



## **PCORI-Funded Research Team Exhibit and Table Fair**

*Minneapolis Regional Workshop  
June 19, 2014*

Patient-Centered Outcomes Research Institute

# Project: Evaluation of Parent-Based Interventions to Support Children after Traumatic Injury



**Marizen Ramirez, MPH, PhD**

**Principal Investigator**

**University of Iowa –College of Public Health- Iowa City, IA**

Dr. Ramirez is an Associate Professor in the Department of Occupational and Environmental Health and is the Associate Director of Research with the Injury Prevention Research Center (IPRC). Dr. Ramirez has a record of funding and research in pediatric injuries and intervention studies. As PI, Dr. Ramirez will be responsible for carrying all aspects of the research as planned. She will oversee implementation of the qualitative and quantitative aspects of the study, coordinate with all Co-Investigators and patient/parent advocates and stakeholders of

the Collaborative Board, oversee activities with the two Children's Hospitals and their respective project managers and support staff, and ensure that all aspects of the study are developed and implemented as proposed.

To assure the success of this project, she has brought together a multidisciplinary team composed of seasoned investigators with a track record of funding and research from Psychology, Epidemiology, Biostatistics and Pediatrics. She will design and oversee the formative research activities proposed at Blank Children's Hospital and will develop and design the randomized trial to be conducted at the two hospitals.



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**Lisa Roth, BS**

**Community Liaison**

**University of Iowa- College of Public Health- Iowa City, IA**

Ms. Lisa Roth will serve as the primary Community Liaison for this study to coordinate communications between the research team (at both hospitals), and the Collaborative Board. She will lead the development of the strategic plan and dissemination plan, and will help coordinate Collaborative Board meetings with the PI.

With over 15 years of experience in public health and injury prevention, including both research and outreach she will play in integral role in the project. Her previous experience coordinating two parent based intervention, extensive knowledge of motivational interviewing (MI) and familiarity training parents in MI will be invaluable to developing, and carrying out the proposed research.

# Project: Evaluation of Parent-Based Interventions to Support Children after Traumatic Injury



**Eric Webb, BS- Child Life Specialist- Patient/Family Advocate**  
**Blank Children's Hospital- Des Moines, IA**

Mr. Eric Webb has been a Child Life Specialist at Blank Children's Hospital for the past five years. As a Child Life Specialist he provides support to families and the children themselves who are admitted to the hospital or receive medical procedures. He will be trained in LPC, will assist in recruitment and consent, and will deliver intervention materials (either LPC or Trauma Education) to patients and their parents. The Child Life Specialist will also conduct all follow-ups with patients and families.

Child Life Specialists play a key role in helping foster healing and recovery by helping children express their concerns and cope with fears. They are a critical link in the continuum of care by providing education and resources to parents and family members.



# Project: Evaluation of Parent-Based Interventions to Support Children after Traumatic Injury



**Kristel Wetjen, RN**

**BSN-Pediatric Trauma Nurse Coordinator- Clinical Nurse**

**University of Iowa Children's Hospital- Iowa City, IA**

Ms. Kristel Wetjen is the Pediatric Trauma Coordinator at UI Children's Hospital and has engaged closely as a stakeholder on Dr. Ramirez's pilot research team. Ms. Wetjen has the closest interaction with trauma patients and their parents, and has provided valuable input to the development of the proposed research protocol. She has integrated Dr. Ramirez into the trauma care system and trained the team on how to access medical records of trauma patients. She has developed the ideas for recruitment and training and is motivated to pursue this research. Furthermore, Ms. Wetjen has provided access to the trauma patients and parents

who participated in the pilot focus groups (she herself attended them and participated heavily in the discussions), and has tracked injured patients, recruited them, and provided the LPC intervention to families in the pilot study.

Ms. Wetjen is a key collaborator for this study, and will engage as one of the primary stakeholders as well as an active member of the research team. During the recruitment phase of the study, she will facilitate access to patients and their parents in the hospital setting, and engage in recruitment and training as needed.

