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Welcome to the Oregon Health and Sciences University (OHSU) Adult Cystic Fibrosis clinic! Whatever path led you to us, you should be proud to enter a new chapter of your life and we are excited to be a part of it. The purpose of this CF Handbook is to help you learn about our team and our clinic. While there are similarities among different CF clinics across the country, we also realize there are certainly differences. We hope this handbook gives you a better understanding about us. This handbook is a “living document”, meaning as things change, we will keep this updated. There will be a quiz at the end of the handbook!

Our clinic’s goals are to:

- Offer you the most up to date CF care based on the latest research and our experience
- Learn as much about you and your CF so we may deliver the best care for you, as opposed to a “one size fits all” style
- Involve you in your care, also known as “shared decision making”
- Ensure access to our clinic by various means (e.g. clinic visits, phone calls, My Chart)
- Keep ourselves and you updated on the latest advances in cystic fibrosis care
- Offer you the opportunity to participate in clinical trials which you may qualify for
- Make efforts to continuously improve our center and to involve our patients in that process

We look forward to working with you!

Gopal Allada, MD
OHSU Adult Cystic Fibrosis Director
CF Clinic Providers

Because of the complexities of cystic fibrosis, excellent CF care requires a multidisciplinary approach. We have many different clinicians who each perform a vital role in your care. Here is a brief introduction about who we are and what we do.

PULMONOLOGISTS
The doctors at the CF Center are pulmonary specialists with advanced experience in cystic fibrosis care. Their expertise extends to aspects outside the lungs, but they also work closely with other specialties, including gastrointestinal, bone health, diabetes and ear-nose-and-throat providers.

Dr. Gopal Allada, MD is an associate professor of medicine and the Director of the Adult Cystic Fibrosis program. He has served as the program director at OHSU since 2005. He actively participates in clinical research trials for CF therapies as an investigator for the CF Therapeutic Development Network (TDN). He also serves on the national CF Foundation (CFF) center committee which assesses CF centers across the country for accreditation. He serves on the national CFF patient education committee and volunteers on the Oregon Chapter of the CFF board of directors. Dr. Allada has consulted for Vertex Pharmaceuticals which developed the first CFTR modulator therapies available for patients. When not attending to CF matters, Dr. Allada serves as the general pulmonary clinic director, the pulmonary clinic quality improvement director, and he is the medical director of the OHSU Physician Assistant school. He also supervises pulmonary fellows in general pulmonary clinic and attends in the medical intensive care unit. In his spare time, he enjoys spending time outdoors, hiking and all things related to University of Michigan sports.

Dr. Jeff Gold, MD is a professor of Medicine and Associate Director of the OHSU Adult Cystic Fibrosis Center since 2010. He is a recipient of a CF PACE award and has been actively involved in both basic science and quality improvement research for Cystic Fibrosis patients. He currently serves as the Interim Chair for the Division of Pulmonary and Critical Care Medicine and has an active research group focused on safe and effective use of computerized medical records in health care. On a personal note, he is an avid road cyclist and loves all things Blazers!

Dr. Aaron Trimble, MD grew up near Anchorage, Alaska, and then headed across the country to attend college in Virginia. After finishing medical school and residency at the University of Virginia, he moved to Chapel Hill, North Carolina for fellowship, with a particular interest in cystic fibrosis. Afterward, Dr. Trimble spent an additional year at UNC dedicated to CF clinical research and care. His desire to move back to the Pacific Northwest brought him to OHSU in August 2018. He enjoys cycling, cooking, and spending time with his wife and three young boys.
NURSE PRACTITIONER
Nurse practitioners are licensed professionals with training in adult health care. The nurse practitioner coordinates clinic appointments, hospital visits, and equipment needs. The nurse practitioner also handles refills, advice, sick calls, and concerns over infection control.

Virginia Satcher, ANP has worked with our CF team since 2008. She sees CF patients independently, assists with medication issues, sick calls and clinical research. She also sees some of our CF patients while they are in the hospital.

