Comprehensive Duchenne Care

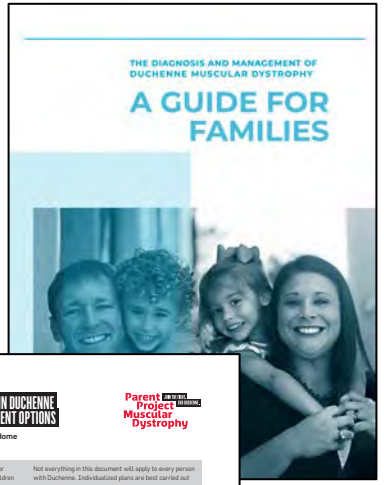
Parent Project Muscular Dystrophy

JOIN THE FIGHT. END DUCHENNE.

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



#EndDuchenne

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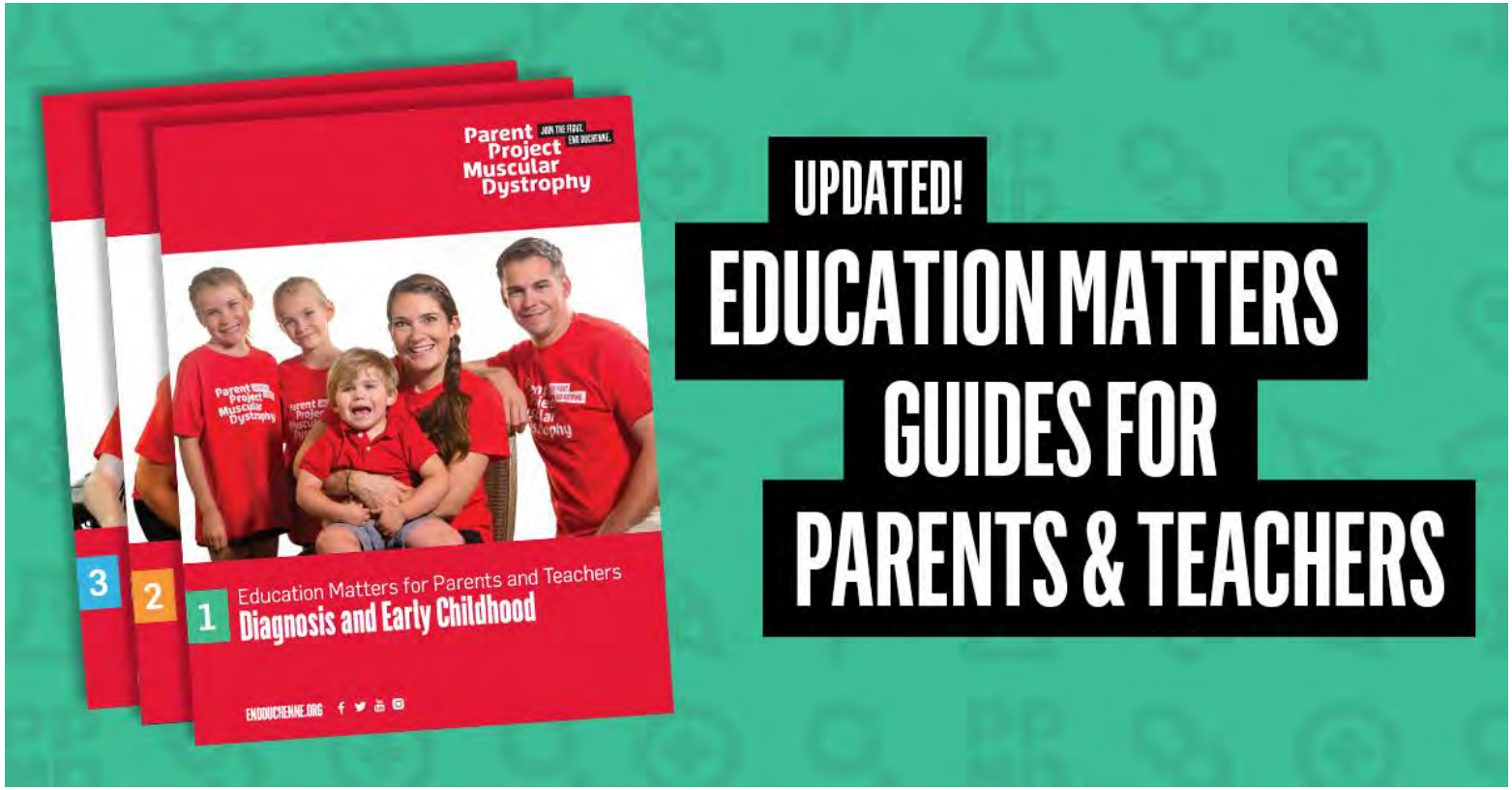

