Casey Hooke: Her Practice and Passion for Reducing Fatigue in Children with Cancer

The Center for Children with Special Health Care Needs is delighted to welcome Mary (Casey) Hooke, PhD, RN, CPON, to the School of Nursing as a tenure-track assistant professor. Hooke, who joined the school in January 2011, continues to practice as a pediatric clinical nurse specialist (CNS) at Children's Hospitals & Clinics of Minnesota. She brings a rich 25-year history of clinical practice as a CNS in pediatric oncology and is a nationally known nursing leader in the Children's Oncology Group, the world’s largest, cooperative children’s cancer research entity that brings together nurses, treatment centers, and other health care providers to treat cancer in children, adolescents, and young adults. Hooke also co-chairs the Nursing Research Sub-Committee of the Children’s Oncology Group.

Dr. Hooke is passionate about promoting the healthy development of children and adolescents with cancer by reducing symptoms that interfere with their health and quality of life. Her program of research focuses on reducing fatigue and related symptoms in children and adolescents during and after cancer treatment. Hooke continues to build on her dissertation research Fatigue, Physical Activity, and Carnitine Plasma Levels in Children Receiving Chemotherapy, by examining the relationship between fatigue, physical performance, and carnitine among children (ages 6-12 years) and adolescents (ages 13-17 years) undergoing chemotherapy treatment for cancer.

Hooke is currently the principal investigator of two studies. In her study Physical Activity and Fatigue in Children and Adolescents with Cancer, funded by the St. Baldrick’s Foundation, she is evaluating increased physical activity to decrease fatigue in children with leukemia. The goal of this study is to explore innovative measurement of physical activity and evaluate an activity intervention during maintenance chemotherapy for acute lymphocytic leukemia. In her second study, Yoga for Children and Adolescents after Completing Cancer Treatment, funded by Alex’s Lemonade Stand, Hooke is assessing the effect of a six-week yoga program on fatigue, sleep, and balance.
FROM THE DIRECTOR

Leadership has been a hallmark of our Center for Children with Special Health Care Needs since it was first established in 1993, with funding from the Maternal Child Health Bureau (MCHB)/Health Resources and Services Administration (HRSA). Our history and focus on preparing graduate level pediatric leaders with a specialty in children and youth with special health care needs (CYSCHN), positions the center to boldly address the recommendations in the Institute of Medicine report, The Future of Nursing: Leading, Change, Advancing Health.

Center faculty, trainees, and graduates are actively engaged in a broad range of leadership roles to advance the health and quality of life for children and youth with special health care needs. Through advocacy and policy, education, research and scholarship, faculty promote high quality community-based health care and services for CYSCHN and their families. We prepare pediatric nursing leaders and provide continuing education and technical assistance in the center to address the faculty and pediatric nursing workforce shortage—educating nurse leaders who promote the health of this vulnerable population.

Preparing pediatric nursing leaders. To date, 172 pediatric graduate student trainees have been supported by the Center for Children with Special Health Care Needs. Congratulations to our 16 pediatric graduates (two PhD; six DNP; and eight master’s pediatric nurse practitioner graduates), who completed their programs this year A special thank you to the preceptors and mentors who provided excellent learning and leadership opportunities for these graduates.

Providing continuing education and technical assistance. Center faculty, students, and alumni are leaders in providing continuing education and consultation on a variety of pediatric, family-centered care and leadership topics. Take advantage of these free CE modules and resources available on our website at www.nursing.umn.edu/ccshcn.

We so value our consultations and partnerships with our outstanding 25 CSHCN Advisory Board Members who represent key local, state, and regional representatives serving CYSCHN. The Advisory Board includes representatives from family advocacy organizations, the Minnesota Department of Health and Title V programs, health care and school systems, and interdisciplinary MCH educational partners. Advisory Board members provide input about center recruitment initiatives, continuing education topics, student leadership experiences, and opportunities and topics for our annual Leadership Forum.

Ann Garwick PhD, RN, LP, LMFT, FAAN

ADVISORY BOARD

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Partnering to Prepare Leaders

Center faculty, students, and alumni are committed to enhancing the quality of care for children and youth with special health care needs through advocacy, education, evidence-based practice, research, and health care reform. Collaborations with stakeholders and partners at the local, state, and national level are key to preparing future pediatric nursing leaders and achieving quality outcomes for children and youth with special health care needs. The following examples illustrate the range of leadership activities of center faculty, graduates, and trainees in local, state, and national practice, policy and research initiatives.