# Project: Individualized Care Plans for Hematopoietic Cell Transplant Survivors



**Elizabeth A. Murphy, RN, EdD**

**Vice President of Patient and Health Professional Services** Elizabeth Murphy has worked at the National Marrow Donor Program (NMDP)/ Be The Match® for 11 years. She has 35 years of health care administration experience in the areas of patient and health professional education, clinical operations, research administration and medical journal publishing. Dr. Murphy served as the NMDP's director of Patient Services for six years prior to being promoted to her current position as vice president of Patient and Health Professional Services. She is responsible for administering

NMDP's system for patient advocacy to identify and reduce barriers for patients, families and caregivers throughout the hematopoietic cell transplant (HCT) and survivorship process. She also directs the building of strategic partnerships with national patient advocacy and health professional organizations. Additionally, Dr. Murphy oversees the NMDP's Health Services Research program, a collaboration with the Center for International Blood and Marrow Transplant Research (CIBMTR) to study HCT-related health policy and health services issues. In that capacity, she serves as Principal Investigator for the PCORI-funded research project "Individualized Care Plans for HCT Survivors."

Prior to joining the NMDP, Dr. Murphy served as the corporate vice president for medical education and research at Allina Health System in Minneapolis, Minnesota. She holds a bachelor's degree in nursing from St. Catherine's University in St. Paul, Minnesota, a master's degree in health services administration from St. Francis University in Joliet, Illinois and a doctoral degree in educational leadership from the University of St. Thomas in St. Paul, Minnesota.

# Project: Comparative Effectiveness of Behavioral Interventions to Prevent or Delay Dementia



**Glenn Smith, Ph.D., L.P.**

**Neuropsychologist, Mayo Clinic College of Medicine**

Dr. Glenn Smith is a board-certified clinical neuropsychologist who specializes in neurocognitive disorders. He is a professor of psychology at Mayo Clinic College of Medicine, and a member Division in the Neurocognitive Disorders, Mayo Clinic Department of Psychiatry and Psychology. He is past principal investigator of the Mayo Alzheimer's Disease Research Center Education Core and the clinical director of the Alzheimer's Disease resource on MayoClinic.org. He is associate director of the research education programs within Mayo's Clinical and Translation Sciences Activities. Dr. Smith is the founder and director of a program called HABIT (Healthy Action to Benefit Independence and Thinking) for persons with Mild Cognitive Impairment.

# Project: Comparative Effectiveness of Behavioral Interventions to Prevent or Delay Dementia



**Angela Lunde**

**Director of Education, Alzheimer's Disease Research Center**

Angela Lunde is the Director of Education at the Mayo Clinic Alzheimer's Disease Research Center (one of 29 research centers across the country funded by the National Institutes on Aging and the National Institutes of Health Center) in Rochester, MN. She is a dementia education specialist serving on a multi-disciplinary team that responds to dementia related behavioral problems in local care facilities. Angela has spoken to hundreds of professionals and family caregivers at local and regional conferences on topics such as: early stage dementia issues, making difficult decisions, caregiver anger/stress, and managing difficult behaviors. She has facilitated support groups including an early-stage education and support series. Angela writes a blog on MayoClinic.org that receives 50,000 hits per month. She is certified Yoga Therapist and delivers yoga and support group interventions in the Mayo HABIT program.



# Project: Comparative Effectiveness of Behavioral Interventions to Prevent or Delay Dementia

## Marvin Lofquist

Patient and Partner Advisory Group (PPAG) Member

- BA in chemistry from Augustana
- PhD in chemistry
- Associate Dean - Northwestern University
- Associate Dean – Ferris State
- 15 years teaching, 25 years university administration
- President of the Evanston Historical Society
- Member of ALZFORUM – networking for a cure
- Completed HABIT program in October 2012



# Project: Comparative Effectiveness of Behavioral Interventions to Prevent or Delay Dementia

## Elaine Lofquist

Patient and Partner Advisory Group (PPAG) Member

- Wife and partner of Marvin
- Completed HABIT program in October 2012
- 16 years education
- Medical technologist
- HABIT Partner Advisory Group



# Project: Comparative Effectiveness of Behavioral Interventions to Prevent or Delay Dementia

**Donna Walberg, MBA**

## **Research Project Team Member**

Donna has been involved in Alzheimer's work for 35 years, for the last 14 years with the Minnesota Board on Aging. She has written and administered 9 federal Alzheimer's Disease Support Services Program grants and has been a leader in program and policy development in Minnesota and nationally.

