

GR-PBRN Executive Committee

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The Greater Rochester Practice-Based Research Network

The Greater Rochester Practice-Based Research Network (GR-PBRN) was founded in 2007 to improve patient care and health outcomes through practice-based research. It is a dynamic, coordinated network of pediatric, family and internal medicine practices, from across the Greater Monroe County area. The GR-PBRN is an important part of the Clinical & Translational Sciences Institute and the Center for Community Health.

One of the goals of the GR-PBRN is to protect practices by ensuring that researchers are educated on practice-based research *before* approaching practices for participation. The GR-PBRN carefully reviews research and quality improvement projects for relevance to primary care practice, contribution to quality care, and burden on the practices.

Practices who participate in the GR-PBRN will receive a certificate that they may wish to display in their office, demonstrating their commitment to research and improvement in quality of care.

A Practice-Based Research Network (PBRN) is a group of separate practices that collaborate with each other and with outside researchers to assess and address primary care-related questions.

Also, the GR-PBRN will work with researchers to emphasize the importance of incentives for participation in research projects, including Maintenance of Certification or CME credits.

In addition to pre-screening projects and educating researchers on practice-based research, the GR-PBRN will offer opportunities for informing research protocols, ongoing information about local research, and additional training to physicians in conducting research.

Joining the GR-PBRN is easy. We will ask you for the name of a research liaison, usually a clinician in your practice, some basic practice descriptives and areas of research interest for your practice. Contact Karen Gibson, Network Coordinator at (585) 224-3085.

Examples of Current Projects

The Rochester Aging Study – William Hall, MD Working to discover a biometric profile for Alzheimer’s Disease. In the future, this profile will aid physicians with early detection and treatment of the disease. Physicians making referrals to the study receive the results of all neuropsychological testing for those patients who choose to participate.

STRONG Kids – Steven Cook, MD, MPH -- a prospective, longitudinal investigation of 200 boys and girls to assess changes in body composition, metabolic syndrome components, and their relation to tobacco exposure during a critical stage of early puberty. Physicians making referrals to the study receive results of all physical measures for those patients who choose to participate.

Sickle Cell Disease Study – Phyllis Bazen, NP – a cognitive appraisal of pain and other chronic stressors in adults living with sickle cell disease, assessing correlates and predictors of emotional and quality of life adjustment outcomes.

If your practice is interested in participating in any of these studies, please contact Karen Gibson, Network Coordinator at (585) 224-3085, or email karen_gibson@urmc.rochester.edu.



Greater Rochester Survey of Primary Care Physicians

We asked physicians in Monroe County and the surrounding counties to identify barriers and incentives to practice-based research

63% of Survey Responders report being likely to collaborate as a site for research.

The Incentives and Barriers to Practice-Based Research Survey was sent to primary care physicians (including physicians in pediatrics, family medicine, and internal medicine) in Monroe County and 4 surrounding counties. Thirty-three percent of the physicians in Monroe County responded to the survey.

To what extent would aspects of collaboration with academic researchers be important to you?

The three most frequently cited options identified as important were:

- Intellectual stimulation (65%)
- Contribution to clinical knowledge (75%)
- Opportunity to enact quality improvement (78%)

How important are potential barriers to your collaboration in research?

The three most frequently-cited potential barriers to collaboration in research were:

- Paper work required (74%)
- Lack of time-even if compensated (73%)
- Staff time (72%)

Concern for patient reactions was cited least often (16%).

Please indicate how likely you would be to collaborate in processes related to research:

More than 70% of responding physicians reported being “likely” to participate in each of the 7 types of research listed in the survey. The most frequent choices were:

- Implementing practice change for quality improvement (95%)
- Permitting the use of research flyers in the office or exam rooms (92%)

Fewer physicians were interested in participating in activities for generating or creating research, but each of these activities were endorsed by more than one-third of respondents.

Please indicate how likely you would be to collaborate in activities related to research:

- attend meetings designed to generate research questions (49%)
- participate in the design of research studies (40%)
- participate in analysis of research studies (35%)
- participate in writing research papers (34%)

For a copy of the survey or more complete survey results, please contact Karen Gibson, Network Coordinator, at (585) 224-3085.

The GR-PBRN welcomes the Primary Care Network Practices

In 2008, the practices within the University of Rochester Medical Center's Primary Care Network joined the GR-PBRN. The Primary Care Network (PCN) is comprised of 23 practices and 127 physicians in Monroe and Livingston Counties. The PCN shares the vision and goals of the URMC's Center for Primary Care. Among these goals are developing effective strategies to strengthen primary care educational programs, practice-based research, and physician services.

Dr. Wallace E. Johnson, Director of the Center for Primary Care and PCN physician describes the importance of the GR-PBRN to the PCN in this way, "The GR-PBRN is an immensely valuable project. Expanded Primary Care Network involvement in GR-PBRN activities will bring new opportunities to our patients. Additionally, involvement with the GR-PBRN will revitalize the connection between our busy community-based physicians and the broader URMC research initiatives."

Some PCN practices are already collaborating with research projects including the Rochester Aging Study. By helping recruit patients for this study, physicians gain valuable information about baseline cognitive function in their elderly patients as neuropsychological test results are shared confidentially with physicians and participating patients. One participating physician commented that, "The detailed information I gain about my patient's cognitive status is invaluable in helping me to gauge future declines in cognition and possibly subtle changes signaling the onset of dementia. My patients and I also feel like we are contributing something very important to the ongoing acquisition of knowledge of the underlying biology of neurodegenerative conditions such as Alzheimer's disease and Parkinson's disease as a means of early detection and potential effective treatments."

PCN practices, and other practices that have recently joined the GR-PBRN, will receive a Practice Enrollment Form, which asks for some basic practice descriptives and what areas of research may be of interest to physicians in the practice.

The Healthy Living Library Opens to the Public

The **Healthy Living Library** at Prince Street, a project of the Center for Community Health, provides an array of health information resources and services.

In addition to books, DVD's, pamphlets, and anatomical models and charts, the **Healthy Living Library** features computer workstations with simple, targeted icons that direct visitors to high-quality, trusted health information on the web.

Visitors can also experience a "virtual encounter" with a librarian at the Edward G. Miner Library at the URMC. Using a two-way remote communication tools (video webcam and phone), visitors can see and talk with a librarian if they need help finding health information on the Web or elsewhere. Someone with diabetes, for example, could ask about resources to learn more about the disease, options for treatment, proper diet, and any local clinical trials.

The **Healthy Living Library** is located at the Center for Community Health, at 46 Prince Street. It is open Monday-Friday, during normal business hours. No appointment is necessary. Visitors are welcome, and physicians and others are encouraged to refer their patients to the library.

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Coming Soon



The GR-PBRN will launch
its website in Early 2009.



No More Hand-Me-Downs: Research Designed for Children A Website for Educating Parents and Pediatric Healthcare Providers about Pediatric Clinical Research

The prospect of children participating in research often gives pause to parents and providers alike because the concepts and safeguards of research are poorly understood. A comprehensive new award-winning NIH web-based educational tool can help erase the confusion, allay the concerns, and empower parents and children with the information they need to understand clinical research and make informed decisions about participating in a study. In a format geared to all educational levels, the site combines text, graphics, and documentary film based on hundreds of hours of interviews with experts, parents, and children themselves to give viewers an "inside view" of pediatric clinical research.

You will find the site useful in helping you to answer your patients' questions about research. Families who are contemplating enrolling their child in a clinical study can use the information to augment their understanding and complement the informed consent process. The site has sufficient content to be used as an educational tool for trainees and junior faculty about the key concepts of pediatric clinical research. You can also download the DVD-based documentaries to run in your waiting room.

Please visit the site at:

www.ChildrenAndClinicalStudies.nhlbi.nih.gov



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