

FDC BEAT

Newsletter of the Familial Dilated Cardiomyopathy Project at Oregon Health Sciences University
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Creating Your Family Medical History: A Step-By-Step Guide to Making a Medically Useful Family Tree

In this article, we hope to provide you with the tools and resources necessary for compiling a complete family medical history and pedigree. This can initially seem like a daunting and overwhelming task; however, if it is done in a thorough, step-by-step manner, the end result can be extremely informative and helpful for generations to come. As our society becomes more technically and medically advanced, the important role genes play in one's overall health has become increasingly apparent. With such an emphasis on a person's genetic makeup, the importance of knowing your family's medical and genetic history is greatly increased. This family medical and genetic history can give health care providers and researchers information with which they can use to provide better preventative health care for you and your family.

STEP 1: MAKE A LIST

The first step to making a complete family medical history is to compile a list of all the people in your family. Although it may be interesting to trace your family back further, it is sufficient to use your grandparents as a starting point.

STEP 2: DRAW A PEDIGREE

After you have compiled a complete list, you can create a pedigree (family tree). An abbreviated table of appropriate symbols used by genetic counselors is shown to the right. It is usually easiest to start with the

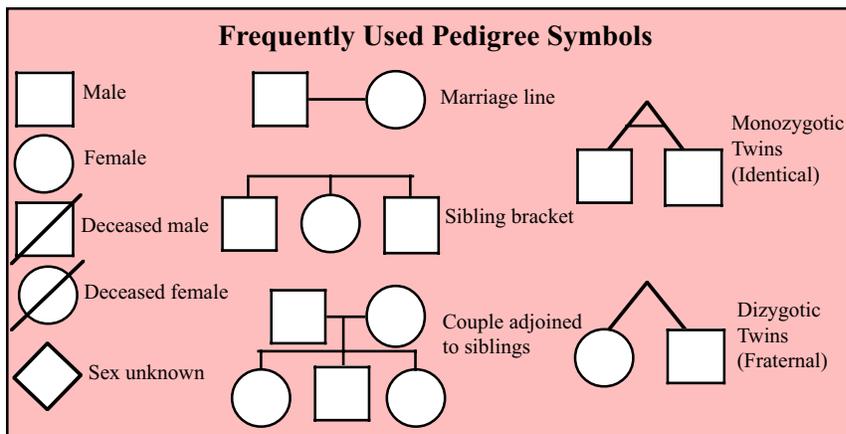
health information on your biological (blood) relatives. In general, it is easiest to start with your immediate family and work your way out to more distant relatives. For people outside your immediate family, a complete medical history is not necessary. Instead, it is important to document any disorders that are known to run in your family, as well as any major chronic illnesses (i.e. heart disease, cancer, etc.). Keep in mind that you may run into resistance with some family members as they may not be comfortable disclosing their personal health history to you. Usually, if you explain your purpose in gathering this information and that it will only be shared with health care professionals and adult immediate family members, people will be willing to help you. If a blood relative is deceased, there are ways to extract his/her health information. The first is through living relatives who were closest to that person (i.e. spouse, sibling, child). You may also be able to obtain that information through death certificates (which can be requested through the appropriate state's Office of Vital Records), military records and/or obituaries.

STEP 4: ADD INFORMATION TO PEDIGREE

Once you have a reasonably complete family medical history, you can transfer it to the pedigree. Dates of birth, dates (or age) of death, cause of death, genetic diseases, major chronic illnesses and age of onset of the disease are all important pieces of information that

STEP 3: COLLECT MEDICAL INFORMATION

After you have made your basic pedigree, you can begin to collect



can and should be included on your family's pedigree. You can save space by abbreviating various illnesses and disorders; just make sure

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FDC and Your Medical Family Tree

Assembling family history information in a family with FDC can be challenging because of the variability of the disease. Within a family, the same gene can cause severe disease (for example, leading to heart transplantation) in one individual and mild or unnoticeable disease (for example, a minor arrhythmia) in others. When taking a family history for FDC, therefore, one must be suspicious of all types of heart problems even though they may seem unrelated.

Getting medical records (or death certificates) on family members is the best way to determine whether a person may have had FDC. However, medical records may not be available if a person has been deceased for several years. Furthermore, the tests that we use to diagnose FDC today may not have been available when that family member was living. For example, echocardiography, which today is the “gold standard” for evaluating heart size and function, was not widely in use until the 1960s.

