

Hypertrophic Cardiomyopathy Association



The HCMA is issuing this as a guidance document regarding the COVID-19 virus.

We are currently experiencing an unprecedented medical phenomena in our country. Concerns over the coronavirus – COVID-19 have impacted thousands of meetings and activities throughout the world. The HCMA has taken action to evaluate what the appropriate response is for our community under these unprecedented circumstances. We encourage all patients, families and healthcare providers to keep current on updates from the CDC using this link: <https://www.cdc.gov/coronavirus/2019-ncov/index.html>. According to the CDC those over 60 and those with heart disease and chronic medical conditions are at higher risk of developing more serious illness. This applies to the HCM community.

The HCMA has made the following decisions regarding these upcoming events:

- The Patient Focused Drug Development meeting on April 27, 2020 will be postponed and an alternative date will be chosen shortly for this very important event.
- The May 17, 2020 NYU- HCM Strong Tour has been postponed we will be choosing an alternative date shortly
- Our San Francisco meeting scheduled for earlier in March was also postponed and again a new day will be chosen shortly.

As for recommendations for the HCM community HCMA CEO, Lisa Salberg has spent the day on the phone with representatives from many HCMA Recognized Centers of Excellence programs. We have spoken to representatives from the following institutions; Tufts Medical Center, UPMC, University of Pennsylvania, University of Texas Southwest, University of Virginia, Westchester Medical Center, Advocate Aurora St. Luke's, Cleveland Clinic, Mayo Clinic, NYU, St. Thomas Heart and Spectrum Health. In addition to those we have spoken to directly the HCMA conducted a conference call with additional Center of Excellence programs to solicit their input. We thank each and every one of you for your time and conversation today to help us organize a response that is intended to provide guidance to the HCM Community over the next 60 days. We will provide updates as they are warranted.

In these phone calls there was not 100% consensus on how these topics should be handled, but there was some very good dialogue and here is the general consensus as of March 11, 2020.

1. Patients traveling by air or train for elective myectomy or consultation may consider the following options over the next 60 days:
 - a. Contact your COE and inquire as to their recommendations for the region based on current COVID19 status if you should keep your appointment or change it.
 - b. Rescheduling these appointments until after this crisis has passed.
 - c. Telemedicine consults may be available and assist in decision making. Check with your Center for availability of Telemed or phone consults.
 - d. Patients driving to appointments including surgery should keep appointments.
2. Patients experiencing significant heart failure symptoms who are traveling to myectomy by plane or train may wish to spend additional time in their city of surgery after their procedure. These cases should be reviewed on a case by case basis and consideration should be given to the location the patient is traveling from and the length of travel time.
3. Any patient experiencing a change in symptom or in need of device replacement, device implant should communicate with their individual health care provider to identify the appropriate timing of the clinic visit or surgical date.
4. Patient with class 3 or 4 heart failure specifically those with depressed ejection fractions and those awaiting transplantation should be advised to stay close to home and minimize exposure in social gatherings.
5. All patients should be encouraged to practice good personal hygiene including frequent handwashing, use of disinfectants on all surfaces doorknobs and banisters.
6. In the event an HCM patient becomes positive for the virus they are advised to contact their HCM specialist immediately and coordinate care with their local physicians and HCM team.
7. Please follow the recommendations from your state and local government.

Amendment #1 3/12/2020 (omissions from original document, nothing above has been changed)

1. It is recommended that leisure travel is postponed (estimate 60 days)
2. Have your flu vaccine.

