

FDC ♥ BEAT

Newsletter of the Familial Dilated Cardiomyopathy Project at Oregon Health & Science University
Portland, Oregon, USA

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Genetic Test Results



As a participant in the FDC Research Project, you may have submitted a blood sample to us at one point for genetic analysis. We are frequently asked whether or not we can give you individual genetic test results from the analysis we perform on the blood sample. In this article, we hope to help explain and clarify why we are currently unable to provide you with individual results and the efforts we make to provide you with the maximum amount of information possible.

In 1988, Congress passed the Clinical Laboratory Improvement Amendments (CLIA) in an effort to establish quality standards for all laboratory testing. These standards help to ensure the accuracy, reliability and timeliness of all patient test results. A laboratory is defined as any facility which performs testing on specimens derived from humans for the purpose of providing information for the diagnosis, prevention, treatment of disease, or impairment of, or assessment of health.

In order to provide patients (and research participants) with individual test results of any kind, a laboratory must complete an application, pay fees and be surveyed. By becoming CLIA-certified, a laboratory has ensured to patients and health professionals that they are able to provide quality laboratory testing that is accurate and reproducible. Through the use of frequent surveys and monitoring visits, CLIA-certified laboratories are able to reduce the likelihood of incorrect results, sample mix-ups and other related errors.

Due to the fact that the FDC Research Project does not have CLIA-certification, we are currently unable to provide our participants with individual genetic test results. Obtaining CLIA-certification

can be time consuming and expensive, however, in the future, we hope to become certified.

If we do find the gene that we think causes FDC in your family, we will make every effort possible to refer you to a CLIA-certified laboratory who can provide you and other family members with genetic testing for a fee. In some cases, however, this may not be a possibility. Therefore, wanting genetic test results should not be a motivating factor for you to participate in the FDC Research Project. Whether or not you decide to have genetic testing is a highly personal decision involving several factors including your life experiences, family history, age and health. We strongly recommend that regardless of your decision in considering genetic testing that you meet with a genetic counselor or medical geneticist to discuss the risks, benefits and limitations of genetic testing.

Regardless of whether or not genetic testing becomes widely available and accessible, clinical screening and follow-up are critical in tracking disease in family members. Echocardiograms and electrocardiograms are key to determining if there are problems with the heart's size and function. Early detection of an enlarged or dysfunctional heart can lead to early treatment and an improved quality of life and life expectancy.

For more information about the Clinical Laboratory Improvement Amendments, please visit the Health Care Financing Administration website at:

<http://www.hcfa.gov/medicaid/clia/cliahome.htm>



Research Papers, Posters and Presentations



◆ Our group has published two new scientific papers in medical journals; please encourage your physicians to take a look at them:

Jakobs P.M., Hanson E.L., Crispell K.A., Toy W., Keegan H., Schilling K., Icenogle T.B., Litt M., & Hershberger R.E. 2001. Novel lamin A/C mutations in two families with dilated cardiomyopathy and conduction system disease. *Journal of Cardiac Failure* 7(3):249-256.

Hanson E.L. & Hershberger R.E. 2001. Genetic counseling and screening issues in familial dilated cardiomyopathy. *Journal of Genetic Counseling* 10(5):397-415.

◆ We have also had several abstracts accepted for poster or slide presentations at national meetings. Recently presented as a poster at the *Heart Failure Society of America* meeting in Washington, D.C. in September:

Crispell K.A., Coates K., Toy W., Hanson E.L., & Hershberger R.E. 2001. Results of follow-up screening six years after initial screening in a large family with dilated cardiomyopathy.

◆ Recently presented as a poster at the *American Society of Human Genetics* meeting in San Diego in October:

Jakobs P.M., Keegan H., Hanson E.L., Litt M., & Hershberger R.E. 2001. Novel mutations in four families with dilated cardiomyopathy and conduction system disease cluster in the rod domain of lamin A/C.

◆ To be presented in a slide session at the *American Heart Association* Scientific Sessions in November in Washington, D.C.:

Hanson E.L., Jakobs P.M., Crispell K.A., Toy W., Keegan H., Schilling K., Icenogle T.B., Litt M., & Hershberger R.E. 2001. Novel lamin A/C gene mutations in three of sixteen large families with dilated cardiomyopathy.

***This work would not have been possible without your and your family's help –
thank you again!***



FDC Heart-to-Heart Reach Out Reminder



Just a reminder to everyone who was considering submitting a piece for our First Annual FDC Heart-to-Heart Reach Out...we are still accepting submissions for anyone with a story to share! Types of submissions include, but are not limited to, stories, drawings, reflections, photos and/or poems. They can address a wide variety of topics, including how FDC has impacted you or your family, memories of a family member who had FDC, what kind of interactions you have had with the FDC Research Project personnel, why you chose to participate in the research program, and/or what your hopes are for the future of FDC diagnosis and treatment. If you have further questions, please contact Kelly Coates on the FDC Project toll-free number

(1-877-800-3430, ext 1). Submissions may be published anonymously at your request. You can send your submissions to us by:

- 1) sending it as an attachment in an email to coatesk@ohsu.edu;
- 2) visiting our website at <http://www.fdc.to> and send it in an email from the "Contact Us" page;
- 3) writing us at:

FDC Research Project
Attn: FDC BEAT
Division of Cardiology, UHN-62
3181 SW Sam Jackson Park Road
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Goodbye...sort of!



At the end of August, the FDC Research Project was forced to say goodbye to a person who consistently put her heart and soul into everything our research strives to accomplish. Emily Hanson, M.S. may have moved on to bigger and brighter pastures in Wisconsin, but she has still managed to keep the FDC Project close to her heart!

It is not easy to say goodbye! After three years of working on the FDC Research Project, I am leaving OHSU and Portland to move to Madison, Wisconsin. The bad news is that I will no longer physically be sitting in my office at OHSU. The good news, however, is that I will continue to work on the FDC project from Madison. You will still be able to reach me easily through out toll-free number (1-877-800-3430) by pressing my extension, or through email (hansone@ohsu.edu). I feel privileged to continue working with all of you as well as with the talented personnel - physicians, scientists and research assistants - who run the day-to-day operations of the FDC Research Project.

I would like to introduce Jessica Kushner, the genetic counselor who will be filling my position as a Research Associate with the FDC Research Project. Jessica received a B.S. degree in Zoology and a M.S. degree in Genetic Counseling at the University of Wisconsin, Madison. After graduate school, Jessica worked for the Departments of Genetics and Perinatology at Kaiser Permanente in Portland. She now comes to us from the Section of Clinical Genetics at Chicago's Children's Memorial Hospital, where she has been a genetic counselor and clinical study coordinator. We are fortunate to have her coming on board with the FDC Research Project. Please help us to welcome her!

Looking back on the past three years, one of the most amazing parts of working on this project has been your unconditional willingness to help our research

effort (making my job easy!). You have offered countless stories about your families and how they have been impacted by FDC. You have encouraged your brothers, sisters, parents, grandparents, children, aunts, uncles and cousins to participate in our project. You have offered to have your blood drawn, even though it may not have been the most pleasant experience! You have spent hours researching and compiling your family's medical information. You have called relatives

who you hardly know or have not spoken with for years in order to gather more family history data. You have taught your physicians about FDC so that they might be able to help other patients in your situation. You have driven, sometimes several hours, to family screenings that we have organized in your area. You

have come up to OHSU and braved "the hill" and the confusion of our large university campus. You have allowed us to attend your heart transplants and obtain tissue from your old heart as we watched a new one be implanted! You have stayed in touch and updated us on the triumphs and losses your family has experienced more recently. You have helped us out even when it may not have been YOU who has FDC. In summary, you have made this your cause as well as ours.

Thank you for all you have done and continue to do to help make our project a success. I hope to be in touch with many of you in the coming weeks and months.

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well as ours...

FDC BEAT Newsletter

FDC BEAT is a triannual publication of the Familial Dilated Cardiomyopathy Project in the Division of Cardiology at Oregon Health & Science University in Portland, OR. The newsletter is not copyrighted and readers are welcome to photocopy its contents to share with family members and health professionals.

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FDC Bulletin Board



Notes, Announcements and Reminders

Our thoughts and prayers go out to all the victims and families who were affected by the tragedies that took place on September 11.

FOLLOW-UPS

If you have a follow-up with your physician at home, we would like a copy of your results. Please contact us and we will send you a medical record release form.

REMINDER

If we have sent you blood tubes and you have not yet had your blood drawn, please do so as soon as possible. If you have questions or are having difficulty finding someone who will draw your blood, please call us!

Remember....if you are currently followed by a cardiologist, he/she may see other patients who have family histories suggestive of FDC. Please pass our phone number and website along to your cardiologist so we can include more families in our research.

HEART-TO-HEART REACH OUT

We encourage everyone to participate in our 1st Annual Heart-to-Heart Reach Out. See page 2 for details. If you have questions, please call us at 1-877-800-3430.

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Address Service Requested

TO: