WELCOME

to the Adult Cystic Fibrosis Program at UPMC

As part of the Antonio J. and Janet Palumbo Cystic Fibrosis Center, our primary mission is to provide the best CF care possible to help adults with CF achieve optimal health.

UPMC
LIFE CHANGING MEDICINE

The Adult Cystic Fibrosis Program at UPMC is one of the oldest and largest in the country. Established by Joel Weinberg, MD, and David Orenstein, MD, more than 30 years ago, we currently work with more than 250 adult individuals with cystic fibrosis.

Research has shown that to achieve the best health and longest survival, individuals with CF should receive continuity of care by a multidisciplinary team of specially trained caregivers. Our philosophy (and that of the Cystic Fibrosis Foundation) is one of team care with you, the patient, at the center, driving the plan.

Let us introduce you to our experienced team of CF specialists.

The Adult CF Team

PHYSICIANS


Pilewski


Myerburg

Joseph Pilewski, MD
Co-Director, The Antonio J. and Janet Palumbo Cystic Fibrosis Center (CF Center), UPMC Children's Hospital of Pittsburgh

Associate Chief for Clinical Affairs, Pulmonary, Allergy and Critical Care Medicine

Associate Professor, University of Pittsburgh


Robinson

Michael Myerburg, MD
Associate Director, Adult CF Program
Pulmonary, Allergy and Critical Care Medicine

Associate Professor, University of Pittsburgh

Keven Robinson, MD
Pulmonary, Allergy and Critical Care Medicine

Assistant Professor, University of Pittsburgh

OTHER SPECIALISTS WHO PARTNER WITH YOUR CF CARE

- **CF Ears, Nose, and Throat (ENT)**
- **CF Endocrinology**
- **CF Gastroenterology**
- **CF Palliative Care**


Richless


Dunbar


Walker


Fayad


Vicini


O'Leary Amato


Hayes

NURSES

Connie Richless, MN, RN
Program Coordinator

Sandra Dunbar, BSN, RN
Carolyn Walker, BSN, RN

CLINICAL DIETITIANS

Kristina Fayad, RD, LDN
Kathryn Vicini, RD, LDN


Moore


Brinker

SOCIAL WORKER

Ann O'Leary Amato, MSW, LSW

CLINICAL PHARMACIST

Cody Moore, PharmD, MPH, BCPS

RESPIRATORY THERAPIST

Beth Hayes, BS, RRT

PALLIATIVE CARE CRNP

Tammy Brinker, MSN, CRNP

Outpatient Care

The Adult CF Clinic is easy to access. The clinic meets regularly on Wednesday afternoons in the Comprehensive Lung Center (CLC), which is on the fourth floor of the Falk Medical Building, in the Oakland section of Pittsburgh, adjacent to UPMC Presbyterian.

Located at 3601 Fifth Avenue, the Falk Medical Building has valet parking in the rear. There are elevators in the lobby to take you to the fourth floor. The Falk Outpatient Pharmacy is located on the second floor.

Blood work can be drawn in clinic or on the second floor.

Chest and other routine x-rays can be obtained on the second floor of the Falk Medical Building.

Pulmonary Function Tests (PFTs)

Pulmonary Function Testing is a very important component of your routine care. These measurements will be done at each of your clinic appointments to help track the status of your lung function, as well as to monitor the effectiveness of your current treatments. In most cases, symptoms such as shortness of breath or cough are not specific enough indicators to assess lung health.

PFTs are also particularly important after you are treated for a lung infection to determine if you have gotten back to your baseline, or if additional intervention is needed.

The Pulmonary Function Laboratory is in the Comprehensive Lung Center.

Clinic Visits

During your visit, you will be seen by one of our CF physicians. You may see a medical resident or pulmonary fellow, but you will always see a CF physician as well. The nurses will review your current medication list at each visit and can arrange for any refills that you may need. To reduce your out-of-pocket expenses, we try to use medications that are covered by your insurance company, and will assist with obtaining prior authorizations as needed. Be sure to share with us if you experience any insurance or coverage concerns.

We know that your time is important to you. **Before your visit, think about your goals, priorities, and needs**. Be prepared with particular questions or any areas of concern to guide our discussions during your visit. We have valuable information that we want to share with you. With this in mind, we will try to make your appointment as efficient as possible — while making your time spent here worthwhile.

You will have the opportunity to meet with our experienced CF dietitian, social worker, respiratory therapist, clinical pharmacist, and research coordinator during your regular appointments.

CF Foundation Guidelines for Routine CF Care

- Visit the CF clinic every three months and more frequently if needed
- Do aggressive airway clearance twice a day
- Optimize nutrition
- Exercise regularly
- Get regular sputum cultures and yearly blood work
- Obtain chest x-rays and CT scans as needed
- Get a flu shot each year

Airway Clearance

Airway clearance continues to be essential to your care. In adulthood,the need for airway clearance does not go away. Work and school responsibilities, along with family and social life, may bring new challenges that make your schedule even more difficult to juggle.

