

International SCN8A Alliance Partners w/ Children's Hospital Colorado to Expand Multidisciplinary Care for SCN8A

New partnership expands expert, family-centered care for SCN8A disorders at Children's Hospital Colorado, improving access and outcomes for affected families.

DENVER, CO, UNITED STATES, April 8, 2025 /EINPresswire.com/ -- The International [SCN8A](#) Alliance is thrilled to announce a collaboration with Children's Hospital Colorado Neurogenetics Clinic to enhance care for individuals living with [SCN8A-related disorders](#). This partnership will

expand access to expert multidisciplinary care, providing families with a dedicated clinical team that understands the complexities of SCN8A-related disorders, which often include intractable seizures, movement disorders, autism, and a range of other neurological and physical challenges.

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Comprehensive, patient-centered care at the renowned hospital enhances access to specialized treatment and accelerates research for families affected by SCN8A-related disorders”

Gabrielle Conecker

The clinic, led by Megan Abbott, MD, at the hospital's state-of-the-art Multidisciplinary Clinic (MDC) on Anschutz Medical Campus, offers a model of care designed to address the unique needs of patients with rare genetic disorders. The MDC is the largest of its kind, featuring 26 exam rooms, advanced telemedicine capabilities, and a patient-centered design that fosters both clinical excellence and family comfort.

“We are thrilled to partner with Children's Hospital

Colorado to ensure that SCN8A families have access to the highest level of expert, coordinated care,” said Gabi Conecker, Executive Director of the International SCN8A Alliance. “It is powerful to also be partnering with the FamilieSCN2A Foundation to ensure that our families, who share



many features and often struggle to find doctors that understand our conditions, have access to informed, specialized care. By bringing together experts in neurology, genetics, and other key specialties, we are providing a crucial resource for families navigating these challenging disorders."

Collaboration Driving Innovation in Rare Disease Care

This initiative marks an important step forward in the effort to improve treatment and accelerate research for SCN8A-related disorders. The partnership between the International SCN8A Alliance, FamilieSCN2A Foundation, and Children's Hospital Colorado represents a unique model of cross-disorder collaboration, recognizing the overlapping challenges faced by families impacted by SCN-related disorders.

Leah Myers, Executive Director of the FamilieSCN2A Foundation, the largest global advocacy organization for SCN2A-related disorders, expressed

the foundation's enthusiasm for this expansion. "When your child has a rare disease like SRD, parents often have to become experts because most doctors have never even heard of it. That's why having access to specialized care is so meaningful to our community. Knowing that Dr. Abbott will oversee the care of our SCN2A Warriors brings immense peace of mind—because every decision, every treatment, and every moment matters. There's no room for guesswork when a life depends on truly understanding the complexities of this condition." said Myers.

A Comprehensive Approach to SCN8A Care

Families visiting the MDC at Children's Hospital Colorado will benefit from a streamlined approach to care, reducing the burden of navigating multiple appointments across different specialties. The clinic provides:



Collaborating for a cure

International SCN8A Alliance - Collaborating for a Cure!



Families affected by SCN8A from across the globe, pictured in daily life, showing the real faces behind the disorder.

- Specialized neurological care, including precision treatment plans for epilepsy, movement disorders, and neurodevelopmental challenges.
- Genetic counseling to help families understand their child's diagnosis and available treatment options.
- Access to multidisciplinary specialists, including epilepsy experts, developmental pediatricians, physiotherapists, and more.
- A family-centered environment, featuring large exam rooms, a cozy lounge, and custom-designed play areas to create a welcoming space for children and families.

Dr. Megan Abbott, who leads the initiative, emphasized the clinic's dual focus on clinical excellence and research advancement. "Today marks a significant milestone as we open the doors to our new multidisciplinary clinic dedicated to supporting individuals with SCN2A and SCN8A-related disorders. Our mission is to provide specialized care, advanced treatment options, and compassionate support for families navigating these rare genetic conditions. I am thrilled to start this clinic and give patients and families the personalized care they truly deserve!"

Looking Ahead: Expanding Access to Rare Disease Care

The International SCN8A Alliance remains committed to expanding clinical resources and research opportunities for families affected by SCN8A-related disorders. Through ongoing collaboration with leading hospitals and advocacy organizations, the Alliance continues to drive progress toward better treatments and, ultimately, a cure.

To learn more about the International SCN8A Alliance and its efforts to support families, visit www.scn8aalliance.org.

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