

The Familial Dilated Cardiomyopathy Research Project

At the Miller School of Medicine, University of Miami

Information for Patients & Families

This page provides information for individuals and families with dilated cardiomyopathy (DCM) that is known or suspected to be idiopathic and/or familial.

Background on DCM – addresses frequently asked questions about cardiomyopathy

The Genetics of DCM – provides essential genetic information and general comments on genetic testing

Screening recommendations – reviews key information for you and your family

Participation – invites you and your family to join this research effort

We hope you find this information useful. If you have questions that have not been addressed here but you would like to have added, please **contact us** . We are updating and improving this website continuously.

PLEASE NOTE: This information is provided as a service of our FDC research program. It is NOT intended to substitute for consultation with a licensed health care professional, nor does it address all physical and emotional issues that may arise with an FDC diagnosis.

Background on Dilated Cardiomyopathy, IDC and FDC

What is dilated cardiomyopathy? Cardiomyopathy means **heart muscle disease** ('cardio' = heart, 'myo' = muscle, and 'pathy' = disease). Many forms of cardiomyopathy exist, but by far the most common category is **dilated** (= enlarged) **cardiomyopathy** . The cardiac dilation, or heart enlargement, occurs because the heart muscle becomes weakened. The heart is a pump, and its job is to pump blood to the body. When the heart enlarges as a result of muscle weakening, the pumping action of the heart becomes weaker also. As a result, less blood than normal may be pumped to the body, especially during vigorous activity.

What is the most common cause of dilated cardiomyopathy? The most common cause (65-70%) of dilated cardiomyopathy in the US results from coronary heart disease, usually from a previous myocardial infarction ("heart attack"). A myocardial infarction occurs when the heart does not receive adequate blood and oxygen, usually when a cholesterol plaque ruptures in a coronary (heart) artery, blocking the flow of blood to the heart muscle. This condition is called **ischemia**. Prolonged ischemia results in the death of part of the heart muscle. When a large part of the heart muscle dies from a heart attack, in some patients the remaining heart muscle weakens and dilates over time. This type of cardiomyopathy is called **ischemic cardiomyopathy** (we do not study this).

What is idiopathic dilated cardiomyopathy? The next most common type (20-25%) of dilated cardiomyopathy is called **idiopathic dilated cardiomyopathy**, or **IDC**. Idiopathic means "cause is unknown." Thus, for a patient to have a formal diagnosis of IDC, other potential causes of heart muscle disease should have been excluded, as much as it is possible to do so. This could include coronary heart disease. Other potential, less common causes of dilated cardiomyopathy include excessive alcohol use, certain drugs such as Adriamycin used to treat cancers, problems with heart valves, viral infections, and other cardiac problems.

What is Familial Dilated Cardiomyopathy (FDC)? Idiopathic dilated cardiomyopathy that is inherited, or familial, is called **familial dilated cardiomyopathy**, or **FDC**. For many years, the familial form of idiopathic dilated cardiomyopathy was not well recognized. Even until the early 1990's, it was thought only about 1-2% of cases of IDC ran in families. In 1992, however, a U.S. study demonstrated that 20% of patients with IDC had first-degree family members (parents, siblings, or children) with a similar disease. Data published in 1998 from two European studies confirmed that 35-50% of cases of IDC were likely to be FDC, that is, inherited or familial. Thus, we now know that there are many families in which familial dilated cardiomyopathy occurs.

How is FDC diagnosed? A diagnosis of FDC can be made when IDC is identified in two or more members of the same family.

Why did it take so long to discover that IDC was familial? Part of the reason is that family members may have very different symptoms from one another, and they may develop these symptoms at different ages. Also, in some cases FDC causes affected individuals to die suddenly, and in years past this may have been attributed to a "heart attack" rather than to FDC. Finally, the right types of clinical studies were not done to carefully examine this issue until recently.

