

## Cardiovascular Screening for FDC Research Participants



Dear FDC Study Participant:

You have agreed to participate in the Familial Dilated Cardiomyopathy (FDC) Research Project because your relative(s) has/have a heart muscle condition called dilated cardiomyopathy (DCM) of unknown cause. With DCM, the heart becomes enlarged and weakens, causing the heart to pump less efficiently, which can cause problems such as fatigue, shortness of breath, ankle swelling, heart rhythm disorders, heart failure or sometimes may lead to sudden death. When the condition is diagnosed, treatment can begin to reduce the symptoms and ideally avoid serious consequences. Sometimes, people can have early signs of DCM with cardiac testing before they have symptoms, but early treatment will help.

When the cause of DCM is unknown in a person it is called idiopathic dilated cardiomyopathy (IDC). In about 1 in 4 (25%) of these families genetic cause can be found.

As a participant in our research study, we have asked you for the following:

- 1) **Blood draw:** Please have your blood drawn using the tubes we provided. The tubes should be labeled and shipped (according to the instructions we provided) to the FDC Research Project in Miami, FL. This blood draw can often be done at your doctor's office; however, this is for research only and therefore can be done as a courtesy, or, if you need to pay for this, the FDC Project will reimburse the cost if you provide us with a receipt.
- 2) **Cardiovascular screening:** The **physical exam** should include elements of an annual physical exam, including height, weight, blood pressure and pulse. This exam should be performed by an appropriate health care provider (physician, physician's assistant or nurse practitioner). The **electrocardiogram (EKG) and echocardiogram (echo)** can be done in your doctor's office or at a facility that your primary care doctor or cardiologist recommends. The research study cannot reimburse you for this screening; however, these procedures are often covered by health insurance. We have provided instructions for screening and information on insurance coverage in the attached letter for your physician. We will request copies of all test reports, your EKG and a copy (DVD) of your echo.

Please share this information and the letter "For Physicians" with your health care provider. If you or your health care providers have any questions, please feel free to call us at any time at 1-877-800-3430.

Sincerely,

The FDC Research Team

### Cardiovascular Division

#### Familial Dilated Cardiomyopathy Research Project

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