What is a Patient Registry?
A patient registry simply stores an individual’s personal information and their medical history. Since registries are usually disease-specific, the collective data of all patients that share a disease help clinicians and researchers to better understand causes of the disease and potentially lead to discoveries that can help the patient groups.

Why is a Patient Registry important?
A critical amount of clinical information is needed to understand the cause of any disease and we are just at the beginning of bringing together this information in order to understand ADCY5.

The purpose of registries is to gather information from each patient that may shed light on understanding how to pursue treatments. Since diagnosis of ADCY5 mutations are rare, few patients have been identified. As a result, it is critical that every child is registered to gather the maximum amount of information. As research progresses and clinical trials become possible, no time will be lost on gathering patient information needed for the trials as it will already be completed.

About Us
ADCY5 Connect supports and provides resources to the ADCY5 community. The organization whose goal is to connect affected families with research and clinician communities to accelerate the alleviation of ADCY5-related dyskinesia.

www.adcy5.org

Contact Us

Our Partners

RARE Science is a non-profit research organization whose mission is to accelerate finding therapeutics for children with rare disease through a common computational platform that enables data sharing across all stakeholders.

E-mail:info@rarescience.org
Web: www.rarescience.org

Agility Clinical is the first orphan drug-focused clinical trial services organization in the US. Due to experience and innovation in small trial design the organization has become known for successful Orphan/Rare clinical trial design and execution.

E-mail:info@agility-clinical.com
Web: www.agility-clinical.com
What is ADCY5?

A mutation in the ADCY5 gene, results in ADCY5-related dyskinesia, a motion disorder that causes involuntary muscle movement such as tics and spasms. With the small group of patients identified there is broad variation of how individuals are affected. The disorder’s onset ranges from infant to late adolescent age. Infants with severe cases may experience a delay in motor milestones.

ADCY5-related dyskinesia is likely under-recognized or misdiagnosed as another motion disorder such as Cerebral Palsy. At this point, because of the low number of patients that have been identified, it is challenging for researchers and clinicians to characterize the disease. Currently diagnosis can only be achieved through genetic testing and there are inadequate medicines available to treat or cure patients. As more individuals are gathered through a registry, faster ways toward diagnosis and treatments may be determined.

How do I join the ADCY5 Patient Registry?

Joining our patient community is easy and can be started with a call or email to (insert contact info for ADCY5 connect)

The steps are simple: first, signing a medical release so the medical record information can be collected, and second, retrieving your medical records. This can be completed independently or with our assistance.

**Coming together is the beginning. Keeping together is progress. Working together is success.**

--- Henry Ford

What will we do with the data?

The medical records will be held in a secure HIPAA compliant computer database. Data from medical records will then be standardized into a common format and entered into an anonymized secure database. The database will ensure privacy, but will enable clinicians and researchers to conduct analytical analysis to identify biological trends of the disease both on an individual level and across the patient community. The more patients analyzed, the better the biology of the disease will be understood. This will enable creation of a “baseline,” or measured understanding of the disease, for clinical trials.

Seven Benefits of having a Patient Registry

1. A connection to the ADCY5 community for support and resources
2. A resource and tool to organize and compare medical records
3. Increased awareness for the disorder to drive faster diagnosis
4. Collectively, the information builds a foundation for clinical researchers to understand the disease and potential treatments.
5. A registry is not bound to any geographical location; it can unite patients across the world
6. Once patients are registered, the registry can be an avenue to access potential ADCY5 clinical trials
7. Can lead to collaboration and improved care, even in the absence of an immediate cure.

Moving towards a cure one child at a time

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Every child is an important piece of the puzzle