Comprehensive Duchenne Care
Duchenne is not just a disease of the muscles. It affects every system in the human body.
Care Guides

• Duchenne Family Guide
  – Partnered with MDA, Treat-NMD, and WDO
  – Includes the Duchenne Care Considerations in an “easier to digest” format

• New Diagnosis and Early Care Guide
  – Introduction to Duchenne/Becker and genetic testing, adjusting to the diagnosis and support, early care, and introduction to clinical trials

• Imperatives for Healthcare Providers
  – One-page fact sheets for healthcare providers unfamiliar with Duchenne
  – Versions for pediatric and adult patients
  – Also available in Spanish

• Range of Motion Guide
  – Summary of current physical therapy guidelines for parents and physical therapists

#EndDuchenne

parentprojectmd.org/supportmaterials
UPDATED!
EDUCATION MATTERS GUIDES FOR PARENTS & TEACHERS

www.parentprojectmd.org/classroom
Emergency Care Information

- PPMD App
  - Includes Duchenne emergency information
- PPMD emergency information cards
  - Also available in Spanish
- PPMD large weatherproof emergency information cards for wheelchairs, scooters, and backpacks
- PJ Nicholoff Steroid Protocol
  - Guide for families and healthcare providers to navigate steroid stress dosing, tapering, and what to do in the case of a missed dose
- Online Resources
  - Emergency care and hospital checklists
  - Caring for the Flu
  - Fracture management

#EndDuchenne
parentprojectmd.org/supportmaterials
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PPMD's 2020 End Duchenne [Remote] Tour: St. Louis, MO

Rehabilitation
Transition to Adult Care

Ann Modrcin, MD, EMBA
Pediatric Rehabilitation Medicine
Medical Director, PPMD Clinic
Medical Director, Transition to Adult Care Program

Children’s Mercy Kansas City
# Nerve and Muscle Clinic a PPMD Clinic

Comprehensive Diagnostic Workup and Longitudinal Care
We follow over 300 patients with muscle disorders

## Our Team

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Our Team

- Medical Director: Ann Modrcin, MD, EMBA
- Team Leaders: Rehabilitation Physicians/NPs
- Clinic Coordinator: Alexis Hazlett, RN

**Core Physicians/Providers:**
- Pulmonology
- Cardiology
- Genetics
- Rehabilitation

**Consultants:**
- Nephrology/Bone Density
- Ortho spine (consult)

**Same Day in Clinic Services**
- Physical Therapy/Occupational Therapy
- Respiratory Therapy with PFTs
- EKG, ECHO
- MSW
- Nutrition
- PACCT
- Wheelchair assessment/repair
- Orthotist/bracing
- Registries and Research Links
- Specialty Medication Programs

To make an appointment call Alexis at x73387 or email adhazlett@cmh.edu

Clinic is held all day, Mondays (except 4th) in Rehabilitation

Our Team
Rehabilitation Focus:

**Emphasis on FUNCTION**

- Multidisciplinary Care addresses the WHOLE PERSON medically
- The team communicates and sets goals together
- Best practices guide each specialist on when and what care you need
- Medications and research are always explored
- Our clinic is geared to take on any new medication through existing proven pathways

**Not just about Medical Care**

- What is important to you and your family?
- What are your hobbies and interests?
- Is your environment at home or school getting in the way of your independence?
- Equipment doesn’t have to be boring!
- Wheelchairs are not a sign of giving up, they are a way to stay independent, get to the playground first, go hiking
- We talk about exercise, sports, games, and inclusion
- We see more than Duchenne’s. We see HOPE and potential
Partners in Research

University of Kansas
Department of Neurology

Children's Mercy
KANSAS CITY

KU MEDICAL CENTER
The University of Kansas

Certified Duchenne Care Center
Transition to Adulthood Program

Learn how to manage and direct your health care, living situation, school or employment, income, insurance.