PHARMACIST
Pharmacists keeps track of each patient’s medication profile and ensures dosages are correct, interactions are accounted for, and patients’ needs are being met. The pharmacist works closely with the team in optimizing our knowledge of the latest CF therapies.

Dr. Cori Muirhead, PharmD graduated from pharmacy school at University of Washington in 2007. After working as a pediatric hospital pharmacist for 5 years, Cori joined the CF team in 2012. She was hired to support both the pediatric and adult CF teams at Doernbecher and OHSU. She has presented research abstracts at the North American CF Conference. Cori enjoys playing soccer and spending time with her kids, Nolan and Sebastian.

SOCIAL WORKER
Clinical social workers provide assistance and support for people with CF as they strive to live a normal life while balancing the demands of CF care. Social workers are licensed professionals, their job is to help reduce any social, financial or psychological issues that arise.

Wendy Palmrose, LCSW graduated from the University of California, Santa Barbara and received a post-graduate counseling certification prior to earning her master’s degree from Portland State University, School of Social Work. Upon graduation, she joined the CF center at Doernbecher and OHSU. For over 30 years, Wendy has been dedicated to helping people with CF and their families. She is also an artist, enjoys gardening and reading scientific articles.
MENTAL HEALTH COORDINATOR
Mental health coordinators provide mental health screenings for patients and their families during clinic visits and hospital stays. In addition to screenings, the MHC can provide education, counseling, referrals, crisis intervention, and safety planning for patients and their families.

Alex Tharp, LCSW graduated from Fordham University, New York City, and received a master’s degree in social work. Prior to starting at OHSU, Alex worked as a mental health counselor with both children and adults. She enjoys spending time with her husband and cat, skiing, and being outdoors.

DIETITIAN
Dietitians are responsible for tracking patients’ growth and development and care-planning to ensure optimal health. They are highly-trained to detect nutritional issues – such as diabetes, malabsorption, or feeding issues – that will impact the health of people with CF.

Daniella Gardner, RD graduated from Cal Poly, San Luis Obispo in 2008 and completed her Dietetic Internship at OHSU. She has spent most of her career working as an inpatient Dietitian, obtaining a wide range of experience with many different medical conditions. She hopes to provide clear and consistent nutrition guidance in both clinic visits and hospital admissions. Daniella loves to spend her free time hiking with her family and dog.

RESPIRATORY THERAPIST
The RT performs pulmonary function tests to track lung health. They also provide important education on machine usage/cleaning and training on proper methods to clear out the sticky mucus that lines the airways.

Kim Keeling Loop, RRT has been a Respiratory Therapist at OHSU since September 1993. She took over the Pediatric Pulmonary Function Lab in 2006 and help develop the Special Diagnostics group in respiratory care. She has worked on development of educational models and protocols for the cystic fibrosis patients. She is married and lives in Saint Helens. She loves camping, cooking, and most of all, being a Nana to her granddaughter.

PHYSICAL THERAPIST
Physical Therapists (PTs) use knowledge of the human body and exercise to improve people’s physical function through strengthening and flexibility. Most people relate PT to rehabilitation for back pain, after surgery, after a sports injury, after a stroke or other neurological injuries. There is an increasing amount of research that suggests PT and exercise for people with Cystic Fibrosis improves airway clearance, posture, strength, flexibility and a person’s overall quality of life.
Ellen Desmarais, DPT graduated from Boston University in 2016 with her doctoral degree in physical therapy. She has been a physical therapist at OHSU for over 2 years now and has spent most of that time in both the inpatient and outpatient settings treating a wide range of patients and medical conditions. Her role in clinic is to provide education and guidance about appropriate exercise prescription and pain management skills for the CF patient. Ellen loves spending time outdoors hiking, camping, and rock climbing.

NON-PULMONARY CF PHYSICIANS
Gastroenterologists are physicians who specialize in the gastrointestinal tract, which includes not only the everything from the esophagus to the colon, but also the pancreas, gall bladder, and liver.