She helped draft and pass the legislation that lead to the development of Minnesota's Alzheimer's plan and served on the state-wide work group that drafted the plan. Donna serves on the executive and steering committees of ACT on Alzheimer's, the collaborative that is completing the implementation of the Minnesota Alzheimer's plan. She is intimately connected to all phases of Alzheimer's development work, has pushed to integrate Dementia into Older American's Act caregiver support services and is working to connect HCBS supports with the health care system in Minnesota.

Donna is also a care partner, her husband Lee was diagnosed with early on-set Alzheimer's 2 years ago. She has a Master's in Business Administration from the University of St Thomas.

# Project: Measuring Patient Outcomes from High Tech Diagnostic Imaging Studies



**Leif I. Solberg, MD**

**Family Physician, Associate Medical Director, HealthPartners Medical Group**

**Director for Care Improvement Research, HealthPartners Institute for Education and Research**

Dr. Leif I. Solberg is a family physician and Associate Medical Director at HealthPartners Medical Group as well as Director for Care Improvement Research at HealthPartners Institute for Education and Research and long-time board member and leader for the Institute for Clinical Systems Improvement, our regional quality improvement collaborative. He has published over 200 peer-reviewed papers and is internationally known for his research on quality measurement and improvement, clinical guidelines, clinical preventive services, chronic disease care, stakeholder involvement in research, and implementation/dissemination.



# Project: Improving the Lives of Alzheimer's Patients and Their Caregivers: A Patient-Centered Statewide Approach



**Patricia Coon, MD**

**Geriatrician, Health Services Researcher, Medical Director  
Center for Clinical Translational Research, Billings Clinic**

Patricia Coon is a Geriatrician, Health Services Researcher, and Medical Director of the Center for Clinical Translational Research at Billings Clinic in Billings, Montana. Dr. Coon completed a Geriatric Fellowship at Johns Hopkins School of Medicine and a NIH Medical Staff Fellowship (Metabolism Section) at Gerontology Research Center, NIA in Baltimore, MD. For over twenty-five years, her clinical career has focused on improving the health and quality of the lives of seniors, especially those with Alzheimer's Disease and related dementias (ADRD). In her role as Medical Director at a long-term care facility, she works to ensure patient-centered quality care and safety for a frail high-risk older population. Research interests and endeavors include exploring innovative, effective ways to manage obesity and vascular risk in rural areas, care transitions, and ADRD.

# Project: Improving the Lives of Alzheimer's Patients and Their Caregivers: A Patient-Centered Statewide Approach



**Elizabeth Ciemins, PhD**

**Health Services Research Scientist, Research Director**

**Center for Clinical Translational Research, Billings Clinic**

Elizabeth Ciemins is a Health Services Research Scientist and Research Director of the Center for Clinical Translational Research at Billings Clinic in Billings, Montana and part time faculty at the University of Montana, Missoula and Montana State University, Billings. Dr. Ciemins received a PhD in Health Services and Policy Analysis from University of California, Berkeley and an MPH in Population/Family Health and MA in African Studies at University of California, Los Angeles.

She also served as a Health Educator/Nutritionist in Niger, West Africa where she worked with

traditional birth attendants to improve the health of women and children.

