FamilieSCN2A Foundation Announces Third SCN2A Multidisciplinary Care Center at Boston Children's Hospital

New center expands access to specialized, coordinated SCN2A care while connecting families to cutting-edge research and emerging treatments



FamilieSCN2A opens Multidisciplinary Center at Boston Children's Hospital

BOSTON, MA, UNITED STATES, September 17, 2026 / EINPresswire.com/ -- The FamilieSCN2A Foundation is proud to announce the official opening of its third SCN2A Multidisciplinary Care Center (MDC) at Boston Children's Hospital, marking another major step in the Foundation's effort to build a network of specialized clinical centers for individuals living with SCN2A-related disorders.

The Boston Children's SCN2A MDC will be led by Heather Olson, MD; Kimberly Wiltrout, MD; and genetic counselor Lacey Smith, MS, CGC, bringing together extensive expertise in epilepsy, neurogenetics, genetics, and the complex neurological and developmental needs associated with SCN2A-related disorders.

SCN2A-related disorders (SRDs) encompass a broad spectrum of neurodevelopmental conditions caused by changes in the SCN2A gene. Individuals may experience epilepsy, autism, intellectual and developmental disabilities, movement disorders, sleep disturbances, gastrointestinal challenges, and other significant medical and developmental needs.

The FamilieSCN2A MDC model brings SCN2A expertise together around the patient and family, providing coordinated, proactive care while connecting clinical care with research. Patients seen through the MDC will also have opportunities to participate in cutting-edge research studies and, when eligible, clinical trials evaluating potential new treatments.

"Opening our third MDC is another important step toward ensuring that an SCN2A diagnosis

comes with access to clinicians who truly understand this disorder," said Leah Myers, Founder and Executive Director of the FamilieSCN2A Foundation. "For families managing an incredibly complex rare disease, having experts who understand SCN2A and communicate across specialties can fundamentally change the experience of care. Boston Children's has been part of the SCN2A story for many years, and we are incredibly proud to formalize and expand that relationship through this center."



The FamilieSCN2A Foundation - learn the difference 'families' make.

Boston Children's Hospital has longstanding expertise in epilepsy genetics and neurogenetic disorders, including years of experience caring for individuals with SCN2A and contributing to research advancing the understanding of the disorder.

"We have had the privilege of caring for children with SCN2A-related disorders for quite some time," said Lacey Smith, MS, CGC. "Establishing this dedicated MDC allows us to bring that expertise to families in a more structured and coordinated way. We want families to know they have a team here that understands their child's unique needs and is committed to providing specialized, comprehensive care."

> We have spent a decade building the research infrastructure needed to move SCN2A toward treatments. Now, as potential therapies move closer to patients, clinical infrastructure matters more than ever."
>
> *Leah Myers, co-founder and Executive Director*

The Boston Children's MDC will also be part of a growing, connected network designed to encourage collaboration among SCN2A experts, share knowledge and best practices, and strengthen both clinical care and research across centers.

"Through a collaboration with FamilieSCN2A, we can expand clinical care and research in SCN2A-related disorders through creation of a Multidisciplinary Center at Boston Children's Hospital. The center will support coordination of multi-specialty care and parallel clinic-based research. SCN2A-related disorders are already a key component of our well-established Epilepsy Genetics Program and will

continue to be so. We now additionally look forward to this opportunity to expand and organize our clinical and research program with direct input from the families who we serve," said Heather Olson, MD

“We are thrilled to officially open the SCN2A MDC at Boston Children’s Hospital,” said Kimberly Wiltrout, MD. “We are committed to bringing together exceptional expertise and personalized care to create a seamless and supportive experience for every family we serve. We also look forward to fostering meaningful collaboration among specialists within our Center and with colleagues across the growing network of SCN2A MDCs, strengthening opportunities to advance both clinical care and research for the SCN2A community.”

For local families, the opening represents something even more personal: access to specialized SCN2A care close to home.

“Watching this milestone become a reality means the world to our family,” said Carla Forbes, co-founder of the FamilieSCN2A Foundation and mother to Colin, who lives with an SCN2A-related disorder. “As a local family, knowing this level of specialized SCN2A care is now available right here at Boston Children’s is incredibly meaningful. It reassures us that Colin is backed by an extraordinary community of experts and advocates who are deeply committed to changing lives and finding the answers our children deserve.”

Building Care Today — and Preparing for Treatments Tomorrow

A critical component of the FamilieSCN2A MDC network is connecting expert clinical care with research and treatment development. Patients receiving care through the Boston Children’s MDC will have opportunities to participate in SCN2A research and, when eligible, clinical trials evaluating potential new treatments.

As the SCN2A therapeutic landscape advances, specialized centers can also help build the infrastructure needed for successful clinical trials by deepening understanding of the disorder, identifying meaningful clinical outcomes, and preparing families and clinical teams for emerging therapies.

“We have spent more than a decade building the science and research infrastructure needed to move SCN2A toward treatments,” Myers added. “Now, as potential therapies move closer to patients, clinical infrastructure matters more than ever. We need centers that know our families, understand the complexity and variability of SCN2A, and are prepared for the treatments coming through the pipeline. Our MDC network is an important part of that strategy.”

The Boston Children’s center becomes the third SCN2A MDC established with the FamilieSCN2A Foundation, joining centers at UTHealth Houston and Children’s Hospital Colorado. The Foundation plans to continue strategically expanding the network in the United States and

internationally to increase access to expert care, research participation, and emerging treatments.

Disclosure Statement: Heather Olson, MD serves on the scientific and medical advisory board for the FamilieSCN2A Foundation.

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