



*The Investiture of*

**Debra E. Weese-Mayer, MD**

as the

Cummings-Mayer Professor  
of Pediatric Autonomic Medicine

**Friday, May 29, 2015**

*Program*

**Mary J.C. Hendrix, PhD**

President & Scientific Director

Stanley Manne Children's Research Institute

Children's Research Fund Professor

William G. Swartchild, Jr. Distinguished Research Professor

Professor, Robert H. Lurie Comprehensive Cancer Center

Northwestern University Feinberg School of Medicine

**Jan-Marino (Nino) Ramirez, PhD**

Director, Center for Integrative Brain Research

Seattle Children's Research Institute

Associate Director, Center on Human Development and Disability

Co-Director, Neurodevelopmental Research Consortium

Professor of Neurological Surgery & Pediatrics

Adjunct Professor for Pathology, Physiology, & Biophysics

University of Washington School of Medicine

**Debra E. Weese-Mayer, MD**

Cummings-Mayer Professor of Pediatric Autonomic Medicine

Professor, Pediatrics-Autonomic Medicine

*Closing Remarks*



**Debra E. Weese-Mayer, MD**, is the Cummings-Mayer Professor of Pediatric Autonomic Medicine and a professor of pediatrics at Northwestern University Feinberg School of Medicine. She also is chief of the Center for Autonomic Medicine in Pediatrics at the Ann & Robert H. Lurie Children's Hospital of Chicago and the Stanley Manne Children's Research Institute. She is recognized internationally for her seminal discoveries, leadership, and clinical and research expertise in respiratory and autonomic disorders of infancy, childhood, and adulthood including Sudden Infant Death Syndrome (SIDS),

Congenital Central Hypoventilation Syndrome (CCHS), Rett Syndrome, Rapid-onset Obesity with Hypothalamic Dysfunction, Hypoventilation and Autonomic Dysregulation (ROHHAD), and Familial Dysautonomia.

Dr. Weese-Mayer was born and raised in Chicago and its environs. In 1974, she earned her bachelor of science degree in anthropology-zoology from the University of Michigan. She then earned her medical degree from the University of Chicago Pritzker School of Medicine in 1978. Dr. Weese-Mayer completed her residency in pediatrics at McGaw Children's Memorial Hospital in Chicago as well as a fellowship in neonatal-perinatal medicine. Simultaneously, she trained as a neonatal fellow and then an American Lung Association research fellow at the medical school at Northwestern University, specializing in respiratory control. She first joined the faculty at Northwestern University in 1986 as an assistant professor in pediatrics.

In September 1989, Dr. Weese-Mayer was recruited to Rush University Medical Center to develop a Center for SIDS Research and Disorders of Respiratory Control, and to serve as its first director. In this position, she was responsible for initiating this unique program that incorporated clinical research, clinical care, and basic science research—an early model of translational medicine in pediatrics. In July 1993, she was promoted to the position of section chief of pediatric respiratory medicine. In this role, she was responsible for expanding the Center into a full respiratory medicine section with expertise in pulmonary physiology, mechanics, exercise, and lung injury, as well as expansion of the respiratory physiology laboratory, building of the pulmonary function testing and exercise laboratory, and advancing the translational research medicine program.

Dr. Weese-Mayer was recruited to McGaw Children's Memorial Hospital in January 2008 to build the first Center for Autonomic Medicine in Pediatrics (CAMP) in the world and to head CAMP research in the translational medicine department at the Children's Memorial Research Center. CAMP is an interdisciplinary translational medicine program dedicated to the study of diseases affecting the autonomic nervous system in children and young adults

with both rare and more common disorders. The Center applies research-driven innovations to transform care of the special patients served by CAMP internationally and locally. As chief of the Center, now a part of Lurie Children's Hospital, Dr. Weese-Mayer is the model physician-scientist who "does it all": innovative basic science and clinical investigator, outstanding clinician, and devoted mentor. At each step of her career, Dr. Weese-Mayer has been recognized as a pioneer and intellectual risk-taker, consistently introducing new disciplines in pediatrics wherever she finds a need to better serve her rare disease patients and to understand the basic underpinnings of affected systems.

Among her numerous honors and accolades, Dr. Weese-Mayer was awarded the March of Dimes Jonas Salk Health Leadership Award in Research in 2005. She patented a PHOX2B genetic test to diagnose CCHS, allowing early confirmation of diagnosis, parental mosaicism, and prenatal testing (patent donated to the Chicago Community Trust, proceeds support CCHS research). She gained approval of a new billing code for Pupillometry (a handheld autonomic tool) by the American Medical Association, and she developed and introduced the autonomic (dys)regulation questionnaire tool to the highly selective NHGRI-funded PhenX Toolkit. She has authored more than 250 peer-reviewed articles, reviews, chapters, and abstracts. Her clinical and research programs have grown to include a wide-ranging referral base in 48 states and 50 foreign countries.

As leader of the largest and most comprehensive integrated Center of Excellence in the world for CCHS and ROHHAD (research and clinical care) and founder and chair of the International Neurocristopathy Research Consortium, Dr. Weese-Mayer has many long term career objectives. The first is to expand the model pediatric autonomic medicine program with wholly innovative protocols and technology to evaluate all systems served by the autonomic nervous system in a normative cohort and in disease, for both in-and out-patient application. She is on a quest to identify the genetic or epigenetic basis of ROHHAD, SIDS, and stillbirth. Through the Neurocristopathy Consortium, Dr. Weese-Mayer aims to expand knowledge of rare disorders of neural crest origin (Hirschsprung disease, neural crest tumors, CCHS, ROHHAD) in the context of related and more common disorders (diabetes, orthostatic hypotension, postural orthostatic tachycardia, Raynaud's phenomenon, regional pain syndrome, and more). This would improve the visibility of rare disease medicine and the value of studying rare diseases to understand basic systems in health. In addition, she looks forward to training the next generation of experts in respiratory and autonomic control, serving as a catalyst for cross-silo care and investigation (rather than one system at a time) by teaching automatic integrated awareness of the individual systems that sustain life with application to day-to-day care.

**The Cummings-Mayer Professorship in Pediatric Autonomic Medicine** was established with a gift made by Mrs. Beatrice Cummings Mayer through the Robert & Beatrice Mayer Foundation. Mrs. Mayer is a generous, longtime benefactor of Northwestern University. For more than 40 years, she has supported the University's annual fund and special projects at the Mary & Leigh Block Museum of Art, as well as student scholarships and other initiatives at the Weinberg College of Arts & Sciences. This prestigious new Cummings-Mayer Professorship will accelerate translational research that centers on children affected by rare diseases of respiratory and autonomic regulation. This is the first endowed professorship in the world in the emerging discipline of pediatric autonomic medicine. As the first faculty to hold this prestigious chair, Dr. Weese-Mayer and her work in pediatric autonomic medicine will serve as a true bridge that transforms clinical medicine in order to: decrease disease burden by improving clinical outcomes and overall survival for affected individuals with neurocristopathies; advance understanding of the basic underpinnings of neural crest development and the autonomic nervous system; and introduce drug development for other rare and more common neurocristopathies.