# Project: Improving the Lives of Alzheimer's Patients and Their Caregivers: A Patient-Centered Statewide Approach



**Betty Mullette RN, MSN**  
**Research RN**  
**Billings Clinic**

Betty Mullette is a Research RN at the Billings Clinic, Billings, Montana. She received her BSN from Montana State University, and an MSN in Community Health Nursing from the University of Wyoming. Her healthcare background spans 39 years with a variety of work experience that includes both in- and outpatient settings and collaborating in the management of acute and chronic health problems. For nine of these years, Betty was on the nursing faculty of Montana State University-Bozeman, at the Billings campus. Ms. Mullette joined the Center for Clinical Translational Research in 2002, and has had a variety of interesting responsibilities. Some of her responsibilities include accountability for numerous projects/studies, which include integrated care for people with a variety of chronic illnesses. Betty has an intimate, as well as global, understanding from both the clinical perspective and the research perspective of the multiple organizational, patient and family interactions that occur within the healthcare environment. Betty currently resides in Billings with her husband Larry, two children and dog Riley. She can be contacted at [bmullette@billingsclinic.org](mailto:bmullette@billingsclinic.org).

# Project: Patient-Defined Treatment Success and Preferences in Stage IV Lung Cancer Patients



**KM Monirul Islam, MBBS/MD, PhD**

**Project Director/ Principal Investigator**

KM Monirul Islam is the Project Director and Principal Investigator for the PCORI-funded study, “Patient-Defined Treatment Success and Preferences in Stage IV Lung Cancer Patients.” His study has more than two dozen members on the team and is currently enrolling patients from four cancer centers in Phase 2 of three phases in a three-year project being conducted in Nebraska and South Dakota (MidWest USA). He is a medical graduate of Dhaka University (MBBS/MD) with an MPH from Tulane University and received his PhD in epidemiology from Case Western Reserve University. A population-based intervention study that he conducted a few years ago enriched his understanding of the value of engaging study participants (especially patients) and patient advocates from the very earliest stages of research. Prior to the initiation of this project, he developed mutually respectful relationships with the four cancer center co-investigators when his team collaborated on a project regarding lung cancer, which was a secondary analysis study that was subsequently published. As a result of this and other experiences, he is leading the current research with emphasis on fostering communications among team members and the high importance of keeping all aspects of the study patient-informed and patient-centered.



# Project: Patient-Defined Treatment Success and Preferences in Stage IV Lung Cancer Patients



**Linda (Lin) K Bauer, BS**

**UNMC Oncology Clinic, Site Coordinator**

Lin Bauer is a Data Coordinator and Non-Therapeutic Research Coordinator for Hematology/Oncology at the University of Nebraska Medical Center (UNMC) in Omaha, Nebraska. She has a Bachelor of Science degree in Natural Sciences Education and has taught honors science classes in Nebraska and Kansas public school systems. After a decade of teaching, she took a position in genetics and molecular biology research with UNMC and has worked on various projects involving cancer biological markers and chromosomal abnormalities. Currently, she coordinates the UNMC clinical site, and is responsible for screening, consenting and interviewing patients, as well as data collection and entry. She has been instrumental in 50% of all patients enrolled thus far for Phase 2. With her background, she is educator at heart and a researcher by mind. This project gives her a golden the opportunity to connect with patients at a critical time point in their care. She understands the importance of this project and how it will help future patients have a better quality of life while going through chemotherapy.

# Project: Patient-Defined Treatment Success and Preferences in Stage IV Lung Cancer Patients



**Janna Binder, RN**

**Avera Cancer Institute, Site Coordinator**

Janna Binder is a registered nurse and is certified in Oncology nursing. Her background also includes Primary Care Clinic, Hospice and Radiation Oncology nursing. In 2010, she joined the Avera Cancer Research Institute in Sioux Falls, North Dakota as a Clinical Research Coordinator. Her primary focus is solid tumor and includes lung, gastro-intestinal, genito-urinary, and central nervous system cancer research and treatments. For this PCORI project she is the Site Coordinator for the Avera-based clinical sites. During Phase 1 (Focus Groups) she screened, recruited, and consented both patient and clinician key informants for more than half of the focus group participants. Currently, in Phase 2 (Patients), her major project roles are identifying, recruiting, and interviewing patients in the study, including data collection and submission of informed consent forms and reports to our project Coordinating Center (UNMC). She is enthusiastic about making and keeping the welfare and well-being of patients at the center of all health care that she is involved with. And, since she believes it is critically important to share findings from the study with colleagues, she was instrumental in a poster presentation about this project at a national meeting of oncologists held at the Avera Cancer Institute last Fall.