Dr. Modiano MD, PhD joined the CF team in 2016 and specializes in gastrointestinal diseases. He serves as the Director of the Inflammatory Bowel Disease program at OHSU. He received funding from a national CF Foundation DIGEST grant to develop expertise in CF-specific gastrointestinal issues. If there are issues involving your GI symptoms such as nausea, vomiting, belly pain, changes in your bowel habits, etc., you may be referred to Dr. Modiano’s team.

RESEARCH COORDINATORS
Research is a vital part of CF care in order to find new therapies and treatments. Our research team works with national partners such as the CF Foundation to implement research protocols to better the lives of people with CF. You may see our coordinators in clinic to inform you on our CF clinical research program and possibly invite you to participate in a trial you qualify for!

Brendan Klein, MPH CCRP was born and raised in St. Louis, Missouri. He received his undergraduate degree in Exercise Science from the University of Michigan before attending graduate school at Oregon State University. After completing his Master of Public Health degree, he worked as research faculty at OHSU on a community health grant funded by the USDA. Brendan joined the CF team at OHSU in July 2014 and loves working with CF patients and their families to find new and better treatments. In his free time he enjoys traveling, trying new restaurants, going on neighborhood walks with his wife, and cheering for his Michigan Wolverines!
Jenna Bucher, CCRC attended the University of Oregon where she majored in Human Physiology. As an undergrad, she volunteered in the Cardiopulmonary and Respiratory lab and has had an interest in working in research ever since. Prior to joining the CF Clinical Trials team at OHSU, Jenna had 4 years of clinical trial experience. In her free time she enjoys cooking, reading and following interior design blogs.

Pierce Nusbaum, BS was born and raised in Portland, Oregon. He attended Portland State University where he received his Bachelor of Science in Community Health Education. Prior to joining the CF team, Pierce had two years of experience working as a research coordinator at OHSU in Pediatric Hematology Oncology. Pierce loves working as a coordinator and having the opportunity to work with patients. In his free time he enjoys the outdoors, playing soccer and spending time with family.

MEDICAL ASSISTANTS (MAs)
Medical assistants have roles in clinic and in our back offices. When you are in clinic, they are the ones who bring from the waiting room and check your vital signs (temperature, blood pressure, pulse, oxygen level) and move you into the clinic room. They also administer vaccinations, collect sputum samples, and can collect nasal cultures for viruses. In the office, they can help schedule patients, arrange for admissions, answer telephones, take basic medical histories, assist with refills and update the patient medical record.

PATIENT ACCESS SPECIALISTS (PAS)
Our Patient Access Specialist staff help schedule and coordinate follow up appointments and help with a significant part of the administrative efforts needed to care for our patients. The PAS staff are responsible for delivering a high level of customer service to all our patients. We have PAS staff in clinic to help you check in and check out of clinic. We have a separate staff in our back offices who triage all calls during office hours and help coordinate pulmonary function testing. While they do not have specific medical training, in the absence of the immediate availability of our medical team, they can take down basic information and let the CF care team know you have contacted the office.

CF Clinic at OHSU Physicians’ Pavilion (PPV)
About Physicians Pavilion
3147 S.W. Sam Jackson Park Road
CF Clinic – Medical Specialties Clinic, 3rd floor Suite 320
Portland, Oregon 97239
Physicians Pavilion is located on the right side of SW Jackson Park Road as you are driving up to Marquam Hill to OHSU. In the lobby of Physician’s Pavilion, you will find an information desk, elevators, and pharmacy. Take the elevators up to the third floor and the CF clinic will be to your left.

About Your CF Clinic
The adult CF clinic is located on the 3rd floor (Medical Specialties clinic suite 320) of the Physician's Pavilion (PPV) building at OHSU. Laboratory (across from waiting room) and radiology services (4th floor) are very close by.

The multidisciplinary CF clinics are on Wednesday and Friday mornings. You will perform spirometry before you are seen by your provider at PPV. The location may change to Multnomah Pavilion or Doernbecher Children’s Hospital so please make sure to verify PFT location when your appointment is made. If you have any urgent problems, please call us first before coming to clinic. We are not equipped to see unscheduled "walk-ins". Our nurse practitioner can see patients at other times or urgent issues if scheduled through our offices, however, the rest of the CF team would not be available. These off-clinic appointments are not offered for routine CF care.

