Allan-Herndon-Dudley Syndrome Multidisciplinary Care Team Guide





Introduction

Managing MCT-8 deficiency requires collaboration across a diverse team of healthcare professionals. This guide outlines the roles of each team member, care coordination strategies, and how to empower families and caregivers to take an active role in care planning.

Overview of MCT-8 Deficiency

MCT-8 deficiency (Allan-Herndon-Dudley syndrome) is caused by mutations in the SLC16A2 gene, which encodes the thyroid hormone transporter MCT8. This results in impaired transport of thyroid hormones into the brain, leading to intellectual disabilities, severe developmental delays, and muscle weakness.



The Importance of Multidisciplinary Care

Specialists communicate about diseases by sharing medical records, test results, and consulting with each other for advice, often using technology like electronic health records to facilitate secure information exchange and ensure better patient care coordination.

Role of Each Specialist

1. Primary Care Physician (PCP)

- Central coordinator for all medical care.
- Ensures regular check-ups and preventive care.

2. Endocrinologist

 Monitors thyroid hormone levels and manages treatment with thyroid hormone analogs.

3. Neurologist

- Manages developmental delays, muscle tone abnormalities, and seizures.
- Provides treatments for spasticity and motor disorders.

4. Geneticist

- Offers genetic counseling and education on the inheritance pattern.
- Guides family planning discussions.

5. Dietitian

- Creates nutrition plans to address feeding difficulties and undernutrition.
- · Recommends appropriate supplements.

6. Speech and Language Pathologist

 Develops therapies for feeding, swallowing, and communication support.

7. Physical Therapist

- Designs individualized programs to promote mobility, strength, and flexibility.
- Recommends assistive devices if needed.

8. Social Worker

- Connects families to financial resources & counseling services.
- Offers emotional support to caregivers...

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Coordination and Communication

- **Team Meetings:** Schedule regular case reviews to adjust the care plan as needed.
- **Shared Care Plan:** Use a centralized document accessible to all specialists and caregivers.
- Caregiver Involvement: Ensure parents or guardians are involved in all decisions.

Multidisciplinary Care Plan

Patient Name:	
Diagnosis:	
Team Members:	
Current Health Status:	
Care Goals:	
Action Plan:	
Review Date:	



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