Transition
The Journey From the Pediatric World into Adulthood
Parent Project Muscular Dystrophy
End Duchenne Tour
April 28, 2018
What is Transition?
Your Future and A Lot of Work

No longer a Kid? Welcome to the mysterious world of Adulthood

We call it transition – You call it growing up

• Normal to feel excited and nervous
• New responsibilities of adulthood
• Many decisions to make and skills to learn
• Be your own advocate
Transition is Complex

Medical –
• New adult providers
• Family centered to patient centered care
• Medical interventions - involves primary care and specialty care

Psychosocial –
• Social and cognitive development
• Quality of life
• Patient and family functioning including what happens at home
• School
• Work
Six Domains of Transition Planning

- Health Care
- Housing
- Transportation
- Activities of Daily Living
- Education or Employment
- Relationships with Others

DMD Care Considerations Working Group
Health Care

- Pediatric to adult providers
  - Primary care, multidisciplinary team
  - Records transfer, medication and equipment management
  - Family centered to patient centered care
  - Durable power of attorney for health care
  - Age related changes in benefits
  - Advanced Care Planning/Palliative Care
Got Transition  www.gottransition.org

Transition is a process, not an event; it happens over time.
Activities of Daily Living

- CEO – You’re the boss
- CFO - Funding and benefits
- COO - PCA’s and schedules
- Respite for family caregivers
- Leisure/Recreational
- Need for guardianship/conservatorship
Education and/or Employment

- Plan early for future education or vocation
- Evaluate strengths, weaknesses, talents
- Funding
- Post-secondary – accommodations
- Online classes vs on campus
- Employment or vocational planning resources
Housing

- Family home or elsewhere
- Accessible residence/safe residence
- Dormitory with accommodations
- Use of assistive technology – modified phones, switches
Transportation

- Wheelchair
- Public transport
- Driving with vehicle modifications
- Van – funding
- Travel
Relationships

• Develop skills over time
• Community Integration/socialization
• Communication skills
• Sexuality
• Work toward desired level of autonomy and independence
• Spirituality
Barriers to Transition

- Abrupt with little or no preparation
- Reluctance to leave familiar and trusted providers
- Delay in re-establishing medical care with adult providers
- Lack of insurance for adult services
- Limited adult providers with knowledge and expertise in neuromuscular disorders
- Lack of communication between pediatric and adult providers
- Difference between pediatric and adult care
Resources

- Medical Team
- Family/Friends
- Social Work
- Physical Therapy
- Psychology/Neuropsychology
- Therapeutic Recreation
- Occupational Therapy
- Nurses
- PPMD – Toolkit Soon!
Your Mission Should You Accept It