Why is this group studying FDC? Our group chose this area of research following the 1992 report (that 20% of patients with IDC had FDC) in an effort to identify the genes that cause FDC, to better understand how the disease progresses, and to eventually devise new therapies for cardiomyopathy and heart failure. It is our sincere hope that the information gained from studying individuals and families with FDC will lead to earlier diagnosis and better treatments for FDC, IDC, other forms of cardiomyopathy,

and heart failure in general. For more detailed information on our research efforts, please see the "**Our History**" or "**Our Publications**" pages.

What is heart failure? Heart failure, frequently called **congestive heart failure (CHF)**, describes a clinical syndrome in which the heart is not able to pump adequate amounts of blood to the body. Heart failure is not the heart "stopping suddenly" as the words imply. The most common symptoms of heart failure include shortness of breath with activity or exertion, edema (fluid collection) in the feet and legs, difficulty sleeping flat in bed (needing to prop oneself up on several pillows), and at times awakening in the middle of the night short of breath and needing to sit up to the edge of the bed for several minutes to catch one's breath.

Do IDC and FDC always lead to heart failure? IDC and FDC do not always lead to heart failure, although in their late stages most people with IDC or FDC begin to have some symptoms of heart failure.

What other symptoms does FDC cause? In addition to heart failure symptoms described above, FDC can also cause abnormal heart rhythm disturbances, or **arrhythmias**. In some families, arrhythmias are the first sign of FDC.

The normal heart regularly beats between 60-100 times per minute. In IDC/FDC, irregular and/or fast heart rhythms can occur. Some such rhythms cause **palpitations**. Palpitations are the sense of one's heart "skipping a beat," or beating too fast, or beating very hard, and can last from seconds to minutes, and even occasionally hours. With rapid heart rates, individuals may feel dizzy or lightheaded, or experience shortness of breath with minimal activity.

A more severe symptom is called **syncope**, which is the medical term for complete loss of consciousness. Other common terms used for syncope include "a blackout spell" or "a fainting spell." Because syncope may be caused by more dangerous arrhythmias, it *always requires immediate medical attention*.

Syncope which results from an arrhythmia that is accompanied by full cardiac arrest, also known as full cardiopulmonary arrest (loss of heart rate, blood pressure and breathing) is called **sudden death**, or **sudden cardiac death**. If someone suffers an episode of sudden cardiac death, the patient must undergo successful cardiopulmonary resuscitation (CPR) to survive, although in rare cases it is possible that the lethal arrhythmia may stop by itself and the patient may regain normal a normal heart rate, blood pressure and breathing. If a patient survives an episode of sudden cardiac death, emergency medical treatment is needed to evaluate, treat and prevent future episodes from occurring.

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The Genetics of Dilated Cardiomyopathy

How is FDC inherited? In most cases (90% of the time), FDC appears to be inherited as an autosomal dominant trait. This means that each child of a person with FDC has a 50% chance of inheriting the gene that causes FDC. See our newsletter article on **The Genetics of Dilated Cardiomyopathy** for background information about genetics and the genetic causes and inheritance of FDC.

Does the FDC gene cause the same symptoms and presentation in every family member?

No, the symptoms and presentation can vary considerably among members of the same family who have the same FDC gene. Also, the severity of the disease may vary quite a bit. For example, one gene carrier may live into old age with only a minor heart rhythm problem that hardly bothers them. Another gene carrier in the same family might have a sudden, severe onset of the disease at a young age, with episodes of syncope and/or sudden death, or may require heart transplant.

In addition, some individuals carry the gene but have no, or unnoticeable, cardiac symptoms. These "unaffected" gene carriers still have a 50/50 chance of passing on the gene to their offspring, who again could fall anywhere in the spectrum. Unfortunately, right now there is no way of knowing how, when or with which symptoms the disease will present, or begin, in a given family member. Therefore, if you have a family history of FDC, it is important to be aware of your own and your children's health. See your doctor if you are concerned that you are experiencing any of the symptoms of cardiomyopathy or heart failure that have been mentioned here.

