Welcome to the Marie & Raymond Beauregard Adult CF Center at Hartford Hospital. Please visit our website at: https://hartfordhospital.org/services/cystic-fibrosis-center to keep up to date with current practices and how to prepare for clinic visits.

THE CYSTIC FIBROSIS FOUNDATION CARE MODEL REQUIRES

- Seeing every cystic fibrosis patient four times per year
- Obtaining a full set of lab work once a year
- Liver function tests every 3 months for one year after starting any gene specific therapy (modulator), such as trikafta, and yearly thereafter
- CF respiratory cultures quarterly
- Chest X-ray every 2-4 years
- PFTs (spirometry) at minimum twice yearly in person (at every clinic visit)
- DEXA (bone density scan) at age 18 and repeat every 1-5 years based on results
- Colonoscopy starting at age 40 and then every 5 years (CF poses a greater risk of colorectal cancer than the general population)
- Annual mental health screening
- Annual health related social needs screening

CLINIC CARE AT OUR CENTER

Follow-up visits are important for your health. A patient who does not return for follow-up visits, is out of date with laboratory and radiology tests, or does not follow the treatment plan may not have good health outcomes.

We offer pharmacy liaison assistance, respiratory education, social work/mental health counseling, and dietitian counseling visits outside of clinic visits either virtually or in-person upon request.

We ask all of our patients to be on time, wear a mask, and reach out to us with any questions or concerns.

We will follow the above CFF guidelines and will continue to provide a hybrid model of care, which requires at least two in person routine visits per year and allows for two routine visits per year virtually, if you meet the virtual criteria. You may choose to do more in-person visits if you would like, however, we do not plan on scheduling more than two routine virtual visits per patient.
APPOINTMENT CONFIRMATION

In an effort to best accommodate our CF community, please confirm your appointment by noon (12:00pm) on the Friday prior to your appointment. This allows us time to reach out to others who are on our cancellation list or need a hospital follow-up appointment. If we do not hear from you by then, your appointment will be canceled and you will need to contact us to reschedule:

• You can confirm by:
  o Replying to our confirmation email
  o Replying to the Upfront MyChart text message
  o Replying to the Upfront MyChart email
  o Calling the CF Clinic main line (860-972-4644)

LATE/MISSED APPOINTMENTS/LATE CANCELLATIONS

• Please call if you are running late. Any patient arriving 15 minutes later than the planned time is considered a “late arrival” and will be asked to reschedule their visit.

• Any planned visit that you do not attend or cancel with less than 24 hours notice is considered a “no show.” The clinic may decide that they can no longer provide medication refills or care for patients who have 3 or more “no shows” in one calendar year. If you are having challenges attending clinic for any reason, please reach out to our social worker for assistance.

MEDICATION REFILLS

• Please contact our pharmacy liaison at least one week prior to needing a refill to avoid gaps in care.

• Medication refills will only be provided to patients who are up to date with their yearly labs and are maintaining routine CF clinic visits.

• Trikafta, symdeko, and kalydeco will only be refilled at in-person visits.

• If you have not been seen in-person in more than 6 months, a one-time refill will be provided after you have scheduled an in-person clinic appointment. If you have not been seen in-person in more than 9 months and are not current on your lab work, we will not be able to send in further refills or sign forms for patient or prescription assistance until you are seen.

• If you have not been seen in-person for more than one year, you will receive a registered letter with options for next steps for care.

5.7.24 MRBAadultCFCenter
INFECTION PREVENTION:

- For everyone’s safety, please call us prior to your appointment if you are sick. Anyone who tests positive for any respiratory virus (flu, RSV, COVID), has a fever, or any NEW upper respiratory symptoms such as congestion or cough prior to their in-person clinic visit will be changed to a virtual visit if possible or rescheduled if necessary.

- Anyone who arrives to clinic sick with active symptoms or fever will not be able to participate in pfts or sputum samples, however, will be able to see the team.

VIRTUAL/TELEHEALTH VISITS

Criteria:

- Must have a signed virtual consent form on file. Please ask MA for assistance.
- Must have a working home spirometer
- Clinic FeV1 must be above or equal to 55%
- No history of no shows, last minute, or frequent cancellation of appointments
- Up to date with labs, radiology
- Must reside in the state of CT

Reminders:

- Please ensure your My Chart is active and that you have the zoom app downloaded on your device of choice.
- Please be available by phone 15 minutes prior to your scheduled appointment time so our medical assistant can call you for the check in/screening.
- Please find a quiet, private space where you can visit with the CF team without distractions. (i.e. not driving, in a store, or other public place)

HOME SPIROMETER

- You must have a working home spirometer device that you use on a regular basis in order to participate in a virtual visit.
- Please send a screen shot of your FeV1 performed the day of or the day before your virtual or in-person visit OR bring your clean home spirometer to the visit ready to use.
- If using your spirometer during your visit, please ensure that the batteries are working and that your device is paired with the app PRIOR to your appointment. (i.e. Spirobank uses the Breath Easy app)
**PRIMARY CARE PHYSICIANS**

- Please make sure that you have a PCP, as the CF providers cannot serve as your primary care physician.
- If you would like a PCP in the Hartford HealthCare network, go to [www.hartfordhealthcare.org](http://www.hartfordhealthcare.org) and click on find a doctor, find by specialty, primary care.
- Please provide your PCP information when you check in for your appointment.

**FLU and COVID VACCINES**

- Vaccines will not be available at CF Clinic.
- We strongly encourage you to get the both the flu and COVID vaccine.
- You can receive your vaccines from your PCP, local pharmacy, work or school if they offer it.

**CONTACT INFORMATION AND INSURANCE**

- Please make sure that we have all up to date contact information. (email, address, phone)
- Please provide any insurance updates as soon as possible to avoid gaps in refills, incorrect billing, etc.
- Please bring new insurance cards to your visit.
- Please alert us if your insurance requires a prior authorization for a visit.

**EXPERIENCE OF CARE (XoC) SURVEY**

Our center participates in the XoC survey. The XoC is an anonymous, short and easy to take survey that asks about in-person and virtual care experiences. The data/comments captured will help our team to better partner, build trust, and form positive relationships with our CF community. Creating a better care experience is important to all of us. Your voice is important and will help us make changes to improve the care that you receive!

At every CF visit you will have the opportunity to scan a QR code to take the survey. It takes less than 5 minutes to complete. We ask that you please take the survey at the end of your visit prior to leaving clinic so that your clinic experience is fresh in your mind.

**WE HEARD YOU!** Patient comments in XoC resulted in the following:

- Changes to clinic flow pre and post pandemic
- Changes to improve scheduling and confirmation process
- Creation of our own website
- Better packaging of equipment