Local

Integrating Research into Practice
Alumni John Belew, PhD ’10, RN, MS, CDDN, is a nurse researcher at Gillette Children’s Specialty Healthcare in St. Paul, Minnesota. Through leading nursing and multidisciplinary clinical research initiatives to improve patient care, Belew brings rich clinical and research expertise to his nurse researcher role with children and young adults with intellectual disabilities. Read “The Best of Both Worlds” featured in the 2011 spring/summer issue of Minnesota Nursing at www.nursing.umn.edu/magazine.

Community Outreach and Asthma Research - Head Start
Cheri Friedrich, DNP, RN, CNP, serves on the Ramsey County Community Action Partnership-Head Start/Early Head Start Health Services Advisory Committee in St. Paul, Minnesota. This partnership provides an opportunity to share health information with Head Start, open doors for research, and has the potential to provide learning venues for our students. This community-based partnership has also resulted in the development of web-based asthma education and resources through the Get a Head Start on Asthma Project (Ann Garwick, PI). For more information about this project, go to www.nursing.umn.edu/GetaHeadStartonAsthma.

State

Advancing Practice through Policy
Through work with the Minnesota APRN Legislative Coalition, Mary Chesney, PhD, RN, CNP, Linda Lindeke, PhD, RN, CNP, FAAN, and several other School of Nursing faculty are advocating to remove barriers that prevent advanced practice registered nurses (APRN’s) from practicing at the highest level of their education. Read “Advancing the Practice” featured in the 2011 spring/summer issue of Minnesota Nursing at www.nursing.umn.edu/magazine.

Leadership in Health Care Reform
Mary Chesney, PhD, RN, CNP, is the co-chair of the Minnesota Department of Health’s Health Care Home Outcomes Measurement Committee. She was also appointed by the Minnesota Nurses Association to serve on the legislatively mandated Minnesota Health Care Reform Review Council.

Preparing Leaders in Palliative Care in Rural and Underserved Areas
Susan O’Conner-Von, PhD, RNC, is serving as the expert faculty member on the U.S. Department of Health and Human Services, Health Resources and Services Administration, Rural Health Workforce Development Program grant entitled Minnesota Health Net’s Palliative Care Initiative. The goal of this plan is to educate, support, recruit, and retain primary care providers and other health care professionals who have a commitment to providing palliative care in the Minnesota Health Network.

Minnesota Department of Health Asthma Initiative
Ann Garwick, PhD, RN, FAAN, was appointed to the Minnesota Department of Health Asthma Evaluation Advisory Committee. The charge of this committee is to develop an evaluation plan to monitor and evaluate process and outcome data related to the core initiatives in the MDH state asthma plan “Addressing Asthma from a Public Health Perspective.”
National

Health Care Home and Medical Home
Linda Lindeke, PhD, RN, CNP, FAAN, and her colleague Barbara Deloian, PhD, RN, CPNP, Health Services Director for the Colorado Medical Home Initiative, Colorado Department of Public Health and Environment, are co-chairs of the newly formed Pediatric Health Care Home special interest group for the National Association of Pediatric Nurse Practitioners. This group, which is attracting pediatric nurse practitioner members throughout the United States, focuses on evolving models of pediatric care delivery and coordination.

Lindeke is also a member of the MCHB-funded Project Advisory Committee for the Pediatric Medical Home Project of the American Academy of Pediatrics. In that capacity she is leading the development of a webinar on the care of children with asthma and their families in a primary care medical home.

Pediatric Health Care Quality Standards
Linda Lindeke, PhD, RN, CNP, FAAN, is working with several national projects funded by the Agency for Health Quality Research (AHRQ), including the Center of Excellence on Quality Measure Development for Children with Complex Needs (COE4CCN). Under the leadership of Dr. Rita Mangione-Smith, this four-year project is charged by the Center for Medicare and Medicaid Services (CMS) and AHRQ to develop measures of care coordination within the context of the Medical Home for all CSHCN including those with mental health co-morbidities. The RAND Corporation is a key partner in this work, as well as state agencies in Washington state and Minnesota.