Are there features of FDC that suggest one disease gene vs another? In general, no, the features of FDC from different genes in most cases have considerable overlap with one another for most patients and families, even though approximately 20 different genes have been suggested to cause FDC (in the For Professionals pages of this website, a compendium of the different genes that have been shown to cause FDC are provided in a GeneTable). The possible exception to this is the disease gene lamin A/C, which may cause from 5-10% of FDC. Lamin A/C cardiomyopathy commonly presents with prominent conduction system disease (disorders of the heart's electrical conduction system which causes a variety of arrhythmias), sometimes prior to the onset of dilated cardiomyopathy and heart failure.

Can a patient with FDC undergo genetic testing? Because of the many disease genes implicated in FDC, no comprehensive genetic test is available. However, as a first step, lamin A/C testing is now available, chosen in part because it causes FDC as commonly as any other FDC gene and because of its more distinctive clinical presentation.

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Screening Recommendations

If someone in my family has IDC, should I have any cardiovascular clinical testing or screening done? The FDC Project Group has recommended that family members of patients with idiopathic dilated cardiomyopathy (IDC) undergo clinical screening. This recommendation is based upon the knowledge that (1) FDC is present in 35-50% of families of patients diagnosed with IDC, and (2) effective treatment for IDC/FDC is available. This recommendation was initially published in September 1999 in a major US cardiology journal (specific reference can be found [here](#)), and a more recent review of the literature has reiterated this recommendation (specific reference can be found [here](#)). **What testing do you recommend for screening?** Comprehensive screening includes (1) a history and physical examination, (2) an electrocardiogram (EKG) and (3) an echocardiogram. These tests look for signs of the disease that may or may not be accompanied by symptoms.

Who should be screened in my family if I have a diagnosis of IDC? We recommend screening for FDC of parents, children, and siblings (i.e. first-degree relatives) of individuals with IDC. That is, if an individual is newly diagnosed with idiopathic dilated cardiomyopathy, we recommend screening of their first-degree relatives, regardless of whether those relatives are experiencing any symptoms.

If a diagnosis of FDC has been made in part of my family, should the entire family be screened for FDC? We do not have a definitive answer for this question, and we hope that our ongoing work will help us answer this important question in the future. However, based on our experience, we do offer the following recommendation for **stepwise screening**. We have published this recommendation in the medical literature.

What is stepwise screening? As stated above, to have established a diagnosis of FDC, at least two family members must have idiopathic dilated cardiomyopathy. We recommend **stepwise screening** of all first-degree relatives of these family members. **Stepwise screening** is progressive screening of an extended family of the first-degree relatives of those shown to be affected.

For example, if two brothers are diagnosed with IDC, the diagnosis of FDC can be established by definition (see "[How is FDC Diagnosed ?](#)" above). We would therefore recommend screening of the first-degree relatives of the two affected brothers. The brothers' first-degree relatives include their parents, their other brothers and sisters (siblings), and their children. Screening of these first-degree relatives is **step one** in stepwise screening. To take this example to **step two** , if the brothers' father is found to be affected with FDC, then we would recommend that the first-degree relatives of the affected father also be screened. The first-degree relatives of the father include his parents (the paternal grandparents of two sons with FDC), his brothers and sisters (the paternal aunts and uncles of two sons diagnosed with FDC), and his children (who have already been screened). This would be **step two** in a stepwise screening of this family. To continue the example, if in screening the first-degree relatives of the father, FDC is discovered in his sister, we would recommend screening of her (the father's sister's) first-degree relatives. This would be the **step three** in a stepwise screening of this

family. We would recommend continued stepwise screening until all first-degree relatives of those affected with FDC have been screened.

