# Neurogenetic MDC Clinic

*Our Clinic started seeing patients in the winter of 2020, with the generous donations of passionate foundations such as Mila's Miracle Foundation and Rare Sisters Batten Foundation. In the summer of 2021, we welcomed foundations Project 8p, SLC6A1 Connect, STXBP1 Foundation and Ring14 USA to join our collaborative program. These foundations support not only clinical care, but our research to see patients of rare neurogenetic disorders together. The purpose of our program and clinic is to serve patients and families affected by 8p Chromosome changes, Ring14, STXBP1, SLC6A1 and Batten Disease. 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. Our hope is to make the community stronger, by foundations, families and providers of rare disorders working together to improve outcomes and quality of life.*

## Purpose of the Clinic

Our services include consultation and evaluation for all people attending our clinic. ALL AGES ARE WELCOME. 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 providers 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

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| Neurology | Occupational Therapy | Nursing |
| Neuropsychology | Speech Therapy | Family Navigator |
| Special Care Clinic | Palliative Care | Genetics |
| Rehabilitation Medicine | Social Work | Genetic Counseling |
| Physical Therapy | Nutrition | Behavioral Medicine |

## Clinic

Families begin the visit the day prior in Neurology clinic for cognitive assessments with our Neuropsychologist. The next day- 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, Geneticist/Genetic Counselor, doctor of Rehabilitative medicine, Developmental Pediatrician and PT, OT, and ST. 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. Follow up ranges from every 6 months to every 2 years.

## How to get scheduled?

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

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