Many Faces of Hope

What are the similarities and differences in how patients, family members and clinicians view hope and cure in the context of neuromuscular conditions such as Duchenne Muscular Dystrophy (DMD)?

What would be included in broadening a vision of hope for patients with DMD, beyond a strict focus on hope for a cure?

Listen to Me

Based on the film, what does “listen to me” mean for adolescent patients, parents, and clinicians?

This film depicts different viewpoints about treatment decisions such as spinal surgery. How might greater attention to advance care planning help to create a shared vision among adolescents, parents, and clinicians, and mitigate value conflicts?

Unexamined Distress

What are physical and emotional challenges/burdens that may often go overlooked or unexamined for these patients, parents, and siblings?

How might a palliative care approach help clinicians to respond differently to the suffering experienced by adolescents living with DMD?
### An Uncertain Future

As a clinician, how do you acknowledge and plan for an uncertain future while maintaining hope?

What aspects of palliative care might enhance the care of patients with DMD as their disease progresses?

### General Discussion

Given our discussion today, what are some specific ways that a palliative care approach could enhance the quality of life and the quality of care for adolescent patients living with DMD?

Regarding what we have discussed during today's session, what change would you like to see/make in your own practice?