



Notre Dame Rare Disease Patient Advocacy Summit
Friday, September 16, 2022 1:00pm to 5:00pm
Jordan Hall of Science, Auditorium 101

- 1:00 - 1:30 pm** **Welcome and Introductions**
Notre Dame's Commitment to Patient Advocacy
Santiago Schnell, Dean, College of Science University of Notre Dame
- Company Overview and Advocacy in Industry
Josh Brumm, President and CEO, Dyne Therapeutics
- 1:30 - 1:45 pm** **Notre Dame Student Internships-Dyne Therapeutics**
Alyssa DiPaolo, ND'22
Bailey Perczak, ND'22
- 1:50 - 2:45 pm** **Panel - Patient Perspectives**
Moderator: Molly White
Seth Rotberg, Huntington's Disease
Kent and Ann Woodbury- DM1
Jessica and Wyatt Rownd, -DMD
Tim Hollenback- FSHD
- 2:45-2:55 pm** **Abled in the Disabled World- Hartsell Family Story**
Melisa and Scott Hartsell
- 2:55-3:05 pm** **BREAK**



3:05 - 4:00 pm

Panel - Patient Advocacy in Biotech and Pharma

Moderator: Tom Hamilton, Co-founder, Board Director
Larimar Therapeutics; Executive Committee Member,
Friedrich's Ataxia Research Alliance

BJ Viau, Director of Patient Advocacy, Horizon Therapeutics

Molly White, Vice President, Global Head of Patient
Advocacy and Engagement, Dyne Therapeutics

John Crowley, Executive Chairman, Amicus Therapeutics

Cindy Parseghian, President, Ara Parseghian Medical
Research Foundation

4:00 - 4:45 pm

**Panel-Trends and Challenges: Clinical Trials and Drug
Approval**

Moderator: Sean Kassen, Ph.D., Director, Ara Parseghian
Medical Research Fund, University of Notre Dame

Anju Samy, Director of Regulatory Affairs, Horizon
Therapeutics

Tim Franson, MD, Principal, Faegre Drinker Consulting

Elizabeth Berry Kravis, MD, PhD, Rush University Medical
Center

Debra Feldman, SVP, Head of Regulatory Affairs, Dyne
Therapeutics

4:45 - 5:05 pm

Closing

Matt Flesch, VP, Communications and Patient
Advocacy, Horizon Therapeutics

Tim Walbert, Chairman, President, and CEO,
Horizon Therapeutics