Health Care Home Research
Ann Garwick, PhD, RN, FAAN, and Wendy Looman, PhD, RN, CNP, have partnered with U of M Professor Stanley Finkelstein, PhD, and James McCord, MD, from Children’s Hospitals & Clinics of Minnesota, on a four-year, $2.1 million funded NIH/National Institute of Nursing study titled Telehealth Nursing Intervention for Children with Complex Health Care Needs. The study will evaluate the impact of interactive video technology on the quality and cost of care coordination and case management for children with complex health care needs. DNP graduate Mary Erickson and DNP student Catherine Erickson are also working on this project.

Center Study Shows Impact of Health Care Home on Parent Coping
Having a health care home (an approach to primary care where providers, families, and patients work in partnership to improve health outcomes and quality of life for individuals with chronic health conditions and disabilities) has been associated with better outcomes for children, but few studies have looked at how this model of care might be related to a family’s well-being.

Center trainees, Angela Drummond ’10, and Abby Phillips ’10 with Associate Professor Wendy Looman, PhD, RN, CNP, conducted a secondary analysis of data from a national survey of more than 18,000 children with special health care needs. The findings showed that children who had a health care home and who received family-centered care were more likely to have parents who were coping well. These findings, published in the February 2011 issue of Journal of Pediatric Health Care, underscore the importance of family centered care for families raising children with special health care needs.

Kudos to our Graduates

PhD
Jehad Adwan, PhD, RN, is a clinical assistant professor in the School of Nursing whose dissertation focused on *Pediatric Nurses’ Grief Experience: Its Relationship with Burnout and Job Satisfaction*. Adwan is integrating his research findings into his clinical practice and teaching roles and plans to develop interventions for nurses experiencing the loss of pediatric patients in hospital settings.

Mary Mescher Benbenek, PhD, RN, FNP, PNP, is a clinical assistant professor and the new coordinator of the School of Nursing Family Nurse Practitioner specialty. Her dissertation focused on *Enablers and Barriers to Factors Contributing to Bone Health Among Early Adolescent Somali Girls*. Benbenek continues her community-based connections to improve the health of Somali girls and their families through her clinical practice and her scholarship.

Post-Masters Doctor of Nursing Practice (DNP)
The following systems change projects conducted by our DNP graduates are making a difference in improving care for children in primary and specialty care settings as well as in school and community-based settings.

- **Cynthia Brady**: Improving Access to Pulmonary Care for Children with Sickle Cell Disease
- **Joan (Jodi) Chrastek**: Increase Access: Pediatric End of Life Education
- **Kara Jacobsen**: Evidence-Based Protocol for Addressing Weight Concerns in Preschool Children in an Inner-city Pediatric Clinic
- **Tammy John**: An Evidence-Based School Nursing Asthma Intervention in Elementary Schools
- **Cyndy Krepps-Hoffer**: Changing Providers’ Referral Patterns Related to Fluoride Varnish in Well-Child Care Checkups
- **Rachel Sullivan**: Physical Activity and Juvenile Idiopathic Arthritis: Implementing a Web-Based Education Treatment Component

Master’s
The projects listed below—completed by our master’s graduates—have implications for clinical practice and future research.

- **Jennifer Benton**: Characteristics of Children Ages Six Months to Three Years Who have been to the Dentist for Preventive Care
- **Amber Caster**: The Association between having a Healthcare Home and Childhood Obesity
- **Beth Johnson**: Variables Associated with Transition Discussions Among Children with Heart Conditions and their Providers
- **Leah Kann**: The Relationship between Perceived Neighborhood Safety and Screen Time among Children
- **Amanda Kack Flannery**: A Clinical Decision Tool for Assessment, Diagnosis, and Management of Deformational Plagiocephaly: Evidence for Practice
- **Christina McCarthy**: Characteristics of Individuals Receiving the HPV Vaccination
- **Heather Naylor**: The Presence of a Health Care Home and its Relationship to Early Childhood Caries in Preschool Children
- **Kristi Theede**: Education for Donation
**HONORS & AWARDS**

Former CSHCN PhD trainee **Mary Benbenek**, PhD, RN, CNP, dissertation *Enablers and Barriers to Factors Contributing to Bone Health Among Early Adolescent Somali Girls* was selected to represent the School of Nursing in the U of M Graduate School’s Best Dissertation Award competition.

