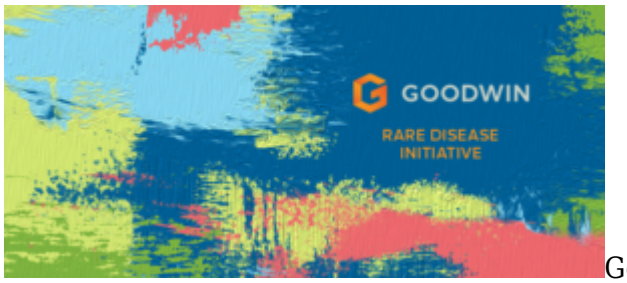
Goodwin Invites You to Join Us For Our Rare Disease Symposium 2025



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!