

# IMPERATIVES FOR DUCHENNE MD

a guide for providers

- D** **IAGNOSIS** • If developmental delay or elevated liver enzymes, do a creatine kinase (CK) (*ChildMuscleWeakness.org*) • If male patients have a high CK (CK>800), order full genetic testing for Duchenne muscular dystrophy • Discuss carrier testing/reproductive options for mother and testing for other family members
- U** **SE SUPPORT** • Direct to trustworthy, reliable online resources • Organize follow up via a comprehensive neuromuscular center with expertise in caring for people living with Duchenne • Offer contact with patient organizations (*ParentProjectMD.org*, *TREAT-NMD.eu*, *UPPMD.org*)
- C** **ORTICOSTEROIDS** • Start early! • Discuss the benefits and possible side effects of corticosteroids by age 3 years, or as young as possible • Evaluate efficacy and manage side effects of corticosteroids at each neuromuscular visit • Discuss the rationale for long term steroid management
- H** **EART** • Cardiology visit with imaging (echocardiogram or cardiac MRI) at diagnosis or by age 6, then every two years until age 10 (or as needed), then annually (or more often if needed) • Discuss cardiac medications if fibrosis is seen on cardiac MRI, for any decrease in cardiac function decreases from baseline or for heart failure (SF or shortening fraction <28%, EF or ejection fraction <55%)
- E** **VERY VISIT** • Monitor weight • Assess/discuss diet (healthy eating, calcium, vitamin D) • Evaluate swallowing/need for intervention • Treat GERD and constipation as necessary
- N** **EVER FORGET PHYSICAL & OCCUPATIONAL THERAPY, PHYSICAL MEDICINE & REHABILITATION** • Specialized evaluations every 4-6 months • Discuss contracture prevention (splints, stretches), appropriate exercise, assistive mobility devices (strollers, scooters, wheelchairs) and other assistive devices (beds, arm assistance, lifts, etc.)
- N** **OR BONE DENSITY** • If taking steroids, check 25-OH vitamin D prior to starting steroids, then annually • Supplement vitamin D as needed • Nutrition discussions of adequate calcium and vitamin D intake • Discuss measurement of bone density and use of bisphosphonates • Assess spine for scoliosis at each visit
- E** **VALUATE BREATHING** • Pulmonary function test at least once while ambulatory and every year after loss of ambulation • Discuss cough assist when cough peak flow is < 270 liters per minute or if cough becomes weaker (use during respiratory illnesses while ambulatory and daily and as needed after loss of ambulation) • Discuss nighttime Bi-PAP as needed or when forced vital capacity (FVC) < 30% • Keep immunizations (including pneumonia and annual flu) up to date • Treat respiratory infections promptly and aggressively • Do NOT give supplemental oxygen without monitoring CO2
- M** **ENTAL HEALTH** • Assess adjustment, coping, behavioral and emotional disorder and social isolation for the patient and family at each visit • Screen for learning disability, speech and language problems, attention deficit disorder (ADD), attention deficit and hyperactivity disorder (ADHD), autism and obsessive compulsive disorder (OCD) • Neurocognitive evaluation done at diagnosis and prior to formal schooling; screening/management as needed • Discuss the need for individualized/special educational plan
- D** **O:** Have patients/parents carry a copy of their last visit/note summary (including medications and neuromuscular contact information) and a Duchenne emergency card with them at all times • Use caution with all anesthesia; avoid succinylcholine

Center for Disease Control and  
Prevention Care Considerations:  
[ParentProjectMD.org/CareGuidelines](http://ParentProjectMD.org/CareGuidelines)

Family Friendly Version  
of the Care Considerations:  
[ParentProjectMD.org/CareGuidelinesFamilyPF](http://ParentProjectMD.org/CareGuidelinesFamilyPF)

Care for Duchenne:  
[ParentProjectMD.org/Care](http://ParentProjectMD.org/Care)