December 2010 • Volume 5, Number 3



## Personalized Medicine Research Project



# Touch screen kiosks to be used in PMRP enrollment

The Personalized Medicine Research Project will soon begin using interactive kiosks to enroll participants.

Although computer-based enrollment in research is not new, the PMRP program is different in that it presents the information through video as well as via the text of the consent form. The PMRP is believed to be the only biobank poised to use computerbased enrollment.

Cathy McCarty, Ph.D., Principal Investigator of the PMRP, delivers key concepts in eight video segments. Dr. McCarty's years of speaking about the PMRP at meetings of various central Wisconsin community groups have honed her skill in explaining complicated research in understandable terms. Do you remember when you enrolled in the PMRP? Before you agreed to give a blood sample a research coordinator explained the study. Researchers have a legal and ethical obligation to provide key information about the research project so that individuals may grant their informed consent to participate – or decline participation.

Research coordinators will continue to greet potential participants. But instead of sitting down with a clipboard, they'll guide individuals to a machine similar in appearance to a ticketing kiosk that you might see at an airport or movie theater. The coordinator will stay with the potential participant during an instruction period to ensure they are comfortable with use of the kiosk, and will then leave the room.

Continued on page 2

### A newsletter for supporters of the Personalized Medicine Research Project

## Inside

From the Director	2
Save the Date!	2
Wisconsin Genomics Initia funds four PMRP projects.	tive 3
Celera scientist joins Cen	ter
for Human Genetics	4

## From the Director ¬



Cathy McCarty, Ph.D.

my days are often dictated by external deadlines related to funding sources. The eMERGE (electronic Medical Records &

As a researcher,

Greetings!

Genomics) project that you have read about in previous

newsletters is a four-year \$3.5 million grant from the National Human Genome Research Institute to study the genetic predictors of HDL (good cholesterol) levels, cataract and diabetic retinopathy. We'll have results from Phase I to share with you in the next newsletter. The initial four-year grant is due to expire next summer and a number of us have been busily working to prepare what is called a "competitive renewal" for an additional four years of funding. In Phase II we are proposing to study the genetic basis of additional eye diseases, including glaucoma, age-related macular degeneration and dry eye, as well as the genetic basis of response to treatment for these conditions.

The PMRP continues to receive a lot of attention at the national level. In July I talked about PMRP at the Mountain States Genetics Foundation Annual Meeting in Denver, Colorado. My first thought was that we should be studying the genetic basis of altitude sickness because I am terribly affected by it in the mile-high city! In August, I was part of a panel discussion on the personalized health care revolution, held at Biotechnology Vision Summit 2010 in Madison, Wisconsin. The panel also included Dr. Murray Brilliant from the Center for Human Genetics, Peggy Peissig from the Biomedical Informatics Research Center, and two of our Wisconsin Genomics Initiative colleagues. In December the PMRP is being represented at a national conference in biobanking in Rhode Island and at a national meeting on public health genomics in Bethesda, Maryland, sponsored the Centers for Disease and Control Prevention. Dr. Deanna Cross is presenting papers at both meetings. Thanks to all of YOU for making this project successful! It couldn't happen without your participation.

## Touch screen kiosks to be used in PMRP enrollment (continued from page 1)

Potential participants will see a touch screen. The names of all eight segments can be accessed via the menu option:

- Introduction
- Why is research being done?
- Length and benefit
- What will happen if you enroll?
- Protecting your privacy
- Risks
- Do you have to participate?
- Results and contact information

Potential participants will be required to finish all the segments to ensure all information is presented to them. After most of the segments, a question or two will appear regarding key concepts presented, such as scope of the study, confidentiality policy and right to withdraw.

In addition, individuals will always have Pause and Repeat navigation options available, along with access to Frequently Asked Questions and the full language of the Consent Form. A Comment option will allow them to record audio comments about the PMRP in general or the computer-based enrollment process.

At the end of the computer-based portion of the process, about 20 minutes, a button is pushed to summon the research coordinator, who will then answer any remaining questions and, if the individual is agreeable, co-sign the informed consent form.

## News in Brief

#### Save the date!

Join PMRP researchers and fellow participants on April 25, 2011 in Marshfield for a reception and short program describing advances in translating genetic discoveries into new medications and diagnostic tests.

