

**The Cystic Fibrosis Affiliate Center of the Hudson Valley**

**Annual Care Planner**

**Age: 20 years and older**

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## CYSTIC FIBROSIS ANNUAL CARE RECOMMENDATIONS

Year: \_\_\_\_\_

Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

### Things to do:

- Annual lab work
- Annual oral glucose tolerance test (if applicable)
- DXA scan (if applicable)
- Annual pulmonary function test
- Annual chest X-Ray
- Annual acid fast bacillus (if applicable)
- Sputum cultures (4 per year)
- Annual visit with Nutritionist/Dietitian
- Annual visit with Respiratory Therapist
- Annual screen for depression & anxiety (if applicable)
- Annual visit with Social Worker/Mental Health Coordinator
- Complete the Patient Annual Demographic Form
- 4 spirometer readings per year (in-office or with home spirometer)
- Abdominal Ultrasound if > 3 years old
- Colorectal screen if > 40 years old or otherwise indicate
- Cataract Screening (if applicable)

Keep track of your progress below!

Date of Visit	BMI	FEV1	Culture Done

**CFF ANNUAL FORM**  
**To be completed by patient/parent**  
**Date: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_**

<b>YOUR NAME:</b>	
<b>DATE OF BIRTH:</b>	<b>ZIP CODE:</b>
<b>EMAIL ADDRESS:</b>	
<b>INSURANCE:</b>	
<b>What type of Insurance do you have?</b> <input type="checkbox"/> Private <input type="checkbox"/> Medicare <input type="checkbox"/> Medicaid <input type="checkbox"/> State special needs program <input type="checkbox"/> TriCare/Military <input type="checkbox"/> Indian Health Service <input type="checkbox"/> Other: _____ <input type="checkbox"/> No insurance	
<b>Are you under a PARENT'S INSURANCE?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No	
<b>Do you receive ASSISTANCE FROM A PATIENT ASSISTANCE PROGRAM?</b> <input type="checkbox"/> Yes <input type="checkbox"/> No	
<b>DEMOGRAPHICS:</b>	
<b>BIOLOGICAL SEX AT BIRTH:</b> <input type="checkbox"/> Male <input type="checkbox"/> Female	
<b>RACE/ETHNICITY:</b> <input type="checkbox"/> Decline to answer  <input type="checkbox"/> White <input type="checkbox"/> Black/African American <input type="checkbox"/> Asian <input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Native Hawaiian or Other Pacific Islander <input type="checkbox"/> Some other race <input type="checkbox"/> Two or more races: select all that apply <input type="checkbox"/> White <input type="checkbox"/> Black/African American <input type="checkbox"/> Asian <input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Native Hawaiian or Other Pacific Islander	
<input type="checkbox"/> Hispanic Origin: <input type="checkbox"/> Yes <input type="checkbox"/> No	
<b>MARITAL STATUS (Age 18 or older):</b> <input type="checkbox"/> Single <input type="checkbox"/> Living together <input type="checkbox"/> Married <input type="checkbox"/> Separated <input type="checkbox"/> Divorced <input type="checkbox"/> Widowed <input type="checkbox"/> Decline to answer	
<b>EMPLOYMENT (Age 18 or older):</b> <input type="checkbox"/> Part Time <input type="checkbox"/> Full Time Homemaker <input type="checkbox"/> Full Time Employment <input type="checkbox"/> Unemployed <input type="checkbox"/> Student <input type="checkbox"/> Disabled <input type="checkbox"/> Retired <input type="checkbox"/> Decline to answer	

**EDUCATION LEVEL:**PATIENT (You):

less than high school  High school  Some College  College  Master  Doctorate  
 Decline to answer

Patient's Father:

less than high school  High school  Some College  College  Master  Doctorate  
 Decline to answer

Patient's Mother:

less than high school  High school  Some College  College  Master  Doctorate  
 Decline to answer

Patient's Spouse:

less than high school  High school  Some College  College  Master  Doctorate  
 Decline to answer

**How many people are in your household, including yourself?** \_\_\_\_\_  Decline to answer

**What is your estimated ANNUAL HOUSEHOLD INCOME?**

\$ \_\_\_\_\_  Decline to answer

**SMOKING**

Did you smoke cigarettes?

