

Directors' Report



Dr. Bob Steiner,
MCRF Exec. Dir.

We are happy to send you our Spring edition of *Research Matters*. And this time, yes, Spring does appear to be here, with temperatures in the 60's. Dr. Bob Haws and I were invited to present at a meeting in Fairfax, Virginia this week on rare disease registry development. I spoke on registries in general, what they are, why they're important, what challenges are being faced in registry development and maintenance, and what the future likely holds. Dr. Haws spoke about the development of the CRIBBS registry (Bardet-Biedl Syndrome Registry) that he directs. I believe both presentations were well received. The audience was especially impressed by the enormous support of CRIBBS and of Bob's work by the BBS Patient Advocacy Group. This is an excellent example of patient centered research. We at Marshfield Clinic Research Foundation have prioritized development of the infrastructure to develop state of the art disease registry, and to develop disease registries ourselves for stakeholders. These stakeholders include patients, patient advocacy groups, funding agencies, pharmaceutical companies, academic institutions, and others. Our Clinical Research Center and Biomedical Informatics Research Centers are leading these efforts, which have begun to bear fruit. Recently, MCRF's efforts in registry development were highlighted by NIH/NCATS in national and international media reports. We are proud of these efforts, which we feel will be helpful to patients and those providing support for patients. Our hope is to become the go-to place for anyone wanting to develop a disease registry.



Dr. Steve Ziemba,
MCRF Assoc. Dir.

I recently returned from the HMO Research Network (HMORN) annual conference in southern California. For those not familiar, the HMORN is a network of research organizations embedded within health systems from around the country, and is focused on a variety of interest areas including clinical trials, health economics, disparities, outcomes, and epidemiology. It has been a productive collaboration for MCRF since we joined nearly 10 years ago. We had a strong showing at this year's conference, with several individuals participating in the meeting. Dr. Bob Greenlee from CCEPH is MCRF's representative on the HMORN Governing Board, and was a coauthor on 2 conference abstracts on cancer topics. Also from CCEPH, Dr. Jeff VanWormer participated in discussions on addiction research, an important area of concern. Jeff is also MCRF's investigator liaison to the Virtual Data Warehouse (VDW) Implementation group, while Valerie McManus from BIRC attended as the MCRF VDW database manager and Deb Multerer from CCEPH as the VDW Operations Committee co-coordinator. Dr. Melissa Simpson from CCEPH moderated one of the concurrent sessions on chronic disease. Dr. Scott Hebbing from CHG talked about his research involving genetic characteristics of twins, which elicited a great deal of interest at the conference. *(continued on next page)*

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Lori Scheller, IRB Administrator, attended the IRB workgroup and joint sessions with research administration. Yours truly led the Research Administrators Forum. We are already looking forward to next spring when MCRF will co-host the event in Atlanta, with Dr. Greenlee serving as co-chair of the scientific program planning committee.

Recent Publications, Grants, and Awards

This column is to highlight recent accomplishments of MCRF researchers and MC clinical investigators.

Please select the hyperlinks to view recent [publications](#) and [February](#) grant awards.

If you have recently published an article or received a grant or an award and want it included in the next issue of *Research Matters*, please contact Alexis Tavano at tavano.alexis@mcrf.mfldclin.edu.

Compliance Notes



Linda Jaros, RCO

National Institutes of Health (NIH) Proposes Single Institutional Review Board (IRB) Model

In December, 2014, NIH released a [draft policy](#) to promote use of a single IRB for domestic sites of multi-site research funded by NIH. NIH promotes use of a single IRB as a means to avoid duplication of effort, noting that the Food and Drug Administration (FDA) and Office of Human Research Protection (OHRP) have issued similar guidance documents.

Proponents of the single IRB model cite decreased administrative burden and time to approval as benefits. Issues to consider include administrative time devoted to coordinating the multi-site IRB deferral process, including harmonization of HIPAA requirements, reporting expectations, etc.

