

[Goodwin Invites You to Join Us For Our Rare Disease Symposium 2025](#)



Goodwin's [Life Sciences](#) team is excited to host its Annual Rare Disease Symposium in Boston on February 5, 2025. Participants are invited to join for an afternoon of engaging fireside chats, inspirational presentations, and networking with peers in the rare disease community.

Please see the agenda below and register to attend [in-person](#) or via our [virtual webinar](#) to join us.

Agenda

12:00 PM - 1:00 PM EDT | Welcome & Networking Lunch

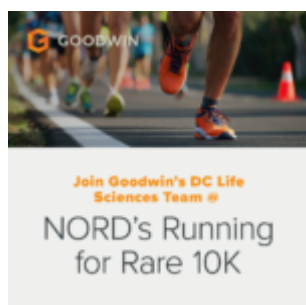
1:00 PM - 4:30 PM EDT | Rare Disease Symposium Program

- **The Patient View**
 - David Downing, GRIN1 Dad
 - Jaime McHugh, Rare Disease Mom and NORD Running for Rare Champion
- **The Research View**
 - Dr. Shira Rockowitz, PhD, Data Science Director, Boston Children's Hospital, Children's Rare Disease Collaborative Co-Leader
 - Dr. Piotr Sliz, PhD, Vice President, Chief Research Information Officer & Associate Professor, Boston Children's Hospital, Children's Rare Disease Collaborative Co-Leader
- **The FDA View**
 - Amy Rick, Director of Strategic Coalitions for FDA's Rare Disease Innovation Hub
- **The Policy View**
 - Karin Hoelzer, Senior Director, Patient Advocacy, BIO
 - Jack Kalavritinos, Founder, JK Strategies and the Washington Health Innovation Council, and Former Director, HHS Office of Intergovernmental & External Affairs
 - Judy Stecker, SVP, Burson, and Former HHS Deputy Chief of Staff for Strategy & Operations - Rare Disease Parent & Founder, Wheeler's Warriors
- **The View from the National Organization for Rare Disorders**
 - Pamela Gavin, Chief Executive Officer, NORD
- **The View from the Rare As One Network**
 - Heidi Bjornson-Pennell, Senior Program Manager, Science in Society, and Lead, Rare As One Network
- **The Biotech CEO View**
 - Paula Ragan, PhD, CEO, X4 Pharmaceuticals

4:30 PM - 5:30 PM EDT | Networking Reception

We look forward to kicking off **Rare Disease Month** with you!

[Running for Rare for NORD](#)



Support Goodwin's DC Life Sciences Team as they raise money for the National Organization for Rare Disorders (NORD) as part of its "Running for Rare" team at the annual 10K race held during the upcoming DC Marine Corps Marathon on October 27th.

Assist NORD's mission to drive public policy, accelerate research and improve care for people living with rare diseases by donating [here](#).

Learn more about Goodwin's Rare Disease Initiative [here](#).

[NORD Annual Breakthrough Summit](#)



In October, NORD will also hold its annual Breakthrough Summit in Washington, DC on October 20-22, 2024. This event draws over 1,000 attendees including patients/caregivers, patient advocacy organizations, and healthcare, biotech, and medical technology companies. Registration is available [here](#). This year, [Matt Wetzel](#) will take part in a panel discussion on the growing role of medical devices in the rare disease community.