No  
 Yes, less than 1 pack per day  
 Yes, 1 or more pack per day  
 decline to answer  
 Not applicable

Does anyone in your household smoke cigarettes?  Yes  No  Decline to answer

How often are you exposed to secondhand smoke?

Never  
 Daily  
 several times per week  
 several times per month or less  
 declined to answer  
 Unknown

**VAPING**

Did you use electronic cigarettes (vaping)?  Yes  No  Decline to answer

How often did you vape?  Everyday  Some days  Not at all  Decline to answer

**IMMUNIZATION**

Did you receive the influenza vaccine this year?  Yes  No  Decline to answer

Did you receive COVID vaccine?  Yes  No  Decline to answer

**PULMONARY**Do you use OXYGEN?  Yes  NoIf YES:  Continuous  Nocturnal and/or with exertion  During exacerbation  As neededDo you use any NON-INVASIVE VENT? (assisted breathing, BiPap, CPAP, etc):  Yes  NoDid you have a CHEST X-RAY this year?  Yes  No**EYE CARE**Did you get checked for cataracts this year?  Yes  No  Unknown

If you have diabetes, did you have a retinal exam done by an ophthalmologist?

 Yes  No  Unknown  Not applicable**PREGNANCY:** Not applicableAre you or were you PREGNANT this year?  Yes  No  Decline to answer

If YES, date of last LMP: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

If YES, outcome of pregnancy:

 Live  stillbirth  spontaneous abortion  therapeutic abortion  undelivered decline to answer

Date of outcome: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

**IF AGE 2 YEAR or LESS:** Not applicableDid your child attend DAYCARE this year?  Yes  No  UnknownDid your family receive genetic counseling this year?  Yes  No  UnknownWas your child given SYNAGIS this season (Sept - Jan)?  Yes  No  UnknownPlease return completed pediatric patient forms to:

New York Medical College  
 Attn: Boston Children's Health Physicians  
 Dr. Elizabeth de la Riva-Velasco  
 40 Sunshine Cottage Rd  
 Skyline 1NE29  
 Valhalla, NY10595  
 Fax: (914)614-4261

Please return completed adult patient forms to:

Dr. Timothy Collins  
 21 Reade Place, suite 1000  
 Poughkeepsie, NY 12601

CF Affiliate HVNY 1.26

**Patient Health Questionnaire and General Anxiety Disorder  
(PHQ-9 and GAD-7)**

Date \_\_\_\_\_ Patient Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

**Over the last 2 weeks, how often have you been bothered by any of the following problems? Please circle your answers.**

PHQ-9	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things.	0	1	2	3
2. Feeling down, depressed, or hopeless.	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much.	0	1	2	3
4. Feeling tired or having little energy.	0	1	2	3
5. Poor appetite or overeating.	0	1	2	3
6. Feeling bad about yourself – or that you are a failure or have let yourself or your family down.	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television.	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual.	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting <u>yourself in some way</u> .	0	1	2	3
<b>Add the score for each column</b>				

**Total Score (add your column scores): \_\_\_\_\_**

If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people? (Circle one)

**Not difficult at all**

**Somewhat difficult**

**Very Difficult**

**Extremely Difficult**

**Over the last 2 weeks, how often have you been bothered by any of the following problems? Please circle your answers.**

<b>GAD-7</b>	<b>Not at all sure</b>	<b>Several days</b>	<b>Over half the days</b>	<b>Nearly every day</b>
1. Feeling nervous, anxious, or on edge.	0	1	2	3
2. Not being able to stop or control worrying.	0	1	2	3
3. Worrying too much about different things.	0	1	2	3
4. Trouble relaxing.	0	1	2	3
5. Being so restless that it's hard to sit still.	0	1	2	3
6. Becoming easily annoyed or irritable.	0	1	2	3
7. Feeling afraid as if something awful might happen.	0	1	2	3
<b><i>Add the score for each column</i></b>				

**Total Score (add your column scores): \_\_\_\_\_**

If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people? (Circle one)

**Not difficult at all      Somewhat difficult      Very Difficult      Extremely Difficult**

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**CF ANNUAL NUTRITION SCREEN  
ADULTS (≥ 20 years old)**