**Mary Chesney**, PhD, RN, CNP, was awarded the Best Dissertation Research Award from the Family Health Section of the Midwest Nursing Research Society for her innovative dissertation research on *Discrepancies between Pre-Adoption Expectations and Post-Adoption Experiences for Parents of Children Adopted from Institutional Care*.

CSHCN PhD student **Tambra Dahlheimer**, RN, received the Eileen Vinnes Kalow Fellowship in Children’s Health and the Amy Wenger Fellowship in Pediatric Nursing for the 2010-2011 academic year.

Linda Lindeke, PhD, RN, CNP, FAAN, was inducted as a fellow into the American Academy of Nursing. She was selected for her contributions in promoting the health of children through research, education, and advocacy by way of the advanced practice nursing role and coordination of care for children with special health care needs, improving the quality of life and informing health care reform. Lindeke also received a State Award for Nurse Practitioner Excellence from the American Academy of Nurse Practitioners (AANP). She was honored for her scholarship, advocacy, and mentoring of nurse practitioners.

**Susan O’Conner-Von**, PhD, RN, was named Hospice, Palliative Care, and Home Health Nurse of the Year by the March of Dimes-Minnesota. She was recognized for her outstanding contributions in pain and palliative care of children and adolescents and the development of innovative web-based programs developed for youth undergoing painful procedures.

Former CSHCN trainee **Janet Dutcher**, DNP ’10, RN, NNP, received the inaugural Rising Star Award from the School of Nursing Alumni Society on April 29, 2011. The award was presented to Dutcher for her devoted service and professional accomplishments as a neonatal nurse practitioner and for her work with neonates with life-threatening illnesses and their families. Dutcher is a nurse manager in the Neonatal Intensive Care Unit at the Avera Health Center in Sioux Falls, South Dakota. She has developed an innovative palliative care program that is helping families deal with the devastating realities of having a dying baby or a baby with life-limiting conditions.

CSHCN trainee **Amanda Kack Flannery**, RN, was named a fellow in the U of M Leadership Education in Neurodevelopment and Related Disabilities Program (LEND). Flannery also received an Abbott Nutritional Grant Award to attend the National Association of Pediatric Nurse Practitioners meeting.

**Kathy Kreitzer**, MS ’93, RN, CNP, received the Pediatric Nurse Practitioner of the Year Award from the Minnesota chapter of the National Association of Pediatric Nurse Practitioners (NAPNAP). Kreitzer is a long-standing center preceptor who has contributed to the preparation of our PNP graduates. She has made innumerable contributions to child and family health in her role as a PNP with underserved communities in Minneapolis.

Former CSHCN trainee **Jane Larter**, MS, RN, was named School Nurse of the Year by the March of Dimes-Minnesota. She was honored for creating a model of school nursing that supports high-quality student services and promotes wellness for both students and staff. Larter is a school district nurse at Delano Public Schools in Delano, Minnesota.
SELECTED CENTER

Publications


Faculty are currently working on research projects that are:
• Comparing roles of the school nurse in coordinating asthma care for adolescents in the U.S. and Iceland (Garwick & Looman).
• Developing and testing a telehealth nursing intervention for children with complex health care needs (Garwick & Looman).
• Promoting healthy youth development among high risk youth (Garwick).
• Reducing childhood obesity through family and community-based interventions (Garwick).
• Reducing fatigue and other cancer related symptoms through exercise interventions (Hooke).
• Supporting healthy transitions to adulthood and adult care for youth with mobility impairments (Garwick).

In addition to our Center for Children with Special Health Care Needs grant, center faculty are also leading educational grants to:
• Develop interdisciplinary palliative care experts in rural and underserved areas (O’Connor-Von).
• Evaluate a dual track for acute and primary care for pediatric nurse practitioner programs (Lindeke).
• Support the education of advanced practice nurses (Lindeke; Chesney).

LEADERSHIP THROUGH INNOVATIONS

Research and Education Grants
Center faculty are engaged in a variety of research and education grants funded by federal (CDC, HRSA, NIH), School of Nursing Foundation, and professional nursing organizations that promote the health of children and youth with special health care needs and the preparation of pediatric nursing leaders.

