

**D****DIAGNOSIS**

- 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**UNDERSTAND BREATHING PROBLEMS**

- Pulmonary function test at least every year starting as young as possible ■ 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

C**CORTICOSTEROIDS**

- 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 lifelong steroid management ■ Never stop taking steroids abruptly ■ Discuss the need for stress dosing of steroids for illnesses or surgeries

H**HEART**

- Cardiology visit with imaging (cardiac MRI preferred; echocardiogram if cardiac MRI not available) every year from diagnosis 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% or ejection fraction <55%) or by age 10 even if findings are normal

E**ENDOCRINE**

- If taking steroids, check 25-OH vitamin D prior to starting steroids, then annually ■ Supplement vitamin D as needed ■ Encourage sun exposure ■ 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
- Monitor for puberty starting at 9 years of age for need for testosterone therapy

N**NEVER FORGET PHYSICAL & OCCUPATIONAL THERAPY**

- Specialized PT evaluations every 4-6 months ■ Stretching every day ■ Discuss and encourage contracture prevention (splints, stretches), appropriate exercise, assistive mobility devices (strollers, scooters, wheelchairs) and other assistive devices (beds, arm assistance, lifts, etc.) from the time of diagnosis

N**NUTRITION & GASTROINTESTINAL**

- Monitor weight ■ Assess/discuss diet (healthy eating, calcium, vitamin D) ■ Evaluate swallowing/need for intervention ■ Treat GERD and constipation as necessary ■ See your dentist every 6 months

E**EMERGENCY**

- 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 inhaled anesthesia ■ Never use succinylcholine

M**MENTAL HEALTH**

- Assess adjustment, coping, behavioral and emotional disorder and social isolation for the patient and family at each visit ■ Screen for learning disability (reading and math), 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**DON'T DO IT ALONE**

- 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 organizations (**ParentProjectMD.org**, **TREAT-NMD.eu**, **WorldDuchenne.org**)