**Name** \_\_\_\_\_ **Date** \_\_\_\_\_

**TO BE COMPLETED BY PATIENT:**

1. Have you had any bone fractures, broken bones, or falls in the past year?

Yes, Explain: \_\_\_\_\_  
 No

2. Have you noticed excessive or increased bruising in the past year?

Yes, Explain: \_\_\_\_\_  
 No

3. Have you experienced any of the following changes in bowel function in the last 6 months? Indicate all that apply:

Increase frequency  
 Decreased frequency  
 Loose stools  
 Hard stools  
 Abnormal/Foul smelling stool  
 Color changes in stool  
 Other \_\_\_\_\_  
 None

4. There is not enough food in the home to feed yourself and your family

Often true \_\_\_\_ Sometimes true \_\_\_\_ Never True \_\_\_\_

5. You had difficulty affording supplements, vitamins, formula, or tube feeding supplies

Often true \_\_\_\_ Sometimes true \_\_\_\_ Never True \_\_\_\_

6. Does your weight affect the way you feel about yourself?

Often \_\_\_\_ Sometimes \_\_\_\_ Never \_\_\_\_

7. Do you worry you have lost control over how much you eat?

Often \_\_\_\_ Sometimes \_\_\_\_ Never \_\_\_\_

8. Please indicate which of the following are true for you in the last 6 months:

Weight Gain	Weight Loss
<input type="checkbox"/> 0-5 pounds	<input type="checkbox"/> 0-5 pounds
<input type="checkbox"/> 5-10 pounds	<input type="checkbox"/> 5-10 pounds
<input type="checkbox"/> >10 pounds	<input type="checkbox"/> > 10 pounds
<input type="checkbox"/> Unknown	
<input type="checkbox"/> No weight change	

9. Please indicate which of the following are true for you in the last week:

- Eating more than usual
- Eating less than usual
- Eating the same as usual

10. Please indicate which of the following are true for you in the last month:

- Increased energy, activity, or exercise
- Decreased energy, activity, or exercise
- No changes in energy, activity, or exercise

Thank you for completing this survey!

If you have any questions, concerns, or topics you'd like to discuss with your dietitian please list them below or call 845-214-1850 to make an appointment in person or via telehealth!

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## TRANSITIONING YOUR CARE

The CF Foundation has made tremendous progress in supporting research and development of medications and therapies which has extended the life expectancy of those living with CF. Today, 60% of people living with CF are adults. The CF Affiliate Center of the Hudson Valley provides care for both pediatric and adult patients.

The CF Affiliate Center of the Hudson Valley is committed to provide you with the very best care. Adults living with CF have medical conditions and needs that are best cared for by an adult physician. With this in mind, after your 16th birthday, we are encouraging you to transition your CF care to a CF adult pulmonologist of your choice so that your unique needs will be met. If you decide to stay with our Center, you will still have the same Dietitian and Social Worker/Mental Health Coordinator, however, you will transition to the Respiratory Therapist at the adult center. If you need admission to the hospital you would be admitted to Vassar Brothers Medical Center where the adult pulmonologists care for their patients. There will be a comprehensive hand off between the pediatric and adult physicians so your specific needs will continue to be met.

The first step is to schedule your first appointment with the adult pulmonologist. When you have that date, schedule a final appointment with your pediatric pulmonologist (this should be 2-4 weeks prior to your adult appointment) who will address any current concerns. Then your pediatric physician will call the adult pulmonologist to do the comprehensive handoff and your medical records forwarded. After your first adult physician visit you will be under their care and the transition will be complete.

We understand this is a difficult change but we are here to support you through it. Thank you for trusting us with your care.

All the best,

The CF Affiliate Team

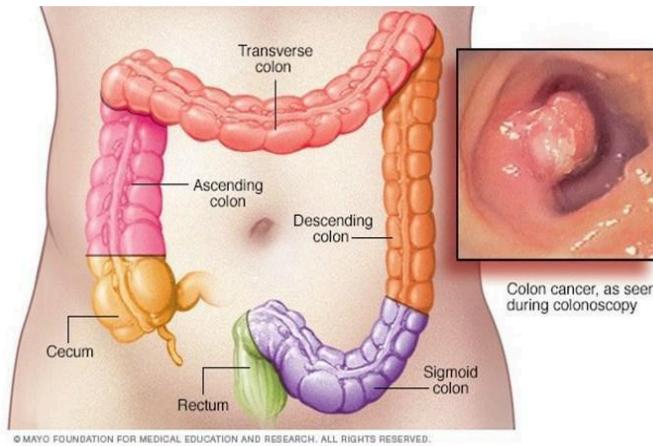
## What you need to know about Colorectal Cancer and Colonoscopies

The average lifetime risk for colorectal cancer is approximately 5 percent, but for adults with cystic fibrosis, this risk is 5–10 times higher and warrants screening starting at 40 years of age.