What are the recommendations for screening of more distantly related family members? At this time we have not given formal recommendations for screening of more distantly related individuals (for example, second or third degree relatives – aunts, uncles, cousins, grandparents/grandchildren) of those who are affected. However, it is important to note that **it is always appropriate to perform screening in any individual with cardiovascular symptoms who is part of a family with FDC.** In some families with particularly aggressive disease, it may be appropriate to screen these more distant relatives regardless of whether or not they have symptoms.

If my screening tests are all normal, when, if ever, do I need to be rescreened?

After an initial normal evaluation, it is difficult to make specific recommendations for how frequently follow-up screening should be performed. A single normal screening can be reassuring; however, it does not completely eliminate the possibility that disease could develop in the future. Therefore, it may not be unreasonable for first-degree relatives to have an EKG and echocardiogram every 3-5 years. Between screenings, it is important to be aware of one's cardiovascular health, and if anyone experiences cardiac symptoms (i.e. shortness of breath, dizziness, fainting, etc.), they should tell their doctor.

What are the recommendations for children at risk for FDC? FDC is usually diagnosed during the adult years (20's to 60's), and thus it is unlikely that younger children will have any symptoms or detectable abnormalities at cardiac evaluation, even if they carry the FDC disease gene.

Our group routinely evaluates all members of an FDC family, including babies and children of all ages, when a large family has been selected for study for research purposes. However, the utility of screening babies and younger children without symptoms other than for research purposes is unclear for two reasons. First, the chance is low that any cardiovascular abnormalities will be detected, and second, a child's heart normally is growing and enlarging rapidly, and consequently it is much more difficult to categorize a child's heart size as "abnormal" at any point in time with confidence. Regardless, if FDC is identified in a family, parents may wish to have their children who are first-degree relatives undergo a complete cardiovascular screening and, if normal, a repeat EKG and echocardiogram every 5 years. Of course, with any abnormal cardiac signs or symptoms, children (like adults) should undergo a complete cardiovascular exam and evaluation.

Is there treatment for FDC? FDC can be treated. Medical therapies such as angiotensin converting enzyme (ACE) inhibitors and beta-blockers are very effective in improving heart function and even reducing heart size in most individuals. It is our hope that our project will lead to improved treatment for individuals with FDC.

How does FDC affect pregnancy? The relationship between pregnancy and FDC is not clear. Normal pregnancy demands extra work from the heart and may worsen an underlying weakness in the heart. Therefore, pregnant women with known FDC should be followed closely by both their obstetrician and cardiologist even if they have had previously healthy pregnancies. Women with known FDC who are planning a family should consult a cardiologist and/or a genetic counselor to discuss the risks of pregnancy. Finally, women with a family history of FDC should be alert to cardiac symptoms during pregnancy, and if symptoms occur, they should seek medical help immediately.

If my family has FDC, should I tell my doctor about my family history? We recommend that you tell your primary care doctor and cardiologist (if you have one) about your family history of FDC. This information can make a difference in your medical care, lifestyle recommendations, and the amount of surveillance recommended for you. Your physician may find the "**For Professionals**" section of this website helpful in answering many of his or her own questions about FDC. If you have specific questions about your genetic risks that your physician is unable to answer, he/she should consider referring you to a genetic counseling professional.

If I have FDC, should I discuss it with my family? Because FDC is genetic, sharing information about your health with your family members can help them to make important decisions about their own health. Knowing that dilated cardiomyopathy may run in the family can help your relatives to look out for and detect signs of the disease earlier than they might otherwise. This is important, as early detection of an enlarged heart or an arrhythmia can help people who have this disease live longer, healthier lives. For this reason, many people want to know if they or their loved ones are affected. Please also remember, however, that not everyone feels comfortable sharing personal health information, even with family members.

I would like to talk to someone about my specific risk for FDC - who should I contact? There is no substitute for one-on-one consultation with a knowledgeable health care provider. If you have a family history of FDC, after consultation with your primary care doctor or cardiologist you may be interested in discussing your personal risks with a genetic counselor or geneticist. You may find a genetics provider in your area by searching the Resource Link on the home page of the **National Society of Genetic Counselors**. You are also welcome to **contact us** with your questions about FDC.