The draft policy proposes that NIH funded institutions will be expected to rely on a single IRB of record unless there is justification for an exception. Public comments are currently being considered. An implementation date for the final policy has not been published.

CCEPH Introduces New Staff



Elizabeth (Liz) Armagost, BA, joined the Center for Clinical Epidemiology & Population Health (CCEPH) as a Research Coordinator in early January. Armagost comes to CCEPH from the Clinical Research Center, Multi-Specialty department. She is working on an industry-sponsored Respiratory Syncytial Virus (RSV) study, the CDC Flu Vaccine Effectiveness study, and will soon be working on an industry-sponsored Lysosomal Acid Lipase Deficiency study. She plans to become a Clinical Professional by achieving the Clinical Research Certification with the Society of Clinical Research Associates in spring 2015.

Armagost is very active in her community, participating as a Secretary and Emergency First Responder for the Vesper Volunteer Fire Department. She enjoys playing summer and winter league volleyball and spending time with her family. *(continued on next page)*

http://mclweb.mfldclin.org/mcrf/?page=mcrf_updates

CCEPH Introduces New Staff *(continued from previous page)*



Terry Foss, BS, rejoined the CCEPH in January as a Research Coordinator. Foss comes to the department from Corporate Communication – Mail Services where he was the Mail Services Coordinator for the Marshfield Clinic system for the past 3 years. During this time, he earned his Mailpiece Design Consultant certification from the USPS. Prior to this, he worked both in CCEPH and Multi-Specialty departments as a Research Coordinator on multiple research studies. Foss earned his Bachelor of Science degree from the University of Wisconsin – Stevens Point in Broad Field Social Science (History minor) in 2001 and an additional Associate Degree in Applied Science from Mid-State Technical College in 2009 in the Clinical Research Coordinator program.



Tenisha Hill, MPH joined the CCEPH on February 9, 2015 as an Epidemiologist – Masters Prepared. Hill completed her undergraduate work at Indiana University-Purdue University at Indianapolis in Biology. She recently obtained a Master of Public Health in Epidemiology from Indiana University School of Public Health. Prior to joining the CCEPH team, Hill was a Health Educator at Indiana University School of Nursing for an NIH-funded study that provided tailored interactive interventions to increase both colorectal and breast cancer screening in women ages 50-75. Hill will be instrumental in the management of MCRF's participation in the Patient-Centered Outcomes Research Institute (PCORI) funded rural obesity study, MMR3 long-term follow up study, as well as industry-funded observational studies. Hill was drawn to MCRF because of the array of research projects being studied.



Kathy Leick, MBA, joined the CCEPH on February 23, 2015 as an Assistant Manager. Leick comes from Division of Education where she was Student Programs Manager. Prior to Student Programs, she worked as a Compliance Analyst in MCRF's Office for Research Integrity & Protections for 6 years. Leick earned her MBA with a Healthcare emphasis from UW-Oshkosh (AACSB International accreditation). She personally maintains her certification as a Professional in Human Resources (PHR) and her membership with the Society of Human Resource Management (SHRM). Leick has been in leadership, supervisory, or managerial roles most of her career. She especially enjoys staff training and development, and is eager to join research work in a new realm.

Clinical Research Center Welcomes New Nurse



A new Research Nurse has joined the Clinical Research Center's Oncology Team at the Eau Claire Center. Amy Sekel began working with the Oncology program on March 9th. Amy comes to us from the Pain Management Department at the Eau Claire Center. Amy holds a BSN from UW – Green Bay and brings with her clinical experience in pediatric neurology and pain management.

http://mclweb.mfldclin.org/mcrf/?page=mcrf_updates

Center for Human Genetics Welcomes Emeritus Research Clinician, Elizabeth McPherson, MD



Dr. Elizabeth McPherson received her MD from the University of Washington in Seattle, and completed a residency in Pediatrics followed by a fellowship in Clinical Genetics under the mentorship of Dr. John Opitz at UW Madison. She practiced clinical genetics for over 35 years, at various sites including UW Madison, Children’s Hospital of Buffalo, Johns Hopkins, Capital Area Permanente Medical Group, University of Pittsburgh /Magee-Women’s Hospital, and most recently Marshfield Clinic Medical Genetics. She will be contributing a clinical perspective to ongoing projects in the Center for Human Genetics

including eMERGE 2 and 3, Precision Medicine, WGI projects such as genetic contributions to lifelong health, and PheSH.