Meanwhile, those who receive a solid organ transplant are 20 times more likely to develop colorectal cancer and often need to begin screening even earlier, at age 30, depending on when the transplant occurs.

A colonoscopy is the **only** preventive screening known to be effective for people with CF. If any polyps are found, they can be removed right away, before they become cancer or — if they are cancerous — when it's at its earliest and most treatable stage. A colonoscopy is a procedure that uses a long, flexible tube about the width of a finger. This tube is attached to a video camera to view your colon and rectum. If there is anything that looks abnormal, the gastroenterologist or colonoscopist can pass small surgical tools through the tube to take tissue samples for analysis and remove any polyps.

The goal of a colonoscopy is to identify and remove as many polyps as possible.



You need to prep for the colonoscopy differently from a person who doesn't have CF. The thick, sticky intestinal mucus that people with CF tend to have makes it more difficult to clean out your colon, so your bowel preparation will be more intensive.

Although the colonoscopy itself will be performed by a gastroenterologist or colonoscopist who is a clinical specialist outside of your CF care team, let your CF team know when you are planning to have a colonoscopy and encourage open communication with the physician performing your colonoscopy. Working closely with your care team and the specialist will help you coordinate your care by addressing your individual CF-specific needs.

Questions you may want to discuss with your CF physician:

- Am I healthy enough to undergo this exam? (For example, general anesthesia for elective procedures such as a screening colonoscopy may not be recommended for people with CF who have lowered lung function.)
- How should we approach the sedation for the procedure? (Factors such as emotional wellness, the use of opiate pain medication, and reduced lung function may warrant a different or deeper level of pre-exam sedation.)
- Should we meet with a gastroenterologist to discuss my screening plan? (As specialists in digestive conditions, a gastroenterologist may be able to provide greater detail for questions about screening or sedation.)
- What if I have CF-related diabetes or hypoglycemia? How might these factors change how I prepare for the exam?

Reach out to your CF team Social Worker or physician if you need assistance with insurance issues, transportation or coordination of care.

# Cystic Fibrosis and the Liver

## Liver and Spleen Ultrasound Screening

The liver is one of the vital organs of the body. It has over 500 functions that keep the body working properly. These liver functions include:

- Making bile which helps break down fats during digestion. The bile is stored in the gallbladder.
- Converting excess blood sugar (glucose) into glycogen for storage to be used as needed, helping to keep blood sugar balanced.
- Regulating blood levels of amino acids, which are the building blocks of proteins.
- Regulating blood clotting to prevent abnormal bleeding or clotting.
- Processing hemoglobin in red blood cells for its iron content (the liver stores iron).
- Clearing bilirubin from processed red blood cells. Bilirubin build-up turns the skin and eyes yellow.
- Making immune factors to fight infection and removing bacteria from the bloodstream.



People with cystic fibrosis may develop liver problems that keep the liver from performing its many functions properly. For example, in people with cystic fibrosis, the bile can become so thick that it makes gallstones. CF can also cause the liver to become stiff and raises the blood pressure within the liver and the spleen.

The best ways to detect any changes to liver health are:

- Regular doctors visits for physical exams.
- Blood tests to screen for any changes in liver functions.
- Ultrasound to screen for any changes in the liver, gallbladder and spleen.

The ultrasound of liver, gallbladder and spleen does not involve any radiation and does not require any special preparation. The Cystic Fibrosis Foundation recommends a screening ultrasound of the liver, gallbladder and spleen every 2 years for children from age 3 to 18 years. Adults with CF should have at least one baseline screening ultrasound.

