Making a Plan & Lining Up Your Care Team

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What is the plan?

• Complex diagnosis and a complex system!
• Determine your goal
  – what’s best for him/me/us?
• Learn who’s on your team
  – Come together to achieve a common goal

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Who’s on my team?

- Team Roster/Key Players
- Coaches
- Cheerleaders & Fans
- Officials/Rule Keepers
- Sponsors

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Where’s the action?

- At home
- In community
- Away

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Your Healthcare Team

Comprehensive & Multidisciplinary

- Changes over time
- Works together
- DMD Knowledgeable
- Communicates with the home team

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Your First Team(s)

• Primary Care
• Neuromuscular Team
Primary Care – Medical Home

• Well child & annual exams - **IMPORTANT**
  – Continuity of Care over time
• Ongoing psychosocial care
  – Whole family health, coping/adjustment
• Keep immunizations up to date
  – Annual flu shots
Certified Duchenne Care Centers
Neuromuscular Care – To Start….

• Neuromuscular Specialist
• Care Coordinator/Nurse/Social Worker
• Physical Therapist
• Genetic Counseling
• Neuropsychology
Neuromuscular Specialist

• Knowledgeable about DMD!
• Presents options for treatment
  – Steroids, mutation specific therapy
• Presents options for clinical trials
• Oversees big plan of care
• Communicates with team & PCP

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Coordination of Care TEAM

- **Nurse** – Point of contact for questions!
  - Clarifies & simplifies information
  - Identifies healthcare needs
  - Available between visits
  - Helps communicate on your behalf

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Coordination of Care TEAM

- **Social Worker** – Point of contact for questions
  - Assesses coping & adjustment
  - Knows financial resources
  - Facilitates needs being met – referrals
  - Ensure exchange of information
Physical Therapist

• Assessment of strength & range of motion
  – Timed tests, motor function scales
• Instruction on stretching & orthotics
• Recommendation on activity/exercise
  – Safety, equipment, school/PE, ADLs
Genetic Counseling

• Explain genetic concepts & terminology
  – Meaning of mutations in relation to treatments or trials
  – Example: explaining terms like exons & genotypes

• Identify family who may benefit from genetic counseling
  – X-linked inheritance – “who may be a carrier?”
  – Review reproductive options
  – Facilitate testing

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DuchenneRegistry.org

- Free access to genetic counselors
- Advance research & speed progress towards treatments

- The Duchenne Registry Coordinator
  Email: coordinator@duchenneregistry.org
  Phone: (888) 520-8675
  Fax: (404) 935-0636
  https://www.duchenneregistry.org
Adding to the team …

- Neuropsychology
- Cardiology
- Pulmonary
- Endocrinology
Get Plugged In - Community

- Websites – Go for reliable!
- Social Media – Caution!
  - “Connect” Groups
- Explore your clinic team options
  - ESO Tours, conferences, fundraisers
- Connect with others in person

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ASSEMBLING A CARE TEAM

It is extremely important that you work with a multidisciplinary neuromuscular team that has experience and expertise managing all aspects of Duchenne and is able to meet the standards of Duchenne Care Guidelines.

Your neuromuscular team will be led by a neuromuscular specialist and will include many sub-specialists, each giving input into the best and most appropriate plan for your care. A care coordinator will help to organize your care, as well as communication between members of your team, your primary care providers, and you.
Thank you!