To schedule an appointment, please call 503 494-1620.

Directions to the Building
As you drive up to Marquam Hill on SW Jackson Park Road, PPV is on the right side of the road across the street from Kohler Pavilion. It is the first building past Shriners Hospital for Children on the right. After passing PPC, turn right onto Pavilion Loop and proceed to the parking garage entrance on the right.

Parking
Physicians Pavilion has a convenient parking garage below the building, and free valet parking is available.

Valet parking
Valet parking is available during regular patient visiting hours. Free valet parking is also available for patients, and for friends and family who are visiting patients who are in the hospital:

Physicians Pavilion garage valet parking
Monday through Friday, from 7 a.m. to 6 p.m.
After parking, take the parking elevators up to the lobby of PPV or to your desired location or floor.
For more information and directions to the campus, please visit www.ohsuhealth.com/maps or call 503 494-8311.

Kohler Parking Garage – more parking is available, however allow 20 minutes to walk to clinic.
Communication with your CF Team

Appointments:
503-494-1620
Urgent clinic requests may be accommodated during non-CF clinic times pending room and staff availability. Our nurse practitioner would see you without the other team members.

Questions/Medical Advice (Weekdays 8-5):
Virginia Satcher, ANP 503-494-1620
Virginia will be fielding all calls for our adult CF patients during business hours. She is the "point person" for our adult patients. When Virginia is not available, one of our medical assistants can take your medical information and make sure it gets to a CF care team member.

We strongly encourage you to sign up for MyChart which is a service provided to patients for free. This allows patients to access their medical record as well as send non-urgent messages to the CF team. We respond to My Chart messages within 48 hours. For more urgent matters, you should call.

After hours/weekends/Holidays:
Ask to page the Adult Pulmonologist on call 503-494-8311. Make sure to ask for the adult lung doctor on call. Please note there are several adult pulmonologists in our group. All of them have experience with CF issues even if you don't see them in CF clinic. You will talk with a pulmonary fellow (pulmonary specialist in training) who can help you.

If you are in need of immediate medical attention, please call 911 and/or proceed to your nearest emergency room. However, please contact us as soon as you can (using the above contact information). This will allow us to assist your local healthcare team in providing you the best care. If you are being seen by providers outside the OHSU system, please have them contact us.

Our CF Center

Standards of Care
The Cystic Fibrosis Foundation recommends attending clinic at least 4 times per year with 4 respiratory cultures and 2 pulmonary function tests (PFTs).

Why Do a Culture?
Sputum cultures allow us to provide the best possible treatment for you. Your sputum culture is tested for different types of bacteria so that we can determine which antibiotics will kill the bacteria. Over time, some strains may become resistant to different antibiotics. Having cultures done regularly allows us decide if we need to make changes to what antibiotics you are taking. A
standard sputum culture checks for bacteria. We annually check for fungi and a group of organisms called non-tuberculous mycobacterium in sputum as well.

**Why Do Pulmonary Function Tests?**
“PFTs” or “spirometry” are done at every clinic session to give the team and you an idea of how your lungs are doing. Our equipment is in the clinic itself so you will not have to go to a separate location. We often talk about your FEV1% predicted. This is the amount of air you exhale in the first second of forced exhalation compared to a person of your same height and sex with normal lungs.

**Infection control (IC)**
The CF clinic strives to follow the infection control guidelines published by the CF Foundation. Upon arrival to our clinic check in area, you will be offered a mask. Our goal is to room you as soon as possible. Please be aware that if the clinic is running late, rooms may not be available immediately upon your arrival. Once you are in your room, you may remove your mask. There are other patients (CF and others) in our clinic area, but as long as you wear your mask in common areas, you will be abiding by CF guidelines.
The latest CF infection control guidelines specifically recommend *against* separating patients who grow burkholderia because all CF patients should follow the same stringent infection control practices. Note that areas outside our clinic space that care for mostly non-CF patients are more challenging for us to influence IC practices, but we are working on improving IC guidelines throughout the medical center.