A prescription for screening ultrasound of liver, gallbladder and spleen will be provided by your CF doctor. The ultrasound can be scheduled at any of the following imaging facilities:

Vassar Brothers Medical Center	Scheduling: 845-790-8855
WMC-Mid-Hudson Regional	Scheduling: 845-431-8776
WMC-Valhalla Advanced Imaging Center	Scheduling: 914-493-2500
MD Imaging	Scheduling: 845-471-2848

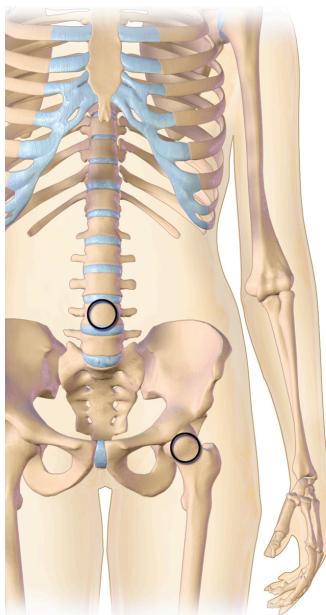
For additional information on CF associated liver disease, speak with your CF physician or visit CFF.org.

# Cystic Fibrosis (CF) and Bone Health

## How Does CF Affect the Health of Your Bones?

Since people with CF can have low bone minerals, they are at risk for osteopenia and osteoporosis. In CF, it can happen at any age but becomes more common in the later teen and adult years. This causes brittle bones and can lead to pathologic bone fractures.

**Osteopenia:** Bones do not have enough minerals



Normal bone



Osteoporosis

**Osteoporosis:** Holes in the bones are too big

**Pathologic Bone Fractures:** A break in the bone that was not caused by force or impact.

### Contributing Factors to Bone Disease:

- Low BMI or weight
- Pancreatic insufficiency
- Calcium, Vitamins D, or Vitamin K deficiencies
- Lung infections and low FEV1
- Steroid use
- Physical inactivity
- Advancing age
- History of fracture(s)
- Delayed onset of puberty

## How to Keep Your Bones Healthy:

Maintain healthy BMI & weight	Maintain normal calcium, vitamin D, and vitamin K levels	Incorporate weight bearing exercises
Follow up with your registered dietitian annually	Complete routine lab work and recommended DEXA scans (bone density scans)	Complete quarterly physician visits

# What is a DEXA Scan?

DEXA (or DXA) stands for Dual-Energy X-Ray Absorptiometry. This radiology test uses a small amount of x-ray to look at the mass and density of bones.



## Why Do I Need a DEXA Scan?

DEXA scans are used for screening purposes to evaluate your bone health and bone density. For people with CF, it is recommended that they have an initial scan at age 18, unless otherwise recommended by their physician.

## How Long Does the Scan Take?

20 minutes.

## Do I have to Prepare for the Test?

No. There is no preparation needed.

## Where can I get the Scan?

**Vassar Brothers Medical Center**

**Scheduling: 845-790-8855**

**WMC-Mid-Hudson Regional**

**Scheduling: 845-431-8776**

**WMC-Valhalla Advanced Imaging Center**

**Scheduling: 914-493-2500**

**MD Imaging**

**Scheduling: 845-471-2848**

# What Happens with My DEXA Scan Result?

Your CF physician or dietitian will review results with you and provide follow up recommendations and/or interventions.

# CFTR Modulators and the Eyes

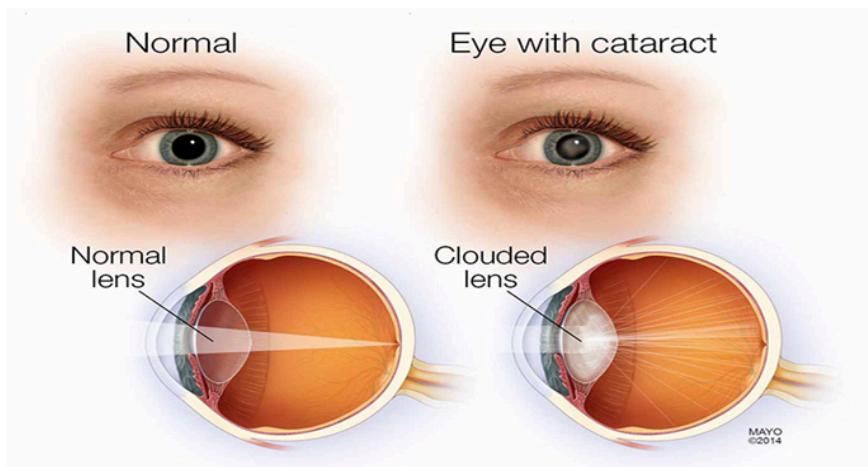
## What are CFTR Modulators?

Cystic fibrosis transmembrane conductance regulator (CFTR) modulators are medications designed to correct the malfunctioning protein made by the mutated CFTR gene. Because cystic fibrosis (CF) can be caused by many different CFTR mutations, there are currently five CFTR modulators for people with certain mutations:

- Alfytrek (vanzacaftor/tezacaftor/deutivacaftor)
- Trikafta (elexacaftor/tezacaftor/ivacaftor)
- Symdeko (tezacaftor/ivacaftor)
- Orkambi (lumacaftor/ivacaftor)
- Kalydeco (ivacaftor)

## What are Cataracts and What are the Symptoms?

Cataracts are a clouding of the lens of the eye, which is normally clear. This can make it more difficult to see over time. Some symptoms include sensitivity to bright lights, having difficulty seeing at night, blurry vision, double vision, seeing bright colors as faded or yellowed.



## How can CFTR Modulators affect Cataracts?

Most cataracts develop due to aging, but CFTR modulators can also cause cataracts. The exact way of how CFTR modulators cause cataracts is unknown at this time. Studies have shown that a small percentage of patients on ivacaftor can develop cataracts within a few years of starting treatment. This is known as ivacaftor-associated or ivacaftor-induced cataracts. As more patients get on modulator treatments, the association between modulators and cataracts will become more clear.

## How are Cataracts Diagnosed?

Cataracts are diagnosed with a comprehensive eye exam that looks for any abnormalities to the lens and other parts of the eyes.

## I am on a CFTR Modulator. When should I get checked for Cataracts?

Ideally, an exam to screen for cataracts should be done prior to starting CFTR modulator therapy. Once on a CFTR modulator, a yearly eye exam is recommended. Talk to your CF physician about getting a referral to an ophthalmologist (a medical doctor who specializes in care and treatment of the eyes) if you are already on a CFTR modulator and have not had an eye exam, or if you are eligible for a CFTR modulator and are considering starting treatment.

### References

[CFTR Modulator Therapies | Cystic Fibrosis Foundation](#)

[What Are Cataracts? - American Academy of Ophthalmology](#)

[Ivacaftor-induced Cataracts in Patients with Cystic Fibrosis - EyeWiki](#)

## Appointment Directory

### Laboratory Services:

- Vassar Diagnostics (845)790-8855 45 Reade Pl., Poughkeepsie, NY 12601
- WMC - MHRH Lab (845)483-5917 1 Webster Ave., Suite 204, Poughkeepsie, NY 12601

### Diagnostic Imaging Centers:

- Vassar Brothers Medical Center (845)790-8855 45 Reade Pl., Poughkeepsie, NY 12601
- WMC - MHRH Radiology (845)431-8776 241 North Rd., Poughkeepsie, NY 12601

### Social Worker & Mental Health Coordinator Appointments (Telehealth available)

- Addison Forgit (914)504-0162 19 Bradhurst Ave, Hawthorne, NY 10532
- Caitlin Lennon (914)504-0166 19 Bradhurst Ave, Hawthorne, NY 10532

### Respiratory Appointments (Telehealth available)

- Claudia Salazar, BSRT, RRT-ACCS
  - Telehealth: Email [claudia.salazar@nuvancehealth.org](mailto:claudia.salazar@nuvancehealth.org)
  - In-Person: Vassar Brothers Medical Center, 45 Reade Pl., Poughkeepsie, NY 12601
    - (845)790-8855 Central Scheduling

### Dietitian Appointments (Telehealth available)

- Michelle Triolo 845-437-3026 45 Reade Pl., Poughkeepsie, NY 12601
- Lauren Jackson 845-214-1850 Vassar Brothers Medical Center  
21 Reade Pl., Poughkeepsie, NY 12601

### Pulmonary Function Tests

- Vassar Diagnostics (845)790-8855 45 Reade Pl., Poughkeepsie, NY 12601
- Westchester (914)493-5491 19 Bradhurst Ave, Hawthorne, NY 10532
- Middletown (845)281-7657 212 Crystal Run Rd, Middletown, NY 10940