

January 10, 2022

Neurogenetics Clinic at Children's Hospital Colorado

Introduction to Families

This presentation will be recorded, but we will stop recording prior to the Q&A.

Feel free to put your questions in the chat throughout the presentation so you don't forget them! We will answer as we can, or during the Q&A session.

You are able to ask questions anonymously if that is more comfortable.



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Welcome



Children's Hospital Colorado Neurogenetics Clinic



Scott Demarest, MD

Neurologist

Clinic Co-Medical Director



Margarita Saenz, MD

Genetics

Clinic Co-Medical Director



Tristen Dinkel, MSPC, RN

Clinic Nurse Coordinator



Lexa Mackie, CCRP

**Clinical Research
Project Coordinator**



Core Providers



Kristina Malik, MD
Special Care Clinic



Kourtney Santucci, MD
Special Care Clinic



Kilby Mann, MD
Rehabilitation Medicine



Lauren Treat, MD
Palliative Care



Ann Reynolds, MD
Developmental Pediatrics



Andrea Miele, PhD
Neuropsychology



Dana Bennink, PT, DPT
Physical Therapy



Drew Mancini, MS, CCC-SLP
Speech Therapy



Andrea Schneider, OTD, OTR/L
Occupational Therapy



Katie Angione, MS, CGC
Genetic Counselor



Alicia Camuto, LCSW
Social Work



Colette Christen, BA
Family Navigator



Clinic Overview

Logistics

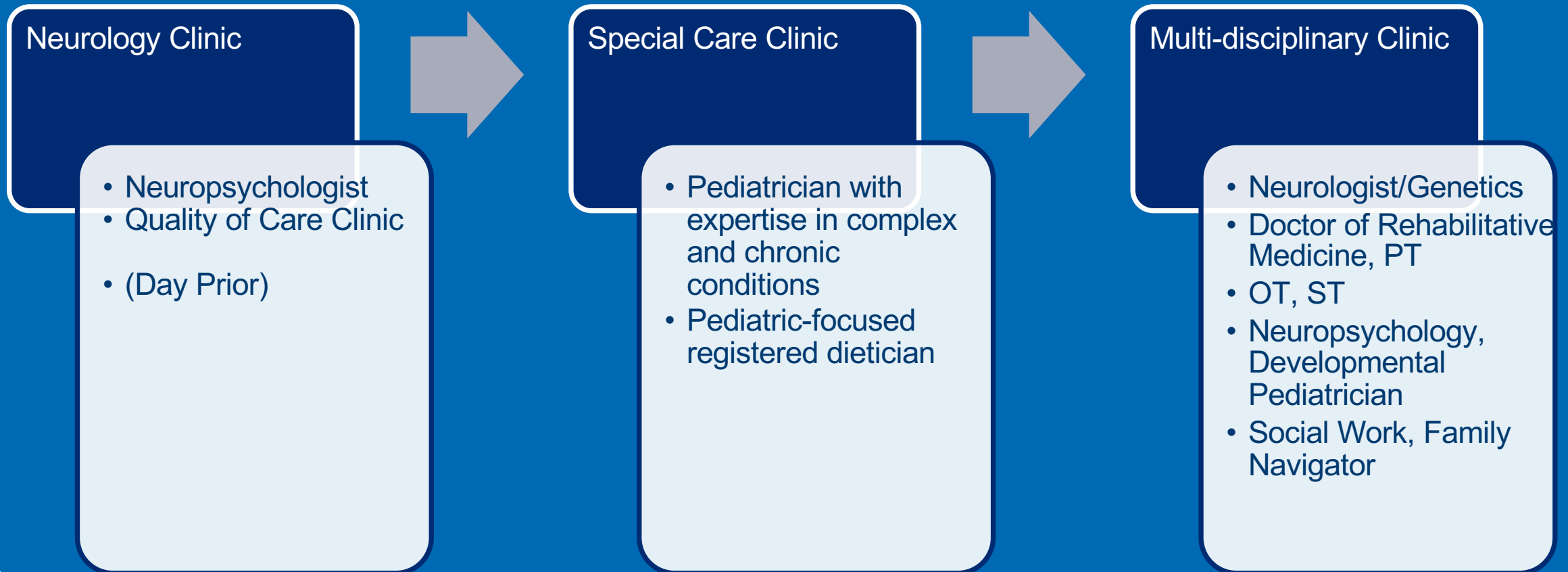
- First Friday of Each Month- Afternoon
 - 12:30-4pm
- Multi-Disciplinary- you stay in one place
- SCC- in morning (1 hour)
- Neuropsychology/Quality of Care Clinic the day prior
- Insurance/Medicaid is billed for appointment
- Out of state - Yes please!
- Out of country- Yes, lets figure it out.

Diagnosis:

- 8p mutation
- Ring14
- STXBP1
- SLC6A1



Clinic Overview – Example Flow



Interested in the Clinic?

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



Research



Research

- Why research?
- Lexa will consent with you.
- Looking at natural history of disorders.
- May require extra questionnaires.
- Shared effort
 - Other organizations may ask for consents as well
- Participation is not required for clinical care and will not change your care.



Clinic VS. Research

- Clinic is for clinical care.
 - Clinic visit vs. Research visit
- Intake forms, Neuropsych testing- are for clinical decision making and providing care.
 - But help provide data for natural history- for consented patients we will build into database
- Some pieces of process might duplicate, please be patient



Q & A



Thank you!



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