- Switching to a new doctor or clinic caring for adults - PPMD Adult Clinic vs Local Neurologist and Specialist Care
- Transition Planning starts at 15 with readiness assessments, goal setting and discussions at each clinic visit.
- Connecting with other teens and other education opportunities
- Tools and resources on our website
  
  www.childrensmercy.org/transition

Blake: Fuse Program Founder
Care Coordination for Duchenne Muscular Dystrophy

Alexis Hazlett, BSN, RN, CPN
Muscle and Nerve Clinic Coordinator
Rehabilitation Medicine Clinic
Children’s Mercy Hospital Kansas City
Role of a Care Coordinator:

- **Puzzle Master**
- **Educator**
- **Communication Specialist**
- **Patient and Family Advocate**

Go to person for any and everything
Multidisciplinary Care Team at CMH

- Physical Medicine and Rehabilitation
- Physical Therapy
- Occupational Therapy
- Pulmonology
  - Pulmonary Function Tests
- Cardiology
  - Echocardiograms, EKGs, Cardiac MRI’s
- Genetic Counselor
- Social Work
- Palliative Care Team
- Registered Dietician
- Nurse Coordinator

- Orthopedics
- Endocrinology
- Bone Mineral Health
- Psychologist/Behavioral Health
- Sleep Medicine
- Gastroenterologist
- Orthotics
- Seating and Equipment Specialists
Thank you!
Physical Therapy Management of Duchenne Muscular Dystrophy

Stephanie Orr, DPT, PCS, CNT
Children's Mercy Kansas City
Muscle/Nerve Clinic
Physical Therapy Role in Muscle and Nerve Clinic

- In the Muscle and Nerve Clinic, the child sees multiple specialists at one visit.
  - This approach helps create efficient and effective care and communication between you and your child’s providers.
- The Physical Therapist performs a thorough evaluation and helps to develop a plan of care based on findings.
  - Our goal is to help maintain function, promote mobility, reduce pain, and delay secondary effects of disease progression.
  - Assessments are completed one to two times per year or as needed.
Physical Therapy Assessment

• History:
  • Change in function since last visit, surgeries, current therapies

• Measures
  • Range of motion
  • Muscle strength
  • Pain assessment
  • Postural assessment

• Functional mobility
  • Transfers, walking, stairs, etc.
  • Standardized assessments for function tracking including 6MWT, Northstar, PUL 2.0

• Equipment
  • Review of current equipment and future needs

• Patient and Caregiver goals
Physical Therapy Recommendations

• The therapist will provide recommendations and interventions based on individual’s needs

• As a collaborative effort between providers, the PT helps with recommendations on equipment, bracing/splinting, equipment for mobility and environmental adaptations

• The PT can also provide exercises for home, recommendations for energy conservation and ways to delay muscle weakness and contractures

• Caregiver education is also emphasized to provide input on mechanics with transfers, assisting with exercises, education for outside therapists and teachers, and review of equipment needed to perform safe and efficient transfers
Cardiac Care in Children with Duchenne Muscular Dystrophy

Nikki Singh, MD
Pediatric Cardiology
Children’s Mercy Kansas City
Cardiac Care in DMD

• Boys with DMD will develop cardiac changes.
  • Dilated cardiomyopathy: Enlargement of heart chambers and decrease in cardiac function/squeeze
  • Variable progression for each child but majority by 18 years of age.

• Early detection with echocardiography.
  • Yearly until changes seen and then every 6 months.
  • Use of cardiac MRI for better imaging and to look for fibrosis

• Starting medications to hopefully delay or slow down changes in the heart.
  • Start medications around 10 years of age, even if cardiac function normal.
    • Angiotensin-converting enzyme inhibitor or angiotensin receptor blocker, mineralocorticoid antagonist, beta-adrenergic receptor blockers, diuretics
  • Unable to prevent changes from occurring
Thank You

Children’s Mercy
KANSAS CITY
Pulmonary Care & Duchenne Muscular Dystrophy
End Duchenne Tour 2020

Samira Naime MD
Department of Pulmonary and Sleep Medicine
Assistant Professor of Pediatric
UMKC School of Medicine
Respiratory Management

- Check for respiratory muscle strength
  - Spirometry
  - MIP
  - MEP
  - Peak cough flow
- Check oxygen and CO₂ level
- This is done every 6-12 months depending on degree of muscle weakness
- New therapies may be started depending on the test results (e.g., Cough assist)
Respiratory Management

- Screening for sleep related problems (e.g. snoring, daytime sleepiness, morning headaches)

- Sleep study may be ordered

- Different treatments for an abnormal sleep study
Goal of Pulmonary Care

- Regular doctor visits to check on breathing muscles
- Prevention of infection (influenza vaccine, pneumococcal vaccines)
- Performing the required therapies

**GOAL:**
- Decrease respiratory complications
- Improve quality of life
- Improve survival

https://www.parentprojectmd.org

Diagnosis and management of Duchenne muscular dystrophy, part 2: respiratory, cardiac, bone health, and orthopaedic management. Binkrant et al. The Lancet.
# Duchenne Pediatric Expert Panel

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