Her current personal research interests include birth defects/developmental anomalies, and stillbirth. Since 2009, she has been director of the Wisconsin Stillbirth Service Program, which has collected records of nearly 3000 stillbirths and late miscarriages over the past 30 years, has trained 4 summer research interns, and has resulted in 7 publications over the past 5 years. Over her career she has had 80 published articles and over 100 platform or poster presentations at medical genetics meetings.

National Farm Medicine Center Consultant Presents at FarmFirst Annual Meeting



Carol Magurany-Brotski, National Farm Medicine Center’s Agricultural Safety Consulting (ASC) Services contractor, presented at the FarmFirst Dairy Cooperative annual meeting in Onalaska on February 13th. Magurany-Brotski recommended that farmers perform their own safety audit – walk the farm and identify dangers. “Investing in safety is investing in your farm, your family, your employees, and your future,” said Magurany-Brotski. Inspecting farm machinery before use, ensuring that workers are properly trained to operate the machinery, installing a rollover protection system and seatbelt on tractors,

and use of machinery guards are all critical to farm safety. Other important considerations include proper storage and labeling of chemicals, ensuring that ladders are in good repair and the right height for the job, steps are even and sturdy, and personal protective equipment such as eye protection and gloves are easily accessible and clean. Magurany-Brotski finished by urging farmers to take care of themselves. “The saying goes, ‘if you lose a farmer, you lose a farm,’” a reference to the many farms that do not survive after the death of the farmer.

The ASC program is made possible by the Dean Emanuel Endowment for Agricultural Medicine. It was established in 2011 and has since assisted farms in correcting an average of 19.3 citable hazards per farm.

National Farm Medicine Center Director to Present at Coulee Livestock Graziers Network Annual Meeting



Dr. Matthew Keifer, Director at the National Farm Medicine Center (NFMC), has been invited to present the Wisconsin Infant Study Cohort (WISC) project at the Coulee Livestock Graziers Network Annual Meeting on March 26th at the Ettrick Town Hall in Ettrick, WI. WISC is a joint research study conducted by NFMC, University of Wisconsin-Madison, Center for Clinical Epidemiology & Population Health (CCEPH) and Integrated Research and Diagnostic Laboratory (IRDLD). The 5-year NIH-funded project, started in 2013, examines the differences in the development of the immune systems, respiratory

illnesses, and allergies of children born in a farming environment compared with those who were not.

The Coulee Graziers consists of a wide range of livestock farmers representing species from dairy, beef, sheep, poultry, and hogs, and all sizes of operations. Attendees will come mainly from Buffalo, Jackson, and Trempealeau counties.

In Addition:

- The next Full Foundation meeting is scheduled for May 18, 2015 at 2PM in the Froehlke Auditorium. Questions can be routed or emailed to Jeanette Normington at 1R3 or normington.jeanette@mcrf.mfldclin.edu.
- The next Board of Trustees meeting will be held on May 14, 2015 at 6PM in the Laird 50 conference room.
- For the latest issue of the UW-Madison newsletter, *ICTR Today*, please click here: <https://ictr.wisc.edu/Newsletters>.
- The new Marshfield Clinic Research Foundation website can be accessed through this link: <http://marshfieldresearch.org/>. You will find in depth articles, news about upcoming presentations, and achievements by the staff. There are also links to each Center, with detailed information about the staff and projects.
- *Research Matters* is always accepting announcements. Your contributions are greatly appreciated.

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