Check out CF Foundation care guidelines at: [https://www.cff.org/Care/Clinical-Care-Guidelines/](https://www.cff.org/Care/Clinical-Care-Guidelines/)

**Lab Tests**
We need these tests at least yearly to screen for issues that can arise in CF patients. We may need to repeat them sooner if we find a problem, or add other labs for additional information. If this happens, we will discuss this with you.

<table>
<thead>
<tr>
<th>Test name</th>
<th>We are looking at:</th>
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<tbody>
<tr>
<td>CMP (complete metabolic panel)</td>
<td>Liver and kidney function&lt;br&gt; Blood sugar&lt;br&gt; Electrolytes and hydration&lt;br&gt; Bone health</td>
</tr>
<tr>
<td>CBC (complete blood count)</td>
<td>If you have anemia or an infection</td>
</tr>
<tr>
<td>Vitamin levels</td>
<td>Levels of vitamins A, D, E, and zinc&lt;br&gt; Nutritional health</td>
</tr>
<tr>
<td>Aspergillus panel/IgE</td>
<td>Possible fungus that could make your lungs sick and screen for an asthma like disease called allergic bronchopulmonary aspergillosis (ABPA)</td>
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<tr>
<td>INR</td>
<td>How well your blood clots (vitamin K absorption)&lt;br&gt; Liver function</td>
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<tr>
<td>Hemoglobin A1c</td>
<td>Average blood sugars over the past few months</td>
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<tr>
<td>Glucose tolerance test</td>
<td>Screening for CF-related diabetes or glucose intolerance</td>
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<tr>
<td>DEXA bone scan</td>
<td>Measure of bone density which estimates fracture risk</td>
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Cystic Fibrosis Medication Assistance Program Information

**CF Foundation: Compass**

**Compass** connects people with Cystic Fibrosis to financial assistance services including drug company programs and special CF care funds.

*Contact Compass to work with case managers to evaluate the full range of available resources and programs in order to maximize available benefits.*

Compass is available by phone at (844) 266-7277 or by email at compass@cff.org

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**HealthWell Foundation**

**HealthWell Foundation** is a nonprofit financial support organization that will cover the cost of copayments from insurance. Approval is based on income.

HealthWell is available through two separate funds: a *treatment fund* and a *vitamins and supplements fund*.

1. The *treatment fund* will cover CF medications and treatments and some nebulizers
2. The *vitamins and supplements fund* will cover vitamins, probiotics and supplements

HealthWell is available online at www.healthwellfoundation.org, by phone at (800) 675-8416 or by email at grants@healthwellfoundation.org

***First enroll in available manufacturer assistance programs, then use HealthWell for remaining costs***

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**Manufacturer Assistance Programs**

**Manufacturer Assistance Copay Programs** exclude patients receiving government insurance (Medicare, Medicaid, TriCare). (*Creon program allows for Tricare).

Creon and Zenpep programs provide *free vitamins and nutritional supplements*, as well as *copay and deductible assistance*.

**Enzyme Programs:**

<table>
<thead>
<tr>
<th>Program</th>
<th>CREON</th>
<th>ZENPEP</th>
<th>PERTYZE</th>
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<tbody>
<tr>
<td>Phone</td>
<td>855-227-3493</td>
<td>888-936-7371</td>
<td>888-865-1222</td>
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Inhaled Antibiotic:

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<tr>
<th></th>
<th>CAYSTON</th>
<th>BETHKIS</th>
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<tbody>
<tr>
<td>Program</td>
<td>Cayston Access Program</td>
<td>Chiesi CareDirect</td>
</tr>
<tr>
<td>Phone</td>
<td>877-722-9786</td>
<td>888-865-1222</td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://www.cayston.com/hcp/cayston-access-program/">www.cayston.com/hcp/cayston-access-program/</a></td>
<td><a href="http://www.pertzyecf.com/savings-support/chiesi-caredirect/">www.pertzyecf.com/savings-support/chiesi-caredirect/</a></td>
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<tr>
<th>TOBI PODHALER/SOLUTION</th>
<th>KITABIS PAK</th>
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<tbody>
<tr>
<td>Program</td>
<td>Tobi Podcare Plus</td>
</tr>
<tr>
<td>Phone</td>
<td>877-999-8624</td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://www.tobipodhaler.com/info/about/podcare-cf-patient-support.jsp">www.tobipodhaler.com/info/about/podcare-cf-patient-support.jsp</a></td>
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Mucolytics:

