

*Promoting healthy lifestyles at home: How can we best support boys with Duchenne muscular dystrophy and their families?*

Presenter: Dr. Amy McPherson, PhD, CPsychol

B. Mistry, L. McAdam, R. Amin, D. Kalnins

# What is the issue?

- Duchenne muscular dystrophy (DMD) is a progressive neuromuscular disease affecting 1/6000 boys (May et al, 2011)
- Steroids → life-expectancy ~ 30 years (Bushby et al, 2010)
- Up to 73% of boys with DMD have obesity by age 13  
(Martigne et al, 2011)
- Higher weights worsen respiratory and cardiac function



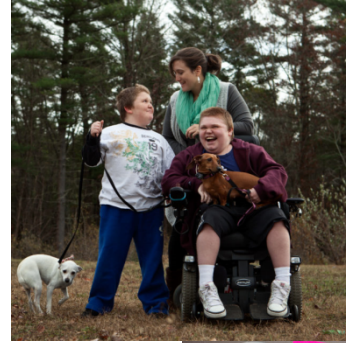
# Methods

- Qualitative, semi-structured individual interviews with children with DMD and their parents
- Explored experiences and perceptions of obesity prevention, weight management and healthy lifestyles in the context of DMD
- Descriptive thematic analysis employed (Swift & Tischler, 2010)



# Themes (23 interviews)

- A moving body is a healthy body
- DMD management involves a significant amount of labour
- Being a 'good parent' is a balancing act



No boundaries

# A moving body is a healthy body

“...we’ve found that **keeping him moving** to his comfort level has proven beneficial to him...in the sense that his muscles will keep moving and as long as he doesn’t hurt himself and as long as he doesn’t over exert himself, it’s **like his muscles aren’t too relaxed and they’re still being used**” (Mother #8)



No boundaries

**Bloorview**  
RESEARCH INSTITUTE

# DMD management involves a significant amount of labour

“I think they [healthcare professionals] don't really understand **what it's actually like to live with it...**they don't even say like, you know 'I know it's maybe hard to do'... But I think some of them are a bit, I don't know, **almost heartless in some cases...**” (Tim, 17)



# Being a ‘good parent’ is a balancing act

“Our time is precious so... like **healthy eating...** sometimes it **doesn’t always take first billing...**we're constantly trying to **make memories for times later** [when] maybe we won't be able to go to do the things that we're able to do”  
(Mother #12)



No boundaries

**Bloorview**  
RESEARCH INSTITUTE

## So what?

- ① Acknowledge demands of living with DMD
- ② Identify differing priorities of all stakeholders
- ③ Use positively- framed conversations about weight



Questions?

Thank  
you!!

No boundaries

**Bloorview**  
RESEARCH INSTITUTE