Is there a genetic test for FDC? No, there is no one comprehensive genetic test for FDC, in part because of the multiple disease genes implicated to cause FDC. However, some laboratories now offer lamin A/C testing. A few generic comments regarding the genetics of FDC are available in this For Families section under "**Genetics of FDC.**"

What can I do now that will be helpful to myself and my family later? Keep good records of your own and your family members' medical care. Hold onto your own and other family members' medical records and death certificates, which may prove

valuable in constructing your family history. If possible, get involved in a research project that may help speed the identification of the genes involved in FDC and lead to improved treatments.

What can I do to help FDC research? If you are a member of a family with known or suspected FDC, you may be able to make an important contribution to research. Please review the page on **Participation** in our research project. We would like to hear from you (see "**Contact Us** "). The clues to discovering the genetic basis and eventually, better treatments, for the disease lie in individuals and families with FDC. We need your help in order to make progress.

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Options for Participation

There are two main categories of participants in our research project: (1) those who participate in the *genetic study* only (individuals, small families, some large families), and (2) those who undergo *full family screening* (very large families). Each of these options is outlined in detail below.

Genetic Study. This type of participation can be done completely via telephone and mail. This option is most appropriate for families in which a diagnosis of FDC can be made (i.e. at least two people have had idiopathic dilated cardiomyopathy that can be confirmed by medical records or death certificates), but only one person who has FDC needs to be living.

What does participation in the genetic study involve? Contact with a Research Assistant or Associate from the FDC Project. The Research Assistant or Associate will help explain the details of the study to you. She or he will also take a complete family history, asking you questions about your own and your family members' health. She or he will also help you decide if it is the right time for you and/or your family to participate, and will make sure your family is most appropriate for the genetic study only (versus the full family screening). You can contact a Research Assistant or Associate at 877-800-3430 or **contact us**.

The contribution of a blood sample (via mail) from at least one person in the family who has FDC, and any other willing family members. Usually, after speaking with you on the phone a Research Assistant from our project will mail you a blood kit and the forms you need to fill out, including a consent form. For individuals who go to the doctor regularly, we usually recommend that you take the blood kit to your next appointment and have the blood drawn along with your usual labs. Usually your doctor's office can then easily mail the blood to us (via Fed Ex) in the materials we provide. For individuals who do not have blood drawn regularly, the cost of a blood draw can be covered by FDC research funds. Shipping costs are covered by these funds as well. In other words, there should be no cost to you or your physician for you to participate in our study.

Participants are also asked to release their medical records to us from their physician(s). Usually, this is done by signing a medical record release form that allows us to communicate directly with the physician's office. We do this to reduce the amount of work for the participant; however, some people prefer to obtain copies of their records on their own (or already have copies) and mail them to us. We always attempt to gather medical records on any family members who may have IDC/FDC and are willing to participate. We also attempt to obtain death certificates on those family members who may have died as a result of FDC or whose cause of death was unknown.

After we have confirmed the diagnosis IDC/FDC in you (and possibly your family members) by reviewing your medical records and have obtained a blood sample, you will be enrolled in the FDC project.

What happens to my blood sample? Your blood sample is sent overnight to our lab. We use the blood to prepare DNA, which is examined for changes in genes that may cause FDC. Additional information regarding the genes that cause FDC can be found in our [newsletters](#) . We also measure the level of a muscle enzyme called creatine kinase that has been shown to be elevated in a few families with FDC.