Select Center

Grants
Adwan, Jehad (PI)
Pediatric Nurses’ Grief Experience over the Death of Their Patients: Its Relationship with Burnout and Job Satisfaction
Sigma Theta Tau International – Zeta Chapter

Benbenek, Mary (PI)
Sunlight Exposure, Dietary, and Dress Habits of Somali Girls
Sigma Theta Tau International - Zeta Chapter

Garwick, Ann (Co-PI)
Scal, Peter (PI)
Internet-Based Health Care Transition Program
Faculty Research Development Program/
UMN Academic Health Center (AHC)

Garwick, Ann (Co-PI)
Looman, Wendy (Co-PI)
A Comparison of the Roles of School Nurses in Coordinating Asthma Care for Preadolescents and Adolescents in Iceland and St. Paul, MN
School of Nursing Foundation

Garwick, Ann (Co-I)
Fulkerson, Jayne (PI)
Healthy Home Offerings via the Mealtime Environment (HOME) Plus.
NIH/NIDDK (R01)

Garwick, Ann (Co-I)
Scal, Peter (PI)
Transition to Adulthood and Adult Health Care for Youth with Mobility Impairments
CDC/U48

Garwick, Ann (Co-I)
Sieving, Renee (PI) Prime Time: Health Promotion for Multiple Risk Behaviors
NIH/NINR (R01)

Hooke, Mary Catherine (Casey) (PI)
Physical Activity and Fatigue in Children and Adolescents with Cancer
St. Baldrick’s Foundation

Hooke, Mary Catherine (Casey) (PI)
Yoga for Children and Adolescents after Completing Cancer Treatment, Alex’s Lemonade Stand
Alex’s Lemonade Stand

Mary Chesney (PI)
Advanced Education Nursing Traineeship (AENT)
Health Resources and Services Administration/ U.S. Department of Health and Human Services

Lindeke, Linda (Co-I)
Pediatric Nurse Practitioner Programs: A Dual Track for Acute Care and Primary Care Association of Faculties of PNP Programs (APFNAP)

Looman, Wendy: Garwick, Ann (Co-Is)
PI: Finkelstein, Stanley
Telehealth Nursing Intervention for Children with Complex Health Care Needs (R01)
NIH/NINR R01

O’Conner-Von, Susan (Co-I)
MN Health Net Palliative Care Initiative
Health Resources and Services Administration/ U.S. Department of Health and Human Services
Continuing Education

Eight self-paced CSHCN continuing education modules with Minnesota Board of Nursing or ANCC contact hours are available at no cost. Check out the center’s Continuing Education page at www.nursing.umn.edu/CCSHCN.

NEW Resources Available!

Federal and Minnesota Health Reform Initiatives: Implications for Child and Adolescent Health
By Mary Chesney, PhD, RN, CNP
Dr. Chesney shares timely information about legislative health care reform initiatives at the state and national level and addresses the important role of nursing in advocating for child and adolescent health. This module updates pediatric nurses, APRNs, physicians, and other pediatric health care providers about recent federal and state health care reform legislation and its potential impact on children with special health care needs and their families.

Be the Change: A Parent’s Perspective on Family-Centered Care
By Theresa Zimanske
Theresa Zimanske, founder of Be the Change, LLC, shares the patient and family perspective in healthcare and her family’s real life experiences to strengthen relationships and create partnerships with health care providers. Zimanske eloquently shares her story of a family’s journey with a son who died from a complicated rare disease. The Be the Change module will be available online after July 1, 2011.

Our Programs

Advance your leadership skills and prepare for faculty, research, clinical practice, administrative, advocacy, and health policy roles. Broaden your scope of practice and become a pediatric nurse practitioner or pediatric clinical nurse specialist.

• Doctorate with a research focus on children and families with special health care needs (PhD)
• Doctorate of Nursing Practice (DNP)

Learn More!

Check out the center’s website to learn more about our educational programs, continuing education opportunities, and free online resources on pediatric nursing and leadership. You will find resources on topics ranging from school nursing to youth with chronic health conditions transitioning to adulthood.

www.nursing.umn.edu/ccshcn