to use:

- Choose one made of washable material that is proven to be effective at filtering microbes with a bacterial filtration efficiency (BFE) of at least 95%. For comparison, the efficacy of cotton is only 43-93%.
- If a fabric mask meets the BFE criteria, be sure to launder regularly and change the mask if it becomes soiled or damp.
- Wash your hands regularly! Using soap and water or alcohol hand rub will reduce the opportunities of contaminating your face, eyes or mask.



While very fashionable, cloth masks do not provide the same level of protection from germs and microbes as disposable masks.

Disposable masks are intended to be worn for brief periods of time and have less chance of accumulating high levels of contamination. Cloth masks are less likely to be cleaned frequently, so the mask itself becomes a source of contamination

University of Rochester Specialty Pharmacy

We offer personalized service and caring support:

- Copay assistance programs including foundations to lower medication costs
- Personal prescription refill reminders and follow up from a dedicated pharmacist and pharmacy technician
- Communication and coordination with your provider and pulmonary team
- Free delivery
- Medication and administration education
- Guidance on medication storage and disposal

Insurance:

- We work directly with many insurance plans to quickly fill your medications

Cystic Fibrosis Medications We Fill Include:

Bethkis	Orkambi
TOBI	Pulmozyme

The Specialty Pharmacy is located within Strong Memorial Hospital. We offer many options for medication delivery, including:

- Free home delivery
- Delivery to clinic appointments
- Pick up in the Outpatient Pharmacy, located in the Strong Memorial Hospital lobby

CONTACT

Pharmacist: Katie Manou
Technician: Marquise Melton

HOURS: MONDAY-FRIDAY 8:00-4:30

Phone : (585) 273-4767
Fax : (585) 276-1089



Education Day June 11, 2016

Do you believe the patient and family are essential members of the CF Team?

Do you see the importance of working together as partners with the CF Care providers?

Would you like to seize the opportunity to work with medical staff, in partnership, to build a plan to make your medical experience better?

Would you like that plan to be based on a tested model for healthcare safety and quality?

If you said yes, this workshop is for you!

Please join us to support education and community. There is no charge for any of the workshops. Lunch and refreshments will be provided.

The workshop will be led by Tiffany Christensen who is not only a nationally recognized public speaker, but also has experience living with CF.

Please register at <https://www.SurveyMonkey.com/r/GC5DVCT>

Send any questions you have to gsmith@CFFamilyConnection.org.

See more information on Tiffany at SickGirlSpeaks.com.

The workshop will be presented in three segments

For CF Healthcare Professionals

Friday 12:30-4:30

Hilton Garden College Town

For CF Patients and Families

Saturday 10:00-12:00

Lake Riley Lodge Cobbs Hill Park

For ALL Members of the CF Team

(Professional, Patient and Family)

Saturday 2:00-4:00

Lake Riley Lodge Cobbs Hills Park

ROCHESTER CYSTIC FIBROSIS CENTER PEDIATRIC PROVIDERS AT STRONG MEMORIAL:

Karen Voter, MD
Clinic Scheduling.....(585) 275-2464
Clinic and Prescription Refill.....FAX (585) 275-8706
Bridget Platania, Nurse Coordinator.....(585) 275-2464
Mary Platt, CF Clinic Nurse.....(585) 275-2464
Kim Bordeaux, Anna Roberts, Respiratory Therapist
Melissa Barry, Nutritionist/Dietitian.....(585) 275-1457
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
Clinic Scheduling.....(585) 276-7900
Adult CF Center.....FAX (585) 288-1381
Donna Germuga, Clinic Coordinator.....(585) 276-7900
Donna Germuga, Respiratory Therapist.....(585) 276-7900
Melissa Berry, Dietitian.....(585) 276-7900

URGENT ISSUES:

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

REFILL REQUESTS:

Please submit your request to your pharmacy and allow 2 weeks advance notice. For urgent requests, call the coordinator line or send a message via MyChart.



University of Rochester Pediatric Cystic Fibrosis Center

601 Elmwood Ave Box 667
Rochester, NY 14642
Phone: 585-275-2464

University of Rochester Adult Cystic Fibrosis Center

Complex Care Center
905 Culver Road
Rochester, NY 14609
Phone: 585-276-7900