Making a Plan and Lining Up Your Care Team

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What is a Care Team

• Complex diagnosis
  – Things change over the lifespan
  – Only focus on you need right now

• Multidisciplinary care
  – Takes a team that works together
  – CDCCs

• Several Subspecialists Needed
  – Need to know their subspecialty
  – Helpful if they also know Duchenne
Comprehensive Duchenne Care Team
Who Do You Need Right Now?

- Primary Care
- Neuromuscular Specialist (NMS)
- Physical Therapy (PT)
- Genetic Counselor
- Neuropsychology
Primary Care

• Primary Care Provider
  – Age appropriate well child care
  – Vaccination updates
  – Management of acute illnesses
  – Awareness of the diagnosis
  – Imperatives for DUCHENNE MD
  – Communication with your NMS
Neuromuscular Specialist (NMS)

- Neuromuscular specialist
  - Awareness of Duchenne
  - Discussion of therapies
    - Steroids
    - Clinical trials (steroid alternatives, gene therapy)
    - Mutation specific therapies
  - Coordination of care and communication with team, primary care and you
Physical Therapy (PT)

- PT
  - Assess current, and ongoing, strength, function and range of motion
  - Evaluation every 4-6 months
    - Generally need local/school PT to see more frequently
  - Daily Stretching
  - Nightly Bracing (moon boots!)
  - Positioning, posture, support
  - Assistive equipment (if needed)
  - Safety/fall prevention
Genetic Counselor

- **Genetic Counselor**
  - Identification of your child’s mutation
    - Genetic testing
    - Muscle biopsies (not usually needed)
  - Carrier testing
    - Test mom
    - Test other at risk female family members
      - Work backward through family history
    - Reproductive options
    - Decode Duchenne for carrier testing
The Duchenne Registry

- Patient reported outcomes registry
- Directed and managed by 2 genetic counselors
  - Free access to genetic counselors
  - For families and centers

Ann Martin and Jen Ely
Neuropsychology

• Neuropsychology
  – Assess cognitive delays
    • Autism spectrum disorders
    • Learning disabilities, pervasive developmental disorders (PDD)
    • Psychosocial issues (ADHD, ADD, OCD)
  – Mental Health
    • Anxiety
    • Depression
  – Assess behavioral issues
    • Normal childhood behaviors
    • Opposition defiant disorder (ODD)

- Recommended treatment/management
During the First Year

• Cardiology
  – Family history
  – Baseline and ongoing imaging

• Pulmonary
  – Meet the team
  – Baseline (when possible) and ongoing evaluation
Emergency Care

- Visit the PPMD website
- Emergency Card
- Download the Mobile App
- Get a Medical Alert Bracelet
- We are here to help
  - 24 hours a day
  - Call, text, email (FB is NOT best!)
  - Can connect with experts
Caring for Your Family

• Get Support
  – PPMD (State Connect Groups)
  – Online social groups (take with a grain of salt!!)

• Get Educated
  – You are here!

• Support Yourself and Your Relationships
  – Don’t forget yourself or your partner

• Support Your Children
  – Age appropriate discussion
  – Time for everyone

• Include Extended Family
  – Let your family in and let them help
You are Not Alone.
Thank you!