

Assessments Offered by the NDRD

- Comprehensive physical and neurological exams
- Nutrition and feeding evaluations
- Hearing and vision tests
- Cognitive testing
- Speech and language assessment
- Motor testing
- Educational testing

Support Services Offered by the NDRD

- Advocacy and education
- Advice about individualized education programs (IEPs)
- Management recommendations, including adaptive equipment
- Medical treatment for seizures and spasticity
- Visual and hearing aids
- Behavioral interventions
- Sensory integration
- Comfort measures
- Medical decision making
- End of life care



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For further information, access our website at www.chp.edu/ndrd or email us at NDRD@chp.edu.

Program for the Study of Neurodevelopment in Rare Disorders (NDRD)

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University of Pittsburgh

School of Medicine

Program for the Study of Neurodevelopment in Rare Disorders (NDRD)



Helping children and families affected by rare genetic diseases through evaluation, education, and intervention.





www.chp.edu/ndrd

History of the NDRD

The Program for the Study of Neurodevelopment in Rare Disorders (NDRD) was established in 2000, in order to help children and support families and service providers facing the challenges of genetic neurodegenerative disorders.



Our program gives parents and caregivers a comprehensive understanding of these disorders and their overall impact on the child's functional abilities. The program initially focused on lysosomal storage disorders, but now includes other genetic disorders of the brain.



Neurodegenerative diseases affect multiple systems of the body, such as the gastrointestinal system, nervous system, and muscles. Therefore, interventions must address

the whole child and all areas of functional impairment.

The specialists in the NDRD program work as a team to evaluate all aspects of a child's development to come to a complete understanding of the child's overall abilities, strengths, and weaknesses.

These diseases often cause developmental delays and difficulty in maintaining the skills needed to carry out basic activities of daily living. Comprehensive interventions that address these developmental challenges can improve a child's ability to function independently.

NDRD Expertise

Since the year 2000, the NDRD program has performed more than 2,100 assessments on more than 700 children with rare neurodegenerative disorders. With this growing comprehensive database of information, gathered from patients across the United States and throughout the world, the NDRD has developed expertise in treating children with these rare genetic disorders.



This broad database of knowledge allows us to design interventions tailored for each child's specific strengths and weaknesses.

Each child can be helped to develop to his or her full potential through use of assistive devices and augmentative communication methods.

The NDRD also supports families by helping them connect with specialists in their area to help with therapy, adaptive equipment, and assistive technologies. For appointments and consultations, call the NDRD at 412-692-9955.