Will you provide me with genetic test results? At this time, no. Research laboratories are prohibited from releasing research genetic test results to research participants, unless they have complied with a law passed by Congress in 1988 entitled the "Clinical Laboratories Improvement Act," or CLIA. CLIA guidelines enforce sample processing and labeling guidelines to prevent sample mix-ups and errors that occur much more frequently in non- CLIA-certified labs (such as research labs) than in formally CLIA-certified diagnostic labs. It also regulates the quality of testing, and ensure appropriate safeguards are used to assure reliable, reproducible and high quality test results. It is therefore considered unethical to release genetic results that could have important clinical consequences for individuals from non-CLIA-certified laboratories, because they have not met these high standards to ensure accuracy. Notwithstanding these important CLIA issues, when we discover any genetic information about a family that we feel may have important implications for the health of family members and future generations, we do inform the family of this knowledge and discuss options with them, even if our laboratory may not be able to provide CLIA-approved testing for that gene. For example, there is an option for family members to pursue genetic testing for a fee through a diagnostic (CLIA-certified) laboratory if we do not have that gene test available. Additional background information and further explanation can be found in our newsletter article "[Genetic Test Results](#)" in **Volume II, Issue 3** of the FDC Beat.

What about confidentiality - who will have access to the information we collect?

All of the information collected is completely confidential and will not be released without your written consent. We do not share your information with anyone (even your family members, unless you are a minor and your parent signed your consent form) unless you request us to do so. If you would like us to share any information with your health care provider, we would need your specific written consent to do so. We are also willing to assist your physician with background knowledge about FDC to enhance his or her

understanding of these results, if so requested. Again, your written consent is always required to release your information.

What if I am interested in participating, but my other family members are not? We encounter this situation frequently. Of course, it is always ideal to have all family members who have FDC included in the project. This is because in order to confirm the diagnosis of FDC in a family, we need to have medical records on at least two individuals confirming that they each have IDC. However, even if only one or two people in a family are willing to participate in the study, we are often still able to include the interested individuals.

Are there any benefits to me for participating? All study participants will receive the triannual mailing of the FDC Research Group newsletter, "FDC Beat," which updates participants on our progress and contains educational information on FDC. Participants may also opt not to receive the newsletter, or to download it from the website rather than receive it in the mail.

It is important to note too, that by participating you are contributing to our understanding of the genetic causes of IDC/FDC and are furthering our scientific knowledge of this condition.

We hope that the information learned from this study will enable the development of clearer guidelines and better medicines for the treatment of individuals and families with FDC. If you are interested in participating, or would like more information, please call us at our tollfree number (877-800-3430) or use the "**Contact Us**" page to email us and let us know how to get in touch with you. Thank you!

Full Family Screening . This type of participation involves very large families who are eligible for screening of the entire family. This option is most appropriate for larger families in which:

1. There are multiple (usually at least three) living family members with diagnoses of idiopathic or familial dilated cardiomyopathy, AND
2. There are at least three living generations, AND
3. The majority of the family is centered geographically around one or two primary locations (it is NOT necessary for the family to be near our center), AND
4. Most family members are enthusiastic about contributing to FDC research.

This type of participation involves the clinical screening (echocardiograms, EKG's, physical exams, and blood draws) of the family and spouses, usually 30-70 people total.

The screening is usually held on a weekend in a central geographic location and is conducted by a team of FDC researchers (physician(s), nurse(s), research assistant(s), echocardiographic technician(s), etc.). Costs of clinical screening are covered by FDC research funds. When we select a very large family to study, we offer to comprehensively screen as many individuals as possible from that family. This means that we routinely screen individuals who are very distantly related to the person initially identified with dilated cardiomyopathy (the research term used to describe the initially

identified person is the "index patient"). It also means that we screen many people who have no cardiac problems at all.

Why do we do screening? The more clinical information we have from one family, the better idea we have of the presentation and behavior of an FDC disease gene in a specific family. For example, screening may help to determine the most common types of symptoms, cardiac tests abnormalities, age of onset, course, and outcome of the disease in a family. In addition, having more family members screened can increase the likelihood of identifying the FDC disease gene in that particular family. This is because we are able to compare the DNA of various family members in an effort to narrow down the region that might contain the disease gene.

What tests are involved with full family screening? Full family screening at our clinic (or another centralized location) involves four parts for each person. The first three are designed to detect pumping or rhythm abnormalities of the heart, and the fourth is a blood sample.