www.parentprojectmd.org/classroom

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?

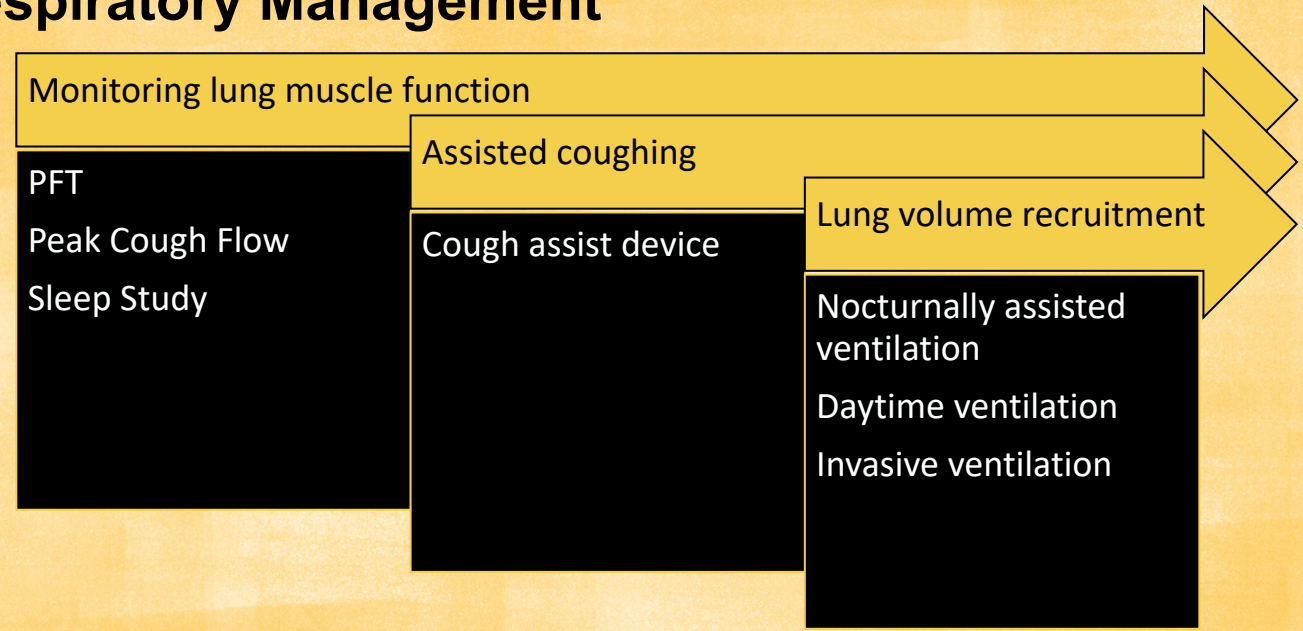
- **Monitor breathing status**
  - Monitor Lung function with PFT's
  - Prevent infections with vaccines
- **Evaluate and treat for sleep problems**
  - Discuss and screen for symptoms of OSA
  - Sleep study and treatment
- **Evaluate for symptoms that show early breathing problems**
  - Ask about recent 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**



HOW

Thank You

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

For any questions:

angj@health.missouri.edu

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