

Batten and Neurodegenerative Disease Program

Created in the fall of 2020 with a generous donation from Mila's Miracle Foundation

The purpose of our program and clinic is to serve patients and families affected by Batten Disease and other Neurodegenerative Diseases. Our program's goal is to provide world-class expertise and multi-disciplinary care to patients, through personalized care plans and access to cutting edge research to advance the care of these rare conditions.

Purpose of the Clinic

Our services include consultation and evaluation for all people with a genetically diagnosed Neurodegenerative Disease. Our expert providers ensure they are receiving the needed therapies, treatments and services to support the best possible quality of life. We work to participate in natural history data collection and ground-breaking clinical research trials, collaborating with other clinics across the country and the world. Our hope is to work with families and their primary medical team to create a care plan that places the child's needs at the center of care.

Program Providers

Neurology	Physical Therapy	Social Work
Neuropsychology	Occupational Therapy	Nutrition
Special Care Clinic	Speech Therapy	Nursing
Rehabilitation Medicine	Palliative Care	Family Navigator

Clinic

Families begin the day in Neurology clinic for cognitive assessments with our Neuropsychologist. Next, they see providers in the Special Care Clinic – a pediatrician with expertise in complex and chronic conditions and a pediatric-focused registered dietician. Finally, they are seen in our multi-disciplinary clinic space, with assessments by a Neurologist, doctor of Rehabilitative medicine, and physical, occupational, and speech therapists. The nurse coordinator plans out the clinic day in advance and communicates with family to make sure the schedule for the day is clear and feasible for the child.

Families can prepare for what is a long day at the hospital by: bringing snacks and/or meals and feeding supplies, communication devices, orthotics and anything needed to get child comfortably through the day. Our goal is to help your child leave the day with a plan of care that streamlines and optimizes their medical and therapy cares. We recognize that this will be a long day, but we hope to bring together an expert team for your child's rare condition, and efficiently offer you the best advice to improve your child's quality of life. We anticipate most patients being seen once or twice a year in multi-disciplinary clinic, though more frequent check-ins with individual providers may also be needed (for adjustment of medications, attention to nutrition, etc).

How to get scheduled?

Please contact us with your child's name, birthdate, your preferred phone number, insurance card(s) and genetic testing results. BND Clinic- Phone- 720-777-7453, Fax- Attn: BND Clinic, Fax: 720-478-7103, email - BNDP@childrenscolorado.org



13123 E 16th Ave, Aurora, CO 80045
720-777-1234 | childrenscolorado.org

Meet the Team

Batten and Neurodegenerative Disease Program



Scott Demarest, MD
Neurologist
Clinic Medical Director



Kourtney Santucci, MD
Special Care Clinic
Clinic Co-Medical Director



Tristen Dinkel, RN
Clinic Nurse
Coordinator



Kristina Malik, MD
Special Care Clinic



Kilby Mann, MD
Rehabilitation Medicine



Lauren Treat, MD
Palliative Care



Andrea Miele, PhD
Neuropsychology



Andrea Schneider, OTD, OTR/L
Occupational Therapy



Camille Stewart, MA, CCC-SLP
Speech Therapy



Dana Bennink, PT, DPT
Physical Therapy



Alicia Camuto, LCSW
Social Work



Colette Christen, BA
Family Navigator