A similar event held in May 2010 to celebrate enrollment of the 20,000th participant was so well received that the PMRP wants to have an annual gathering at which scientists, media and participants can meet. Details will be shared in the next newsletter and online, www.marshfieldclinic.org/pmrp. The computer-based enrollment initiative has been under construction since early 2009. Leading the project has been Valerie McManus, MPH, applications analyst with the Research Foundation's Biomedical Informatics Research Center (BIRC).

David Hoffman, instructional programmer, Corporate Education, did most of the program development with help from Nathan Partridge, instructional programmer. Hoffman is responsible for the many computer-based training programs used by Marshfield Clinic employees. Other key team members included Andrea Mahnke, usability analyst, and Luke Rasmussen, senior programmer/analyst, BIRC; and research coordinators Carol Waudby and Wendy Foth, PMRP.

It is anticipated that the first official use of the kiosks will come early in 2011 during enrollment for a study by Deanna Cross, Ph.D., on prostate cancer risk.

The computer-based enrollment will be available on two kiosks. Besides their practical value in enrolling participants into genetics studies, they will be used to compare computer-based programs to traditional pen and paper enrollment to see whether the computer programs improve participants' recall of the informed consent process.



## Wisconsin Genomics Initiative follows through with funding for four PMRP projects

The PMRP recently learned that four of its research studies will receive funding through the Wisconsin Genomics Initiative (WGI), a historic collaboration among Marshfield Clinic and three other Wisconsin institutions.

Gov. Jim Doyle announced the Wisconsin Genomics Initiative two years ago at a ceremony in Marshfield. \$2 million was earmarked for the WGI in the Wisconsin fiscal 2010-2011 budget.

The four WGI studies:

- "Integrating Genomic Data into a Computational Model for Improved Breast Cancer Diagnosis." PI – Elizabeth Burnside, UW Madison. Summary: This proposal aims to establish a multirelational dataset incorporating patientspecific genomics data, mammography findings and clinical/demographic risk factors that can improve accuracy of breast cancer risk prediction. Co-PIs
  David Page, UW Madison; Cathy McCarty and Peggy Peissig, Marshfield Clinic Research Foundation; Adedayo Onitilo, Marshfield Clinic; Uli Broeckel, Medical College of Wisconsin.
- "Development of a Predictive Algorithm for Age-Related Macular Degeneration." PI – Murray Brilliant, Marshfield Clinic Research Foundation.
  Summary: A predictive algorithm is a mathematical way to express the likelihood that any given person who

does not yet have a disorder will develop the disorder. A predictive algorithm is developed from multiple risk factors, derived from association data that compares the genetic variation and other variables (age, sex, diet, environmental exposures) between those with the disorder and those who do not have the disorder. The accuracy of a predictive algorithm is tested in prospective studies. In this case, researchers plan a future prospective study. Co-Pls - Cathy McCarty and Robert Valenzuela, Marshfield Clinic Research Foundation; Gary Pesicka, Marshfield Clinic.

 "Investigation of Genomic Associations between Heart Failure and Diabetes Mellitus." PI - Nancy Sweitzer, UW Madison. Summary: Studies of selected genetic polymorphisms could provide critical information about varying risk for development of diabetes, left ventricular remodeling (structural changes in the heart due to reasons such as heart attack or chronic high blood pressure), and worse outcomes in patients with heart failure. Knowing which heart failure patients are at a greater risk for a worse prognosis could help practitioners identify patients for whom more aggressive treatment strategies are needed. Co-PI -Cathy McCarty, Marshfield Clinic Research Foundation.



 "Membrane Metalloproteinase-9 Genotype and Aortic Aneurysm." PI -Jay Yang, UW School of Medicine and Public Health. Summary: Researchers will test the working hypothesis that "A statistically-optimized combination of MMP-9 genetic polymorphisms will serve as a biomarker for patients who require surgical intervention for severe aortic aneurysm." This is a case-control study that uses the clinical database and biological samples available through the PMRP. Co-Pls - Peggy Peissig, Marshfield Clinic Research Foundation; Uli Broeckel, Medical College of Wisconsin; Martha Winn and Sijian Wang, UW Madison.

The Wisconsin Genomics Initiative leverages the strengths of Marshfield Clinic Research Foundation, Medical College of Wisconsin, University of Wisconsin School of Medicine and Public Health, and the University of Wisconsin-Milwaukee. Together, the four institutions will tackle an important scientific and public health need that otherwise could not be met, and cannot be accomplished anywhere else but Wisconsin.

## Letter reintroduces participants to PMRP

Time flies. It's hard to believe that eight years have passed since the first participants enrolled in PMRP. Over the summer, Cathy McCarty, Ph.D., Principal Investigator, wrote to participants offering thanks and an update on PMRP activities. Enclosed in the letter was a bookmark doubling as a timeline, with PMRP milestones printed on it.

