

# Making a Plan and Lining Up Your Care Team

**Parent  
Project  
Muscular  
Dystrophy**

JOIN THE FIGHT.  
END DUCHENNE.

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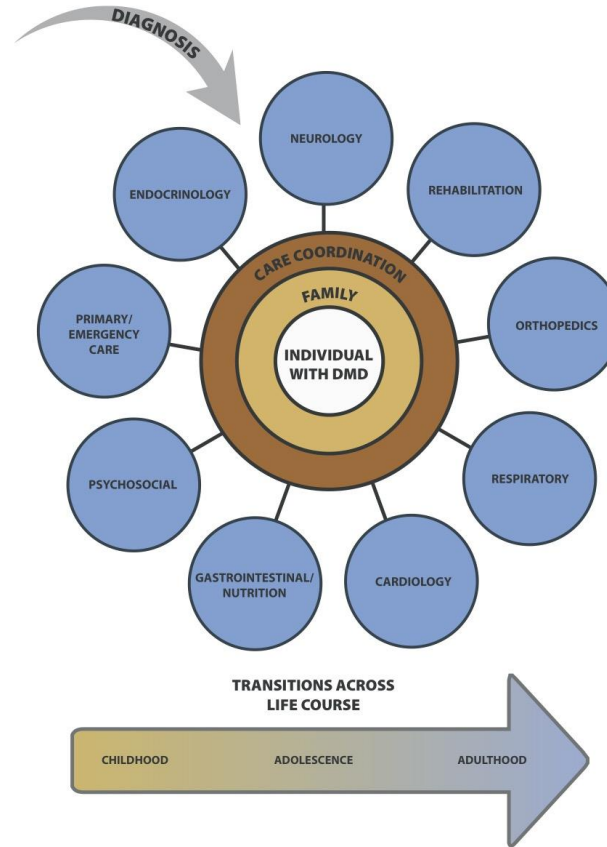
Manager Clinical Care

# 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 disorder (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

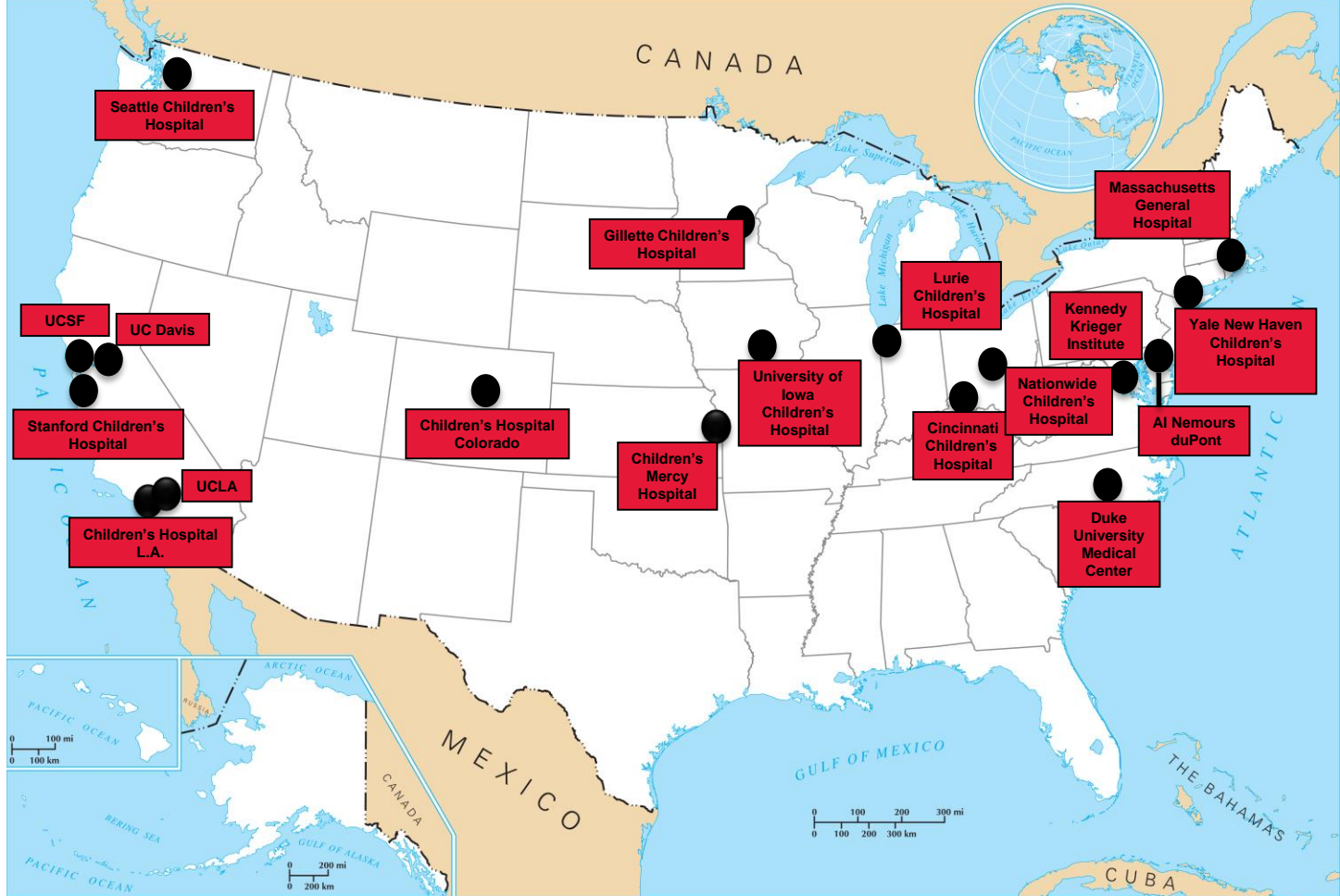
- **Cardiology**
  - Family history
  - Baseline and ongoing imaging
- **Pulmonary**
  - Meet the team
  - Baseline (when possible) and ongoing evaluation



# 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!**