With or without medical records, a high level of suspicion for FDC should be raised when family

members have had a heart transplant, heart failure at an early age (<60), sudden death or “heart attack” at an early age (without a history of coronary artery disease), cardiac arrhythmias (such as atrial fibrillation, sometimes requiring a pacemaker) or heart block. In determining who in your family might have had FDC, here are some questions that are useful to ask:

1. **How old was the family member when he/she first had symptoms of heart problems? If they are deceased, how old were they when they died?** While FDC can present at any age, symptoms in younger individuals should be taken especially seriously.

2. **Did the family member have any cardiac arrhythmias? Did they receive a pacemaker or implantable cardiac defibrillator (ICD)?** In many families arrhythmias are the first sign of FDC. While some people with arrhythmias may go on to develop cardiomyopathy, this will be the only manifestation of

Please see **FDC Family Tree**, page 4

Medical Family Tree Resources

In an attempt to make building your own family tree easier, we have compiled a list of books and websites related to building and working with your medical/genetic family history. We hope that you may find them useful.

*BOOKS

Bennett, RL (1999). *The Practical Guide to the Genetic Family History*. New York: Wiley-Liss, Inc. 251 pp.

*Written for health care professionals as a guide for taking a patient’s family medical history. It is very informative but is more specific to geneticists and counselors.

Daus, C (1999). *Past Imperfect: How Tracing Your Family Medical History Can Save Your Life*. Santa Monica: Santa Monica Press. 240pp.

*Contains very helpful information on how to track down information.

Krause, C (1995). *How Healthy is Your Family Tree? A Complete Guide to Tracing Your Family’s Medical and Behavioral Tree*. New York: Simon & Schuster. 167 pp.

*Walks you through step-by-step with information on how to build a medical family tree. The author also includes personal information and anecdotes to emphasize why a medical family tree is so important.

Nelson-Anderson, DL (1995). *Genetic Connections: A Guide to Documenting Your Individual and Family Health History*. Missouri: Sonters Publishing. 301 pp.

*Provides a comprehensive guide on how to research, understand and document your family history. It also breaks down the human body system by system with specifics on what to look for.

*WEBSITES

www.familytreemaker.com

*A complete genealogy resource with suggestions, links and other resource tools.

www.KeepItSimpleSolutions.com

*Information about Fran Carlson’s [Growing Your Family Medical Tree](#), which is a guide on how to create a family medical tree. Also contains links to other related sites.

www.CyndisList.com

*Contains multiple links to various genealogy websites and other helpful family tree information.