# Project: Patient-Defined Treatment Success and Preferences in Stage IV Lung Cancer Patients



**Sarah Einspahr, RN**

**Saint Francis Cancer Treatment Center, Site Coordinator**

Sarah Einspahr is a Clinical Research Study Coordinator at a community cancer treatment center that is one of the four cancer centers involved in this PCORI project, which is located in the Midwest (three centers in Nebraska: Great Plains/Callahan, St. Francis, and UNMC and one in South Dakota: Avera). As Site Coordinator she has participated as a clinician (nurse) in Phase 1 of the project (Focus Groups). Now, in the current Phase 2 of the project (Patients), she is responsible for screening, recruiting, consenting, and interviewing patients. She also participates in trainings, team meetings, and data collection, input, and transmission of data to our UNMC Coordinating Center, headed by Dr. Monirul Islam. She has been a Registered Nurse for 20 years, with the last 11 years working within Oncology. The opportunity to work with cancer patients and their families in our community is one of her passions. Participating in this PCORI research and using the results of the project will help tailor the care provided to patients that honors their personal and family values and preferences and will help improve the individual experiences and quality of life for patients, both now and in the future.

# Project: Patient-Defined Treatment Success and Preferences in Stage IV Lung Cancer Patients



**Ann Fetrick, RN, PhD**

**Project Coordinator**

Ann Fetrick is an RN with clinical experience in hospitals, clinics, and community health settings. In all her work, she has practiced nursing using a patient-centered approach. Interested in learning more about how to improve the access to and the quality of health care from the patient's perspective, she earned a PhD in nursing and has worked nearly a decade as Quality Improvement Coordinator in public health and for 5+ years as Project Director/ Manager for federal and state government funded projects. Currently, she is Project Coordinator for this project bringing her special interest in, and education, training, and expertise in, quality improvement and ethical considerations (IRB) to bear in day-to-day project management, preparation and maintenance of all regulatory documentation, communications, and interim progress and yearly reports. She is responsible for preparing and supplying four clinical sites with clinical research forms, tracking and maintaining study records, development and maintenance of the manual of procedures, and scheduling, attending, and taking minutes for critical meetings. The current PCORI-funded project builds on her education, training, and 15 years of experience as a project coordinator for a variety of research projects dealing with improvement in culturally-sensitive patient-centered care.



# Project: Patient-Defined Treatment Success and Preferences in Stage IV Lung Cancer Patients



**Apar Kishor Gant, MD, MPH**

**Co-Investigator/ UNMC Oncology Clinic, Site Principal Investigator**

Apar Kishor is actively engaged in medical practice, teaching and clinical research and specializes in the care of patients with lung cancer and head and neck cancer. He carries dual appointments to: (1) the Omaha VA Medical Center and (2) the University of Nebraska Medical Center, as an Associate Professor of Medicine in the Department of Internal Medicine, Division of Oncology/Hematology. He is a member of the Respiratory Committee of the Alliance for Clinical Trials in Oncology (ACTION) and a member of the Small Cell Lung Cancer and the Senior and Adult Oncology Committees of the National Comprehensive Cancer Network. His research interests are geared towards developing safe and effective therapies for patients with lung cancer who are not candidates for standard therapies. His background includes completion of an internship and residency in Fargo, North Dakota, and an Oncology/Hematology Fellowship at the University of Nebraska Medical Center in Omaha, Nebraska. His position on the faculty of the Division of Oncology/ Hematology, Department of Internal Medicine at the University of Nebraska Medical Center since December of 2005 has prepared him to be the Principal Investigator for the UNMC clinical site for this project.