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<tr>
<th></th>
<th>PULMOZYME</th>
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<tbody>
<tr>
<td>Program</td>
<td>Pulmozyme Access Solution</td>
</tr>
<tr>
<td>Phone</td>
<td>877-794-8723</td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://www.genentech-access.com/patient/brands/pulmozyme.html">www.genentech-access.com/patient/brands/pulmozyme.html</a></td>
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CFTR Modulators:

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<tr>
<th></th>
<th>KALYDECO, ORKAMBI, SYMDEKO</th>
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<tr>
<td>Program</td>
<td>Vertex GPS</td>
</tr>
<tr>
<td>Phone</td>
<td>877-752-5933 press 2</td>
</tr>
<tr>
<td>Website</td>
<td><a href="http://www.vertexgps.com/">www.vertexgps.com/</a></td>
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Quality Improvement

QI Committee

Our center is participating in a CF Foundation sponsored Quality Improvement (QI) project called the Cystic Fibrosis Learning Network with several other CF centers. OHSU participates in QI initiatives designed to improve our clinic flow, delivery of care, and patient care. You may be asked to participate in this kind of research, which often includes questionnaires and interviews. We use this information to improve our quality of care.

_______________________________

Patient and Family Experience of Care survey

The Patient and Family Experience of Care survey (PFEC) captures your experience at your CF center visit. We take your feedback to plan improvements in your care. This survey is emailed out by the CF foundation after your clinic visit twice per year. Please make sure we have your email address. It may also be completed by phone.

- All of your answers will be anonymous (not able to be traced back to you), confidential (private), and voluntary (optional).
- Although your participation is not required, your feedback is essential in improving services.
- The survey will take about 15 minutes to complete.
Pre-visit Planning (PVP)

We would like to be a partner in your care. We are doing pre-visit planning through your MyChart. You will receive a MyChart message sent about a week prior to your appointment. Our goal is to ensure that your questions and concerns are addressed. The following is a letter from Tom Byerley, your CF patient representative on our quality improvement committee:

Hello,

My name is Tom Byerley. I am a 60 year old patient of the OHSU CF Clinic. I have volunteered to be a part of the CF Clinic Quality Improvement team that is also in progress at nearly all CF care centers across the U.S.

I am writing to share my thoughts about the Pre-visit Planning (PVP) Questionnaire now being sent about a week prior to Clinic visits via MyChart. I encourage you to join in the new process. The goal of the PVP Questionnaire is to make sure we are prepared to address issues that are important to you that you may forget when you’re in clinic.

You will be asked to complete the PVP at home before your visit.

From personal experience I want to share that when I received the new form, my wife and I discussed events that had occurred and raised questions since my last visit and included the topics on the questionnaire. Having the PVP form in advance gave us extra time to think about any health concerns before sending it back to the clinic.

The goal of the PVP questionnaire, along with the other quality improvement measures, is to support you and your loved ones with the best care possible. I encourage you to ensure your enrollment in MyChart is up-to-date and give this new process a try.

Thank you!