Example of a Family Medical History and Pedigree

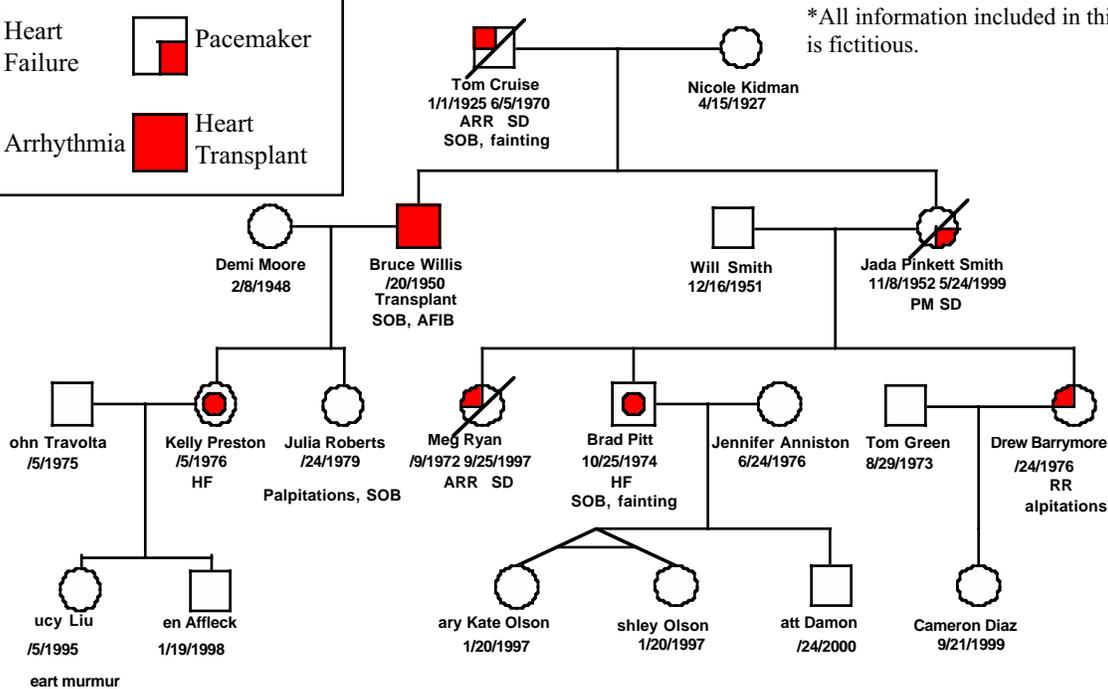
LEGEND

SOB = Shortness of Breath
 AFIB = Atrial Fibrillation
 ARR = Arrhythmia
 SD = Sudden Death
 PM = Pacemaker
 HF = Heart Failure

 Heart Failure  Pacemaker

 Arrhythmia  Heart Transplant

This is an example of a complete family medical history and pedigree from a fictitious family with a possible history of FDC. Note the various elements that are used throughout the pedigree: date of birth, date of death, symptoms. The use of color is effective in bringing particular symptoms or conditions to the reader's attention. Abbreviations are also used to save space. Note that everything is clearly explained in the legend.



Family Medical History

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you include a key to indicate what abbreviations you are using. Some people also use colors and shading within the pedigree symbols to bring certain diseases, conditions and/or illnesses to attention. (See the example pedigree above for an illustrated example of a complete family medical history and pedigree taken from a fictitious family with a history suggestive of FDC.)

STEP FIVE: SHARE YOUR FAMILY MEDICAL HISTORY AND PEDIGREE

Now that you have created a complete family medical history and pedigree, it is important that you share this information with your health care provider, as well as other members of your family. By sharing this family medical history and pedigree with your health care provider, you will be helping him/her to understand your health risk and put together a plan of health care that is specific to your own needs. By sharing this with your family, you can make them aware

of various diseases or disorders that seem to be particularly prevalent in your family. This family medical history and pedigree not only benefits you and your immediate family, but also generations of your family to come.

What Can You Do With This Information?

As research participants in the FDC Research Project, many of you may wonder what to do with this information, since we may have already worked with you to create a family medical history and pedigree. Our intentions behind giving you these various tools and resources is to help you understand what we do and what our approach is when we work with you to build a pedigree, to give you the necessary tools to work with your own family history in more detail, and to provide you with some general education for documenting your family's medical history. For our newer families, we hope you can find this useful in helping us as we work to further expand your family's medical history and pedigree.

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an FDC disease gene in others.

3. **Did the family member have any known history of coronary artery disease (CAD)?** Because CAD is so common, it is important to first rule this out as the potential cause of cardiac symptoms. In more recent years, cardiac catheterizations have been done to look for any blockage in the arteries.

4. **What types of symptoms does/did the family member have?** Shortness of breath and fluid accumulations (such as in the ankles and lower legs) can both be symptoms of heart failure, while symptoms of arrhythmias include palpitations (feeling one's heart beat or flutter), fainting or dizziness.

Remember, a diagnosis of FDC is only made when idiopathic (unknown cause) dilated cardiomyopathy is present in two family members. Heart problems are common in the general population, and cardiac symptoms and arrhythmias are not necessarily related to the presence of an FDC disease gene. The purpose of gathering family history information is to identify those relatives who might benefit from additional testing to look for signs of FDC.

Suggestions, Questions, Comments, Ideas???

We Want to Hear From You!

If you have any contributions (i.e., questions, stories, comments, or suggestions), please:

1. call us toll-free at 1-877-800-3430
2. visit our website at <http://www.fdc.to> and send an email from the "Contact Us" page
3. email us at messages@fdc.to
4. write us

FDC BEAT Newsletter

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Newsletter Layout/Design: Kelly Coates, B.S.
email: coatesk@ohsu.edu

FDC Project Clinical Group:

Ray Hershberger, M.D.	Kathy Crispell, M.D.
Emily Hanson, M.S.	Warren Toy, B.S.
Kelly Coates, B.S.	

**The FDC Research Project
Division of Cardiology, UHN-62
Oregon Health Sciences University
3181 SW Sam Jackson Park Road
Portland, OR 97201**

Address Service Requested

TO: