

# **MULTIDISCIPLINARY AMYLOIDOSIS CLINIC**

## **BEFORE YOUR APPOINTMENT**

You may eat and drink normally before and after your investigations unless you have been instructed otherwise. You may bring a caregiver with you to your appointment (preferably only one person), however, we would ask that you avoid bringing babies/children when possible.

## **ATTIRE**

Please wear comfortable shoes and clothing, allowing for the top and bottom half of the clothing to be removed separately. The wearing of tights and clothes with metallic objects is not recommended. Please do not apply body creams/lotions (except to the face) on the day of the appointment until after the echocardiogram. It is also important to avoid wearing nail polish as this may create difficulties in obtaining certain key measurements with our equipment. Patients having MRI scans or CT will be asked to change out of their clothes and into a hospital gown, and remove all metallic objects such as jewelry, belts, keys, coins, etc.

## **REFERRING DOCTORS' DETAILS**

Please update as necessary the contact details for all your doctors (PCP and consultants) currently treating you on the enclosed sheet along with fax numbers. Please give this to the receptionist on your arrival at the Amyloidosis Clinic.

## **24 HOUR URINE COLLECTION**

A 24-hour urine collection for protein analysis may be required. If so, we will include instructions at the time of your appointment. We will provide you with a container at the time of your appointment.

## **MEDICATIONS**

Continue taking your current medications. Please bring a list of medications/dosages and carry it with you at all times during your visit.

## **PREGNANCY**

We **cannot** perform X- rays if you are, or suspect you are pregnant. If you are a female patient between the ages of 12-55 years old you may be asked to complete a pregnancy test.

## **WHAT TO EXPECT AT YOUR VISIT**

**Please make every effort to arrive 15 minutes before your start time. The start time of your visit will be communicated to you the Friday before your scheduled visit.**

Below is a summary of the procedures that we routinely carry out – however, it is important to note that not all patients require every one of these procedures or tests.

### **1. Vital signs and ECG**

- a. Height, weight, blood pressure, heart rate, and oxygen saturation
- b. Orthostatic vital signs in lying, sitting and standing position
- c. Electrocardiogram

### **2. Blood tests**

The phlebotomist will use a small needle to draw blood for a test.

### **3. Echocardiogram**

The echocardiogram is an ultrasound of the heart. It takes approximately 60 minutes and is used to evaluate cardiac structure and function.

### **4. X-ray and CT scan/MRI**

You will undergo an X-ray of the chest. Other scans and MRI are performed based on clinical assessment.

### **5. Tc 99mPYP scan**

This is a non-invasive scan of the heart used to diagnosis transthyretin amyloidosis

### **6. Pulmonary function test**

This test is to check your lungs. Lungs and functional status that is usually only completed on new patients or patients with pulmonary amyloidosis. Testing consists of two parts including an exercise portion.

### **7. Bone Marrow Biopsy**

This test is only performed on patients with a light chain or suspected light chain amyloidosis if you had a bone marrow recently please make sure our office has a copy of the results

### **8. Consultations**

Your case will be discussed at our multi-disciplinary meeting with all our specialists. Please be prepared to be flexible with your time throughout your visit here, as delays or changes can occur. All patients are seen by an amyloidosis

internist on Monday, subsequent specialist appointments are arranged at the discretion of our Amyloidosis Center Director or added on as needed. The most common specialties are hematology, nephrology, pulmonology, cardiology, and neurology although others are included if needed.

#### **9. Support group**

The amyloidosis support group is held every Tuesday, participation is voluntary.

#### **10. Meeting with Amyloidosis Center Administrative staff**

Our administrative coordinator will meet with you during your visit. A photo will be taken after your consent and you also will be asked to sign consent for blood, urine and clinical data repository.

**You will be given an itinerary when you first arrive at the clinic for your evaluation. Please be flexible and available at all times. The clinic opens at 7:30 am and closes at 5:00 pm. Please provide your cell phone number at the time of check-in. Please remember to fill out all forms during your visit and return them to the clinic staff.**