# Project: Patient-Defined Treatment Success and Preferences in Stage IV Lung Cancer Patients



**June E Ryan, MPA**

**Patient Advocate/ Co-Investigator**

For this PCORI lung cancer project, June Ryan serves as a leading “Voice for the Patient.” She has both professional and personal experience with lung cancer. Personal because her husband was diagnosed and subsequently died from the disease; and professional because of her years of employment by the Nebraska Department of Health and Human Services to develop and manage the Comprehensive Cancer Control Program, a CDC-funded state-wide, initiative. While managing that program, she helped create and build a statewide partnership, now called the Nebraska Cancer Coalition (NC2). Currently, NC2 includes over 500 individuals, representing nearly 350 organizations. In all of this work, she has earnestly endeavored to keep the patient perspective and well-being paramount; therefore, it has been natural for her to bring her experience to benefit this PCORI project. Since collaboration is one of her most rewarding and satisfying personal and professional activities, she expects to engage with many of those among her network of cancer prevention and control partners (including all of Nebraska's cancer centers and many physician providers as well as her relationships with patients who have and will participate in the current project) in disseminating the results of the study.

# Project: Family-Centered Tailoring of Pediatric Diabetes Self-Management Resources



**Scott Hatchett**

**Advisory Board Member**

My name is Scott Hatchett. I am the owner of Ridgeline Construction and Welding Services. I'm a 48 year old father of five children, the three youngest of which have type one diabetes. This is a lifelong disease for them and requires long term care and communication with doctors and other medical professionals. We are glad to be part of the ACE project, and hope to see a positive difference made through communication and patient care for individuals with chronic illnesses.

# Project: Family-Centered Tailoring of Pediatric Diabetes Self-Management Resources



**Daniel Hatchett**

**Advisory Board Member**

My name is Daniel Hatchett. I was diagnosed with Type One when I was 12 years old. After having it now for about four years, I've gotten used to getting shots and pricking my finger many times each day. My goal is to go into the medical field to help newly diagnosed children with type one. But while I'm younger right now I love being able to help out anyone with diabetes (such as with the Project ACE, radiothons, and other diabetes events). I hope I can shed some light on type one diabetes and help people to understand a disease with which millions of people live.



# Project: Family-Centered Tailoring of Pediatric Diabetes Self-Management Resources



**Hannah Hatchett**

## **Advisory Board Member**

My name is Hannah Hatchett. I am 14 years old and I will be entering high school next semester. At age 9 I was diagnosed with type one diabetes. I was the first sibling with type one, so I introduced it

to my family. My dream someday is to be a nurse and to be able to help other diabetics as they go through the adjustments of living with type one!

# Project: Family-Centered Tailoring of Pediatric Diabetes Self-Management Resources



**Dana Mortenson**

**Advisory Board Member**

Dana is 17 years old and is a member of Project ACE's youth advisory board. In addition to competing on horseback, Dana is interested in learning how other teenagers her age are managing their diabetes and their experiences. She is a youth ambassador for Diabetes since Diagnosis and has raised over \$5,000 for research thus far. In 5th grade Dana also organized a Diabetes Walk and raised over \$2,500.

# Project: Family-Centered Tailoring of Pediatric Diabetes Self-Management Resources



**Tasha Scott**

**Senior Research Assistant, Family-Centered Tailoring of Pediatric Diabetes Self-Management Resources**

**University of Wisconsin School of Medicine and Public Health**

Tasha Scott is the senior research assistant in Dr. Elizabeth Cox's research group. She became a member of the team as an undergraduate at University of Wisconsin-Madison and stayed on after graduation. Tasha's 3.5 years with the group have given her the opportunity to be involved in all stages of the research process. Her academic background is in Communication Sciences and Disorders, steering her research interests towards complex medical conditions such as Autism Spectrum Disorder and Cerebral Palsy.