The screening includes:

A medical history and a physical exam with a doctor or nurse. In a medical history we ask a variety of questions that tell us if you have had any symptoms that might be related to your heart. We also ask most of the questions of a general check-up, such as questions about your general health and lifestyle. We also review your family history. The physical examination is focused to detect abnormalities of heart function. We take heart rate and blood pressure and examine the heart and lungs. We also give participants the chance to ask us questions about their heart, their health, and anything else that may be relevant to their family history of cardiomyopathy, the screening process, or our research program.

An electrocardiogram (EKG or ECG). An EKG is a common, painless heart test that records the heart's rate and rhythm, and also tells us about the overall health of the heart conduction system (the "electrical wiring" systems of the heart). It also can reveal other patterns of heart disease such as old heart attacks and other problems. The EKG is done by attaching sticky patches containing conductive gel to the arms, legs, and chest. These patches are then connected to the EKG machine by wires. The EKG machine records several seconds (several beats) of the electrical activity of the heart and prints this electrical activity onto a sheet of paper that can then be interpreted by cardiovascular experts.

An echocardiogram, or ultrasound of the heart. This is a sonogram (picture) of the heart, another painless non-invasive test. The heart chambers and valves are visualized by sound waves that allow us to measure the chamber sizes of the heart and inspect the pumping action and valves of the heart.

A small blood sample is taken . We use the blood to prepare DNA, which is examined for changes in genes that may cause FDC. We also measure the level of a muscle

enzyme called creatine kinase that has been shown to be elevated in a few families with FDC.

If you are screened as part of our research project, what happens to the test results? Our research team carefully reviews the echocardiogram and EKG results. (Please see "**Will you provide me with genetic test results?**" for information on genetic results). Because we conduct off-site screening trips and we may screen several dozen individuals in one weekend, it usually takes us several weeks to months to review all of the data.

Will you be notified of the screening test results? We notify all subjects (or parents of minors) of echocardiogram, EKG, and physical exam results in writing.

What do the test results indicate? If your screening tests are all normal it means that you have no current evidence for FDC. If any of your screening tests are abnormal or a cause for concern, we will inform you of this and may give you specific recommendations for further medical care from your personal physician. This may include recommendations for further testing or for treatment, or both.

What about confidentiality - who will know about your test results? All of the information collected is completely confidential and will not be released without written consent from you. We do not share your information with anyone (even your family members, unless you are a minor and your parent signed your consent form) unless you request us to do so. If you would like us to share your results with your health care provider, we will gladly provide your physician with copies of the test results. We are also willing to assist your physician with background knowledge about FDC to enhance his or her understanding of these results, if so requested. Again, your written consent is always required to release your information.

If my test results are normal, does it mean that I don't have and will never get FDC? Not necessarily. Unfortunately, normal test results at a single screening do not eliminate the possibility that you might develop FDC in the future. This is because the chance of developing the symptoms and signs of FDC increases with age. If one of your family members is affected with FDC, especially if that individual is a parent, child, or brother or sister (first-degree relative), your risk for developing FDC is higher than it would be if you were more distantly related.

Are there any benefits to me for participating? All study participants will receive the triannual mailing of the FDC Research Group newsletter, "FDC Beat," which updates participants on our progress and contains educational information on FDC. Participants may also opt not to receive the newsletter, or to download it from the website rather than receive it in the mail.

It is important to note too, that by participating you are contributing to our understanding of the genetic causes of IDC/FDC and are furthering our scientific knowledge of this condition.

We hope that the information learned from this study will enable the development of clearer guidelines and better medicines for the treatment of individuals and families with FDC. Of course, we may discover the genetic basis of your dilated cardiomyopathy. If you are interested in participating, or would like more information, please call us at our tollfree number (877-800-3430) or use the "**Contact Us**" page to email us and let us know how to get in touch with you. Thank you!

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