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

• 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

Find a routine that fits for your family and child.
Be reasonable in what will work into your daily schedule.
Prioritize based on your child’s needs and your physical therapist’s recommendations.

ANKLE NIGHT SPLINTS
A brace is used to provide a long (maintained) stretch by holding the foot in a better position for the course of several hours. Most often recommended for wearing overnight, if tolerated. They are often made of plastic and are made specifically to fit an individual’s foot and ankle by an orthotist. They are not recommended for wear during walking activities.

RESTING HAND SPLINTS
A splint is intended to support the hand, wrist, and fingers in a neutral or flat position when at rest. Resting hand splints are typically molded from a plastic material with Velcro straps and padding specifically to fit an individual’s hand and wrist. They should be custom-fitted by an experienced occupational therapist, physical therapist, or orthotist.

POSITIONING
Positioning consists of using bolsters, rolls, or pillows to position or support a body part in a good alignment. When individuals are spending increasing amounts of time in a seated position or lying down, muscles and joints become stiff more quickly. It is important to be sure they are in a good position to help maintain their range of motion and comfort.

STRETCHING
Stretching involves moving an individual’s body part (e.g., arm or leg) to their comfortable, available end range of motion. Stretches should be performed with a slow, gentle movement and held for a specific length of time. To view our series of stretching videos, please visit parentprojectmd.org/stretching.

STANDER
Standers are custom-fitted equipment designed to help an individual stand up for a prolonged amount of time.

SERIAL CASTING
Serial casting describes the process used to place a series of rigid casts over an individual’s joint (most often used for heel cords at the ankle). The casts are used to slowly increase range of motion at a specific joint. The joint is stretched “slightly” further with each new cast placement.

#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

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Duchenne Adult Expert Panel

Neuromuscular Care
Raghav Govindarajan, MD
*University of Missouri-Colombia*

Physical Medicine & Rehabilitation
Vovanti Jones, MD
*University of Missouri-Colombia*

Pulmonology
Jonathan Ang, MD
*University of Missouri-Colombia*

Gastroenterology
Vanessa Kuwajima, MD
*University of Missouri-Colombia*
Neuromuscular Clinics at the University of Missouri-Columbia Health Care
PPMD Certified Duchenne Care Center
Clinic Directors

Raghav Govindarajan, MD, Neurology Adult & Pediatrics
Vovanti Jones, MD PM&R Adult
Jane Anne Emerson PM&R Pediatrics
Physician Specialist

Jonathan Ang, MD
Pulmonology

Brian Bostick, MD, PhD
Cardiology

Vanessa Kuwajima, MD
Gastroenterology
Multidisciplinary Care Team

- Neurology
- Physical Medicine & Rehabilitation (PM&R)
- Pulmonary
- Cardiology
- Physical Therapy
- Occupational Therapy
- Social Work
- Nutrition
- Respiratory Therapy-DME provider
- Wheelchair DME provider
- Orthotics
- MA, Nurse
- Urology, Endocrinology, and Gastroenterology available on call
What is a physical medicine & rehab (PM&R) physician?

- Call me a: PM&R physician, Physiatrist, or Rehab Doctor
- We treat a wide variety of medical conditions affecting the brain, spinal cord, nerves, bones, joints, etc.
- We utilize treatments to maximize function and quality of life

- In the neuromuscular clinic our physiatrists (Dr. Jones & Dr. Emerson) specifically manage the rehab team that consists of therapist (PT/OT/speech therapy) and orthotics to design comprehensive patient centered care plans.
Pulmonary Care

Jonathan Ang MD
Pulmonary, Critical Care and Environmental Medicine
What does a Pulmonologist do?

• Monitor breathing status
  • Monitor Lung function with PFT’s
  • Prevent infections with vaccines

• Evaluate and treat for sleep problems
  • Discuss and screen for symptoms of OSA
  • Sleep study and treatment

• Evaluate for symptoms that show early breathing problems
  • Ask about recent hospitalizations, infections, illnesses
  • Check lung function and peak cough flow
What does a Pulmonologist do?

• Provide proper equipment to help with breathing and coughing
  • Cough assist device
  • BiPAP, CPAP
  • Ventilators
  • Education on proper use and care of equipment

• Evaluate Duchenne patients prior to surgery
What does a Pulmonologist do?

• Respiratory Management

- Monitoring lung muscle function
  - PFT
  - Peak Cough Flow
  - Sleep Study

- Assisted coughing
  - Cough assist device

- Lung volume recruitment
  - Nocturnally assisted ventilation
  - Daytime ventilation
  - Invasive ventilation
Thank You

For more information visit: https://www.parentprojectmd.org/care/care-guidelines/by-area/care-for-lung-muscles/

For any questions:
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Duchenne Adult Expert Panel

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