

# FDC BEAT

www.fdc.to

Newsletter of the Familial Dilated Cardiomyopathy Project at the University of Miami  
Miami, FL, USA

Volume VIII, Issue 1

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## The FDC Research Project has moved to the University of Miami

Greetings from the FDC Research Group! We are delighted to announce our move to the University of Miami (UM), Miller School of Medicine. While we will miss our former home at the Oregon Health & Science University, this move will help us to expand our studies and to develop new and exciting collaborations with UM scientists.

All research records from all consented subjects, and all DNA and other tissue specimens were successfully relocated to UM during May, June and July 2007.

The Project move was prompted by the recruitment of Dr. Hershberger to the University of Miami as an Associate Chief of the Division of Cardiology, where he will also lead the advanced heart failure therapies programs (that include heart failure and cardiac transplantation). In a new initiative, he will also develop a cardiovascular genetic medicine program at UM. This program will build on what we have learned in the FDC project over the past 10+ years.

One of the three laboratory scientists supporting the program in Oregon, Duanxiang Li, MD MS, was recruited to Miami by Dr. Hershberger, where he will continue his laboratory investigation in support of the FDC Research Project.

Jessica Kushner, MS, a certified genetic counselor, remained in Portland with her family. A note from Jessica follows inside. Two new genetic counselors, Jason Cowan and Ana Morales, have been recruited to the Program. They will assume the role and responsibilities of Ms. Kushner. They have introduced themselves inside.

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### A NOTE FROM DR. HERSHBERGER, PRINCIPAL INVESTIGATOR FOR THE FDC RESEARCH PROJECT

I am delighted to report that the FDC Research Project has found an exciting and supportive home at the University of Miami (UM). The reason to move to UM was an outstanding offer of space, collaboration and support for this research. It was an offer too good to turn down. The laboratory space of the Project will be housed in the new Biomedical Research Building now nearing completion at UM.

New collaborations are underway with the Miami Institute for Human Genomics, a major research venture just formed in January 2007 at UM.

Newly recruited world-class genetics researchers provide an outstanding environment that will greatly help us with progress in our studies. (see more at <http://mihg.med.miami.edu>).

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## A NOTE FROM JESSICA KUSHNER, GENETIC COUNSELOR:

To FDC Project participants, families, and other readers of the FDC Beat,

As you've read in this edition of FDC Beat, Dr. Hershberger's FDC Project recently relocated to the University of Miami in Florida. With my family and I living in Portland, Oregon, I thus will not be working with the FDC Project anymore. After almost six years as the FDC Project genetic counselor/study coordinator, saying goodbye to everyone is a hard thing to do. I have been very fortunate to work with a great team of doctors, nurses, scientists, and assistants - all smart, good-intentioned people working hard to increase knowledge about FDC, its causes and treatment. Even luckier still, I had the opportunity to work with incredibly giving patients and families, willing to share their personal and family stories (not to mention blood and medical records!) for the good of the research, and in hopes of helping others.

One of the most enjoyable and special things about my FDC project work has been getting to know some of you and your families. I was fortunate to meet some of you in clinic or at screenings, and I got to correspond with people all over the U.S. and other countries. It was wonderful to connect and have continued communication with numerous people, many of whom I've never even met!

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## NEW PERSONNEL

**JASON COWAN, MS**  
Genetic Counselor



I am pleased to be joining the FDC team as we begin an exciting new chapter of research and discovery at the University of Miami. I am new to Florida, but am confident that the move will be as great for me as it promises to be for the project itself. Originally from Ontario, Canada, I completed my Bachelors of Science with Honors at the University of Guelph before beginning my Genetic Counseling at the University of British Columbia in Vancouver. My interest in genetics and cardiology began early in this training and has grown ever since. Before joining Dr. Hershberger's group, I journeyed to the arctic tundra of Iqaluit (the capital city of the Canadian territory of Nunavut) to study the effect of folic acid fortification on rates of birth anomalies among the Inuit. It was an incredibly rewarding experience, in a breathtakingly beautiful but seldom seen part of North America. With the move to Miami, I look forward to working with Dr. Hershberger, Ana, and the rest of the FDC team. Most of all, I look forward to speaking with you, the participants, as we continue the work begun at OHSU.

**ANA MORALES, MS**  
Genetic Counselor



I am honored to join the FDC team while working as a research genetic counselor, which is what I love the most. I received a Bachelor's degree in Biology from the University of Puerto Rico (UPR) and a Master's degree in Genetic Counseling from Brandeis University in Massachusetts. Before becoming a genetic counselor, I worked as a research lab technician, contributing to genetics, molecular and neurology studies. I have worked as a research genetic counselor for several studies, including the Harvard Neuromuscular Disease Project, the Hermansky Pudlak study at the UPR, and the WAGR syndrome project at the University of Miami. For these projects, I worked as a liaison between the lab and candidate participants, as well as handling data and sample management. I have also provided clinical genetic counseling to prenatal, pediatrics and adult patients. I am eager to start applying my previous experience, and genetic counseling skills to this project. Coordinating genetic research studies has provided me with the unique opportunity to develop long term relationships with families, and I hope that I can continue doing the same as I get to know you.

**Continued from page 1:  
A Note from Dr. Hershberger, Principal  
Investigator for the FDC Research Project**

Moving and start up support has been robust. Our NIH grant, which has funded all of the FDC Research Project through the years, is up for renewal this year. The funds committed from UM to the relocation of the Project will sustain our research efforts during this renewal.

The behavior of disease genes causing cardiomyopathy may vary between racial and ethnic groups. This South Florida location offers an enormous diversity of population.

Peoples of Hispanic ethnicity, and Blacks from the US and the Caribbean, will enrich the largely Caucasian population now enrolled in our study, thus improving our understandings of how cardiomyopathy manifests itself.

I'm certain that the FDC Project has a bright future to continue to discover and understand the genetics of dilated cardiomyopathy. We thank you for your continued interest and support in this work.

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**Continued from page 2:  
A Note from Jessica Kushner**

While I will no longer be part of the FDC Project staff, I will keep updated on the project and news about FDC (I've put myself on the newsletter mailing list!). You will be in great hands with Jason Cowan and Ana Morales, the new FDC Research Associates and Genetic Counselors.

As we've said many times, this research would not be possible without you. I know that many of you have experienced serious health problems, and even lost loved ones to this condition. Your generosity of time and support of this research not only made my job easier, but also serves as an example to me both professionally and personally, one that I will always take with me no matter what I am doing.

Thank you so much. Best wishes to all of you and your families for health and happiness.

**The FDC Website 'Contact Us' was not operational  
from approximately June 1, 2007!**

We apologize that during our move this summer our web hosting email account filled up and did not accept and forward any messages to us. If you have tried to communicate with us from approximately June 1 through September 13, 2007, we did not receive your message(s). Our systems are now operational.

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**QUESTIONS ABOUT OUR MOVE**

***Will the project have the same goals?***

Yes, the goals remain the same: to identify and characterize families with FDC, and to determine the gene or genes that cause FDC. Maintaining the strong standards established at OHSU, **your genetic samples and medical records remain intact and confidential.**

***Will you continue working with the families enrolled through OHSU? Will the FDC Project recruit new families?***

Yes, we will continue working with all previously enrolled families, and we will recruit new families to the study. If you or your family members have cardiomyopathy, please continue to keep us updated with any changes in your cardiovascular status.

***Will the toll-free number be changing?***

Our toll free number, 877-800-3430, has been transferred to UM. When calling, you will have the option to speak with Ana or Jason, or to be connected with Dr. Hershberger, or with Dr. Li in our lab. When you call us, keep in mind that we are now in the Eastern Time Zone.

***What about the website?*** The research website, [www.fdc.to](http://www.fdc.to), is being moved to UM also. You may also use the website to contact us.

***What is the new contact information for the FDC Project?***

We now have two mailing addresses, one for letter-mail and another for package-mail, such as FedEx deliveries.

**Letter-mail:**

The FDC Project Group  
Division of Cardiology  
P.O. Box 019132, C-205  
Miami, FL, 33101

**Package-mail / FedEx:**

The FDC Project Group  
University of Miami, Miller School of Medicine  
Clinical Research Building, C-205, Rm 1112  
1120 NW 14<sup>th</sup> Street  
Miami, FL 33136

Please contact us at our toll free number if you have any questions about which address to use.

## FDC BULLETIN BOARD

**CALL US AT  
OUR TOLL  
FREE  
NUMBER:  
877-800-3430**

### **MEDICAL FOLLOW-UP**

If anyone in your family is newly diagnosed with heart problems, please let us know. Also, if you or anyone in your family has heart tests performed, either for follow-up or for the first time, regardless of results, we would be interested in receiving copies. Please contact us and we will send you a medical record release form. If we have sent you medical record release forms, please send us the completed forms as soon as possible.

**EMAIL US  
THROUGH THE  
"Contact Us"  
PAGE ON OUR  
WEBSITE:  
WWW.FDC.TO**

### **WEBSITE EMAILS**

If you have recently contacted us through our website and we have not responded, please resend your request or call us at our toll free number.

### **CONTACT INFORMATION UPDATES**

If you have moved and/or have an email address we can contact you at, please call or email us so we can get in touch with you for any follow-up and continue to send you our newsletter.

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### **FDC BEAT Newsletter**

**FDC BEAT** is a triannual publication of the Familial Dilated Cardiomyopathy Project in the Division of Cardiology at the University of Miami, Miller School of Medicine in Miami, FL. The newsletter is not copyrighted and readers are welcome to photocopy its content to share with family members and health care professionals. We welcome your feedback.

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**ADDRESS SERVICE REQUESTED**

**TO:**