#### In Print

Recent publications authored or co-authored by scientists within the Center for Human Genetics include: Jiang YH, Pan Y, Zhu L, Landa L, Yoo J, Spencer C, Lorenzo I, Brilliant MH, Noebels J, Beaudet AL. Altered ultrasonic vocalization and impaired learning and memory in Angelman syndrome mouse model with a large maternal deletion from Ube3a to Gabrb3. PLoS One 2010;5:pii: e12278.

PubMed ID: 20808828

Cross DS, Ivacic LC, Stefanski EL, McCarty CA. Population based allele frequencies of disease associated polymorphisms in the Personalized Medicine Research Project. BMC GENET 2010;11:51. PubMed ID: 20565774

Giampietro PF, McCarty CA, Mukesh BN, McKiernan FE, Wilson DA, Shuldiner A, Liu J, Levasseur JA, Ivacic LC, Kitchner TE, Ghebranious N. The role of cigarette smoking and statins in the development of postmenopausal osteoporosis: a pilot study utilizing the Marshfield Clinic Personalized Medicine Cohort. Osteoporos Int 2010;21:467-77.

PubMed ID: 19506792

For a list of additional publications, go to http://www.marshfieldclinic. org/chg/pages/default.aspx and click "Publications."





CENTER FOR HUMAN GENETICS MARSHFIELD CLINIC RESEARCH FOUNDATION 1000 N OAK AVE MARSHFIELD WI 54449-5777

NONPROFIT ORGANIZATION U.S. POSTAGE PAID MARSHFIELD, WI PERMIT NO. 417

## **Celera scientist joins Center** for Human Genetics

Cteve Schrodi, Ph.D., began work Jin the Center for Human Genetics on September 13, 2010. Dr. Schrodi's primary research interests lie in discovery of genes that contribute to diseases, applying mathematics and statistics to biology, and population genetics.

Dr. Schrodi previously was a senior staff scientist at Celera Corporation in Alameda, California. During his nine-year tenure at Celera, Dr. Schrodi developed mathematical methods for evaluating hundreds of thousands of genetic markers to pinpoint disease-causing signals. He



Steve Schrodi, Ph.D.

also was heavily involved in designing and conducting genetic studies of rheumatoid arthritis, psoriasis, Alzheimer's disease, liver diseases, and how different people respond to prescription drugs.

From this work, Dr. Schrodi authored 26 peer-reviewed scientific publications. Of note, these studies resulted in the discovery of several immune system genes that increase the risk of these diseases, which was confirmed by numerous other investigators. Currently, other scientists are using that information to create therapeutics that target the specific molecular mechanisms which can give rise to different diseases.

At the Marshfield Clinic Research Foundation, Dr. Schrodi's laboratory will continue to work on mathematical methods to improve the chances of finding disease genes and aid in predicting which individuals are at high risk for different diseases. The laboratory will also apply those methods to Marshfield's superb population-based genetic resources to identify which genes are responsible for various common diseases. Although challenging, he anticipates that these efforts will give us better insight into the disease process and will eventually favorably impact how healthcare is practiced.

### **Contact Us**

This newsletter is a publication of the Personalized Medicine Research Project, Marshfield Clinic Research Foundation, 1000 N. Oak Ave., Marshfield, WI 54449-5790.

To contact the PMRP, phone 1-888-334-2232 or 715-389-7733, or visit the PMRP on the Web at http://www.marshfieldclinic.org/pmrp/

To contact newsletter editor Scott Heiberger, phone 715-389-7541 or e-mail heiberger. scott@mcrf.mfldclin.edu.

## **PMRP** Advisors

Mat Bartkowiak Marshfield Phil Boehning

Loyal

**Sharon Bredl** Stratford

Margaret Brubaker Stratford

**Margy Frey** Marshfield Pat Gall

Marshfield Jodie Gardner Spencer

Nancy Kaster Pulaski

**Colleen Kelly** Marshfield

Mike Kobs Marshfield

Norm Kommer Colby

**Darlene Krake** Marshfield

Mark Krueger Marshfield

**Julie Levelius** Stratford

Jerry Minor Pittsville

Noreen Moen Marshfield

**Marlin Schneider** Wisconsin Rapids

Scott Schultz Osseo

Jean Schwanebeck Pittsville

**Liz Welter** Marshfield