We recommend using one of these Airway Clearance Techniques (ACTs) at least twice daily: **Vest, Oscillating Positive Expiratory Pressure device (Flutter), Chest PT, or Autogenic drainage.**

Infection Control

Preventing the spread of infection is essential. There are many approaches to infection control, and per CF Foundation standards, we discourage direct contact with others with CF. When you arrive at clinic, you must put on a mask as you enter the waiting room and while in any common areas. In addition, you are advised to use the hand sanitizer available in the dispensers as you enter and leave the PFT lab and clinic. When we meet with you, we may need to wear protective coverings, and by protocol, your health care providers will wear protective covering when examining you or having physical contact. Please know that this is to protect you and others. Handwashing is key — if we don't shake your hand, please know that it is a measure of infection control.

Clinic Appointments

How to make an appointment:

Appointments are made upon exiting clinic or by calling the scheduling line:

412-648-6161

It has been shown that patients who get frequent, close follow-up have better outcomes and stay well longer. We encourage you to make your follow-up appointment before leaving clinic. If not, the **scheduling number is 412-648-6161.**

- **Remember that the PFT appointment is usually 15 to 30 minutes prior to your clinic appointment.**
- **Also, our clinics get very full, and we often have individuals on a waiting list to get an appointment. If you must cancel your appointment, please call at least 24 to 48 hours in advance.**

Palliative and Supportive Care

The focus of palliative care is to ease the suffering that results from illness and to improve the quality of life for you and for your family. Palliative care supplements your clinical care and can help provide treatment for your uncomfortable symptoms such as pain, nausea, shortness of breath, depression and anxiety. Supportive conversations with our palliative care expert are centered on treatment strategies to improve coping with a serious illness, and can help you talk with your family about your future care. A palliative care specialist is available to consult with you during or outside of clinic. Ask your CF clinician if palliative care might be right for you.

Addressing Problems Outside of Clinic

Our administrative offices are located in the Antonio J. and Janet Palumbo Cystic Fibrosis Center at UPMC Children's Hospital of Pittsburgh. The Adult Program functions as an independent component of the CF Center, but shares administrative staff and facilities. Outpatient telephone triage is conducted out of the central CF Center office at Children's Hospital. This allows for close communication among team members, particularly during the transition from pediatric to adult care. An active transition process promotes a successful transition to the adult team. This valuable transition process, too, is led by the patient, with support of the social workers, physicians, and staff.

When and Whom to Call

Nurse call line at 412-692-8764

...if you get a cold, upper respiratory infection, or increased cough or change in mucus.

...if you experience constipation or abdominal pain.

...if you have questions about your medications, lab results, etc.

...if you need refills or authorizations (remember that we need two to seven days to get refills due to individual insurance requirements).

After hours on-call line at 412-648-6161 and identify yourself as a CF patient

...if you have an urgent problem and feel you should not wait until the next working day.

Dietitian line at 412-692-8079

...if you have questions about your enzymes, diet, dietary supplements, tube feedings, or have a change in bowel habits.

Social Worker line at 412-692-2124

...if you have questions about insurance, Social Security Disability, legal or educational resources, community and mental health/counseling resources.

...to talk about aspects of day-to-day living and coping with CF.

Respiratory Therapist line at 412-692-7903

...if you have any questions about airway clearance therapies or home respiratory equipment.

Research line at 412-290-6367

...if you want to discuss research opportunities or have specific questions about a study in which you are participating.

Pharmacy line at 412-647-5894

...to receive additional education regarding your medications or have questions pertaining to possible medication-related side effects.

Fax number is 412-692-6645

MAILING ADDRESS:

Antonio J. and Janet Palumbo Cystic Fibrosis Center
UPMC Children's Hospital of Pittsburgh
3rd Floor, Administrative Office Building
4401 Penn Avenue
Pittsburgh, PA 15224

CLINIC ADDRESS:

UPMC Comprehensive Lung Center
Falk Medical Building, Fourth Floor
3601 Fifth Avenue
Pittsburgh, PA 15213

Research

The Cystic Fibrosis Foundation established the Therapeutics Development Network (TDN) in 1998 to facilitate the implementation of clinical studies exclusively focused on CF. As one of the original sites selected for the TDN, under the guidance of David Orenstein, MD, and Joseph Pilewski, MD, Pittsburgh has been a participant in many groundbreaking studies and has consistently been one of the top 10 enrollment sites. These research efforts are forging the way for new cutting-edge therapies that we hope will one day cure CF.

As clinical research continues to evolve and new potential therapies are developed, our research team carefully evaluates any new studies for their value, including patient safety, and potential impact on CF. Development of new drugs, therapies, and ultimately the cure for CF, requires people with CF to participate in clinical trials. **Be a part of the cure! Volunteer for a study today.** Our research staff is available in clinic and by phone to offer you numerous opportunities to get involved, and will make research studies as convenient for you as possible.

Exercise and Rehabilitation

The health benefits of an active lifestyle are widely recognized, but exercise is especially important for people with cystic fibrosis. All people with CF can tolerate some form of physical activity, but the amount and type of exercise will vary from person to person. People with CF should work with their health care providers to develop an exercise routine that is right for them. Aerobic exercise provides the most benefit and includes things such as running, swimming, cycling, or any other vigorous activity that raises your heart rate and makes you breathe harder.

As a general rule of thumb, to achieve the most benefit, exercise routines should include 20 to 30 minutes of aerobic activity three times per week. However, any amount of exercise is better than no exercise at all, and workouts should be adjusted according to each person's level of tolerance. Maintenance of physical fitness is critical to your health.

A pulmonary rehab team can assist you in developing an appropriate and safe program that is tailored to your individual needs, supervise you during the initial stages, and prescribe a safe and effective regimen for you to follow at home or in a gym.

Lung Transplant

Some people with cystic fibrosis may face the possibility of needing a lung transplant. Lung transplantation can improve a person's quality of life but requires a lot of planning, preparation and learning so it's best to start discussing consideration for lung transplantation with your CF care team before you need one. UPMC is home to one of the most experienced lung transplantation programs in the country, and some of our CF patients may be referred to them for evaluation.

Inpatient Care

If you are sick and feel that you might need to be admitted for inpatient care, please call the nurse on the **Adult Call Line** at **412-692-8764**.

If it is a weekend or after hours, you can page the physician on call at 412-648-6161 and ask for the CF doctor on call. Patients requiring hospital care are admitted to **UPMC Presbyterian**. On some occasions, you may be able to be "direct admitted," which means that you can bypass the Emergency Department and go straight to the nursing unit. This decision will be made by your physician, nurse, and you.

All individuals with CF are admitted to a private room and have unrestricted visiting hours. Wireless internet is provided throughout the hospital.

The Dietary Department is consulted and food may be chosen and made available at any time. A Patient Relations representative rounds regularly to assess for additional needs.

Airway clearance, aerosolized treatments, and intravenous antibiotics are critical components of your care while in the hospital. One of the CF team physicians or their Pulmonary Medicine partners will round every day, so be prepared to talk to him or her at that time. In addition, exercise is very important, even in the hospital.

For infection control reasons, we strongly discourage you from visiting directly with other hospitalized CF patients at any time, including when you are in your hospital room or in public areas of the hospital. CF guidelines dictate a minimal distance of six feet between individuals with CF. For your protection, patients and their visitors are encouraged to wash their hands frequently and to use the hand sanitizers to reduce the chances of picking up germs from others.

The infection control guidelines at the hospital will dictate any "special precautions" that must be taken based upon what bacteria grow in your mucus. Staff will wear protective covering routinely to protect you from acquiring infections in the hospital, and we ask that you wear a mask when leaving your hospital room. Most important for good care is good communication. Do not be afraid to ask questions and make your concerns known. Remember that you are the center of a team, and you must communicate with everyone involved with your care — nurses, doctors, respiratory therapists, dietitians, social workers, and other staff. Be your own advocate.

Discharge Planning

If you will be going home on intravenous antibiotics, the staff at the hospital will arrange for a home infusion company and a nursing company to provide your antibiotics, equipment, and care. The home nurse will arrange to come to your home and give you any needed instruction as soon as you are discharged, then will come back at least weekly to obtain blood work if ordered and to change your IV dressing. If home supplemental oxygen is needed, the hospital staff will also arrange for it to be delivered to your home and a therapist to teach you how to use it safely. Before going home, make sure that you have enough medications. If not, they can be supplied at discharge.

Our Commitment

The Adult Program of the Cystic Fibrosis Center of UPMC is proud of its experienced team of dedicated CF professionals, and along with the staff of UPMC Presbyterian, is committed to provide you with the best care possible. Quality improvement and research are part of our mission to fight CF, and we encourage you to be an active participant in your health care and in our research and quality improvement initiatives. Together, we can improve the quality and survival of people with CF, and hopefully one day cure CF.

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For more information

About CF, the CF Foundation, research studies and news about CF, please frequently visit:

cff.org

medlineplus.gov/cysticfibrosis

cff.org/Life-With-CF/Treatments-and Therapies/Lung-Transplantation

upmc.com/lungtransplant

MAILING ADDRESS
Antonio J. and Janet Palumbo Cystic Fibrosis Center
UPMC Children's Hospital of Pittsburgh
3rd Floor, Administrative Office Building
4401 Penn Avenue
Pittsburgh, PA 15224
412-692-5630

CLINIC ADDRESS
UPMC Comprehensive Lung Center
Falk Medical Building, Fourth Floor
3601 Fifth Avenue
Pittsburgh, PA 15213
412-648-6161

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