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Two Pioneers Honored for Lifetime Achievements in Helping Children with Medical Complexity

Aurora, Colo (July 17, 2024) – The Maternal and Child Health Bureau's Children and Youth with Special Health Care Needs Research Network (CYSHCNet) is pleased to announce Nora Wells and John Gordon as the 2024 recipients of [The Pediatric Complex Care Lifetime Achievement Award](#).

The award celebrates individuals who have made lifelong, exceptional, long-lasting contributions to help children with medical complexity in many areas, including clinical care delivery, advocacy, policy, administration, research, and education/training. The award also honors lived experience incorporated into any of these areas.

The recipients were selected for the award based on nominations and letters of support by a multi-disciplinary committee of clinicians, lived experience partners, administrators, policymakers, and researchers for children with medical complexity. Recipients receive an honorarium provided by Lucile Packard Foundation for Children's Health.

Award Presentation

Presentation of the award to Wells and Gordon will occur on Sept. 26, 2024 from 2:30-3:30 p.m. ET through a live-streamed webinar. [Register to join the presentation](#).

About Nora Wells

When Nora Wells encountered a visitation policy that kept her from staying with her infant son, Dan, in the hospital, she didn't remain silent. She reached out to other families and sympathetic medical providers, and helped establish a key network of families and professionals ready to use their voices to advocate for changes that would help countless children with medical complexity and their families. Over five decades of tireless work to ensure families like hers had the policies, support, and resources they need to care for their children, Nora and others forged influential partnerships with local, state, and national stakeholders. She helped families educate providers and policymakers about the critical needs of their families, leading to groundbreaking legislation passed by state public health officials and providers for children with medical complexity. Visionary leaders in the Division of Children with Special Health Care Needs at the

Maternal and Child Health Bureau (MCHB) took notice and family-centered care surged to the forefront of the national health care conversation. In the early 1990s, these efforts led to the formation of Family Voices, a national family-run nonprofit organization serving families of children and youth with special healthcare needs across the country. Nora served as Executive Director of Family Voices from 2014 until her retirement in 2023. Her vision, leadership, and mentorship continue to inspire family engagement throughout the health care system, giving children with medical complexity the opportunity to thrive throughout their childhood and beyond.

About John Gordon

Over twenty years ago, pediatric intensivist John Gordon, M.D., was decades into his career caring for children with medical complexity who were facing serious, life-threatening acute illnesses that necessitated intensive care services for treatment. In 2002, John was offered the opportunity to improve the health and well-being of children with medical complexity and their families by developing a novel program to provide comprehensive care coordination and medical co-management both in and out of hospital. Through his leadership, clinical expertise, and the collaboration of numerous families, colleagues, clinicians, administrators, and payers, the Special Needs Program at Children's Wisconsin has become a financially sustainable complex care model now serving over 800 medically complex and fragile children annually. John disseminated the lessons learned with the program through a series of important peer-reviewed publications and presentations describing program structure, processes, personnel, finances, and outcomes. Through this work, John has influenced clinical programs for children with medical complexity worldwide. Now retired, John's legacy continues to inspire pediatric clinicians everywhere who are striving to help children with medical complexity and their families.

About Children with Medical Complexity

Children with medical complexity (CMC) have one or more complex chronic conditions that may last a lifetime. They often experience severe functional limitations, and use medications and medical technology to optimize their health and wellbeing. They are high utilizers of health care resources, meaning they frequently engage health services across the care continuum to meet their healthcare needs.

About the Award

[The Pediatric Complex Care Lifetime Achievement Award](#) is supported by CYSHCNet [funded by the Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB)], [Family Voices](#), [Academic Pediatrics Association Complex Care and Disability Special Interest Group](#), and [Children's Hospital Association](#).



About CYSHCNet

CYSHCNet brings academic researchers and lived experience partners together to study the health care system issues that matter most to children and youth with special health care needs (CYSHCN) and their families. The network helps CYSHCN and their families by advancing knowledge and implementation of optimal health systems through innovative, rigorous multi-site studies, far reaching dissemination of findings, meaningful partnerships with families, and strong training of emerging CYSHCN investigators. Learn more: <https://cyshcnet.org/>.

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