Tom Byerley
t.byerley@comcast.net

PS- Our PVP project is currently on hold, but we hope to restart soon…. 
Clinic Visits

Outpatient team

- All CF clinics have their own way of running. Your previous CF clinic experience will have similarities and differences with our clinic. Please be aware that your first appointment will take roughly 2 hours of time in the clinic. Follow up appointments are roughly 90 minutes.
- In the OHSU adult CF clinic, you will see our multi-disciplinary cystic fibrosis team. We have a consistent workflow after you check into clinic. An MA will check your vital signs (temperature, blood pressure, oxygen saturation, weight) and then get your pulmonary function testing. After this, you will be roomed and see our pharmacist and dietitian. When they have completed their evaluation, your provider (either a CF pulmonologist or a CF NP) will see you. Occasionally, we have a pulmonary fellow or medical resident see you prior to the CF pulmonologist as part of their training to learn about CF. Our social worker, mental health coordinator, physical therapist and/or research coordinator may see you depending on your needs.
- After your visit is completed, you will be scheduled for your next clinic visit. If lab work is needed, the lab is located right across from the waiting room. If x-rays are needed, there is a radiology department located one floor up on the 4th floor.
- We do not assign patients to a single provider to ensure the best access to care. Please know that every week, we meet as a group to review all clinic patients so everyone on the team is up to date and any treatment plans can be adjusted if needed. Some visits may not need the full team depending on your overall health.
- Tips for a better outpatient experience
  - Please show up earlier than your given appointment time. Unfortunately, the appointment time we give you does not account for checking in or the initial medical assistant evaluation which takes 15-20 minutes. Coming in early will allow us to get you home sooner and prevent delays for other patients.
  - Ask questions. We do our best to educate and treat you, but our first priority is making sure that we serve your needs.
  - Honesty is the best policy. We are not here to judge you. We want to offer treatments that will not only give you the best chance to keep you healthy, but also fit best with your lifestyle. We do like to be aggressive in treating your disease, but you have the final say in your treatments. Help us help you.
  - Make your follow up appointment before leaving clinic. It is critical that we see patients at least 4 times per year to catch any issues early and respond quickly.
  - Keep us updated on your progress when you are home. We have adopted My Chart as a way to convey non-urgent communications. This is also an excellent way for all team members to see how you are doing in one easy way.
  - Please find a primary care provider (PCP) to assist with your non-CF medical issues. Be aware that the average amount of time we attend to your CF needs is 90 minutes. We are not expert in the majority of non-CF issues, but we are happy to coordinate care with your PCP.
  - If you are visiting our clinic for the first time, please make sure your previous team has provided you with enough medications to last through your first appointment with us.
Hospitalizations

While we will do our best to keep you healthy, hospitalization is a common occurrence for adult patients with CF. We hope this section will help you adjust to this part of your care. If you were seen at Doernbecher, your care team will be (mostly) different than the pediatric side.

Inpatient Team

- When CF patients are hospitalized, they go to OHSU hospital. They are generally placed either on the 14th or 5th floor of the main hospital. We have hospitalists (physicians who specialize in inpatient general medical care) see patients with a team of physician assistants, and there may also be residents and students participating in your care. This team is known as the primary team which means they write all the orders for your care, are the first responders to your questions and arrange for your discharge. They can also direct care of non-CF issues.

- The pulmonary team will see CF patients everyday as consultants. With their experience with CF, the consulting team reviews all aspects of CF care during your hospitalization. The team may consist of Drs. Allada, Gold, and Trimble or Virginia Satcher, but more often will be one of our non-CF clinic pulmonologists who have experience managing CF patients in the hospital. The pulmonary team also has pulmonary fellows, internal medicine residents (finished medical school and are doing further training) and sometimes students.

- We have a dedicated CF respiratory therapist who works with our CF patients in CF therapy education, care of respiratory equipment (e.g. nebulizers, Vest) and helps arrange for new equipment with your Durable Medical Equipment (DME) company if needed.

- Even when a CF care team member is not seeing the patient in the hospital, great efforts are made to ensure the CF team is aware of patient issues and responds quickly to issues.

- We are working on ways for our CF providers (those you see in clinic) to see our inpatients more often to strengthen the overall CF care. In general, our adult CF team has more non-CF obligations than our pediatric partners.

- We realize some patients are not used to seeing many providers, especially those that are not directly on the CF team. Please know we are highly invested in your care and take great lengths to ensure the best treatment plan is provided for our patients.

- Tips for a better inpatient experience
  - Be available for your treatments. We want to get you better as best and as quickly as possible. This cannot be done unless we can provide you with standard of CF care.
  - Let us know how you are doing. What’s working? What’s not working? We know we are not perfect and if there is a way we can get better, we will look into it!
  - Be active! It may seem like being in the hospital is like being in jail, it does not have to be! When you are not doing your treatments, we encourage our patients to walk around. Please let your nurse know your plans to make sure you won’t miss any treatments or any providers who need to see you.
  - If you leave your room, make sure you wash your hands, wear clean clothing and wear a mask to prevent transmission of bugs to other CF patients who may roaming the hospital. CF patients should not be within 6
feet of one another and should always abide by infection control practices in any common area at OHSU.

- **Keep you nurse updated.** You will see many different providers in the hospital, but your nurse will have the closest relationship to you. He or she can be a voice for all the other team members seeing you.

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### Research

When the Cystic Fibrosis Foundation (CFF) was founded in 1955, it set high goals to advance understanding of CF, to develop new treatments, and to find a cure. As a result, many new treatments have been developed, and many more are in the works, forming a “pipeline” of potential new CF therapies. There are currently dozens of therapies in development—more than at any time in the CFF’s history.

The OHSU CF Clinic is accredited by the Cystic Fibrosis Foundation and has participated—and continues to participate—in many trials for new CF treatments.

Participation in drug trials is extremely important for advancing CF care. Without patient involvement, key therapies that could benefit patients would not be available. All research is carefully monitored by both the Food and Drug Administration (FDA) and an Institutional Review Board (IRB). Each trial is designed to highly value the safety of the participants. While there is risk in any new medication study, your safety is more important than the clinical trial; always.

For each trial, a CF team member will contact potentially eligible patients by telephone or mail in order to recruit participants. Your involvement is completely optional and your care will not be different if you choose not to participate. Even if you begin a research study, you may drop out at any time, and doing so would never impact the quality of care you receive.

Research is a key component to fighting CF. Working together, we can come up with new drugs, treatments, and plans to defeat CF.

**Interested in participating in research?** We have many studies coming up. **Contact our team at 503 494-8023 (dial option 5) or visit cff.org/Trials/finder to learn more and get involved!**

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**Cystic Fibrosis Foundation**

**CF Foundation, Oregon Chapter**

The mission of the Cystic Fibrosis Foundation (CFF) is to cure CF and to provide all people with the disease the opportunity to lead full, productive lives by funding research and drug development, promoting individualized treatment, and ensuring access to high-quality, specialized care. CFF Oregon/SW Washington is located at 2701 NW Vaughn St. #203, Portland, OR 97210. The team is made up of four staff members that
work closely with volunteers and CF families to organize and execute fundraising events. Additionally, the chapter also helps direct families to patient assistant programs and advocacy opportunities. To learn about ways to get involved with CFF Oregon/SW Washington, call (503) 226-3435 or e-mail oregon@cff.org.


Here is your Transition Book Quiz!

What is the name of the building the adult CF clinic is in? (Answer on Page 12)

If you are feeling sick and need to talk to someone during regular office hours, who do you call? (Answer on Page 12)

If you have problems after hours or on the weekend, how do you get a hold of someone and who is the person that you will talk to? (Answer on Page 12)

What is HealthWell? (Answer on Page 14)

Because your appointment time does not account for checking in or getting your vital signs taken by the medical assistant, how many minutes (at least) before the appointment time should you arrive? (Answer on Page 18)

Where is the closest lab and radiology areas to clinic? (Answer on Page 18)

What percentage of clinic patients are reviewed with the entire CF team present in a face to face meeting? (Answer on Page 18)

When you are in the hospital, there are 2 teams that will be following your care. Who are they and what are their roles? (Answer on page 17)

Which medication assistance program should you enroll in first, a manufacture’s assistance program or HealthWell? (Answer on page 15)

What is the best way to let the CF team know what topics you would like to discuss at your upcoming clinic appointment? (Answer on page 16)

When are CF clinics? (Answer on page 12)

What is MyChart? (Answer on page 13)

What is Dr. Allada’s favorite football team? (Answer on page 5)