



# Andrew Rosen

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## Chief Executive Officer

**NAF**  
National Ataxia  
Foundation

March 27-29, 2025  
Planet Hollywood  
Las Vegas, NV



# Our Vision

**A world without Ataxia.**

# Our Mission

**To accelerate the development of treatments and a cure while working to improve the lives of those living with Ataxia.**



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# Drug Development

- **Biogen** – Approved Drug (FA)
- **Biohaven** – NDA Accepted (SCAs)
- **PTC** – NDA Accepted (FA)
- **Vico** – Phase 1/2a Trial (SCA1 & 3)
- **Arrowhead** – Phase 1/2 Trial (SCA 2)
- **Solaxa** – IND Accepted (SCAs)

## NAF Drug Development Collaborative



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# International Congress for Ataxia Research (ICAR) 2024

- **600+** Attendees
- **32** Countries
- **350** Scientific Posters Presented
- **80** Scientific Talks
- **88%** say ICAR is “very useful” for advancing their work

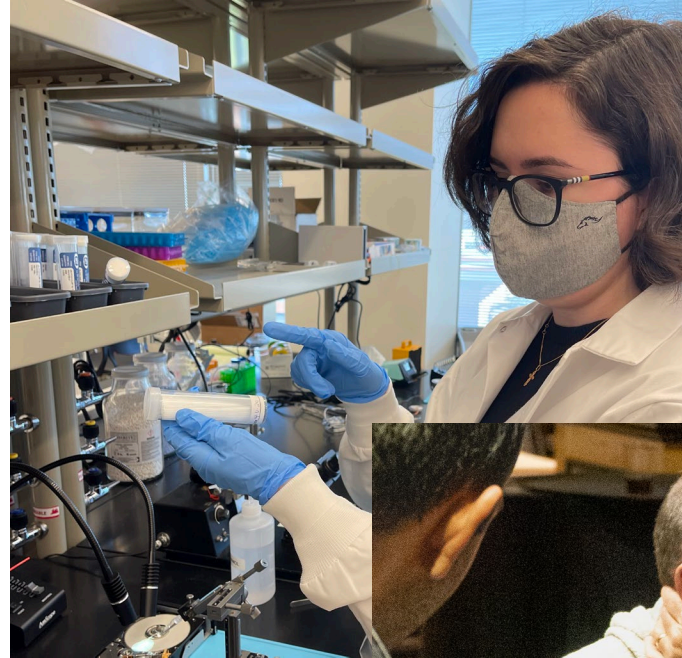


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# Improving Research and Clinical Care

- **18** Research Grants
- **17** Ataxia types represented
- **34** NAF Ataxia Centers of Excellence
- **123** Neurologists Trained in Ataxia Care
- **Over \$2M** in annual research funding provided by NAF



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# Research



**Lauren Moore, PhD**  
VP, Research & Chief  
Scientific Officer



**Kelsey Trace**  
Clinical Services  
Director



**Celeste Suart, PhD**  
Patient Engagement  
Manager



**Laura Crespo**  
Clinical Research  
Coordinator



**Aimee Alcott**  
Research Coordinator



**Mary Ann Peterson**  
Research Services  
Associate





# Advocating to Policymakers

- **\$36M+** Ataxia Research Grants Funded through CDMRP
- **115+** Ataxia advocates for 2024 Hill Day
- Working closely with pharma partners to educate and advocate with FDA



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# Helping People Live Better with Ataxia

- **66** Support Groups
- **581** Support Group Meetings
- **NAF's 1<sup>st</sup> Licensed Social Worker** – New focus on finding local resources
- **Care Partners** – New resources and webinar series



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# Community Services



**Kyle Billadeau**  
VP, Operations &  
Community Services



**Lori Shogren**  
Community Services  
Director



**Kari Brooks, LCSW**  
Community Services  
Coordinator



**Courtney Clark**  
Public Policy &  
Advocacy Intern



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# Largest Ataxia Awareness Campaign Ever!

featuring **Bill Nye**

- 4 Ataxia Awareness Videos
- 2M+ Views
- **Good Morning America** featured interview
- **100+** Congressional Offices Attended Informational Luncheon
- **More to come!**



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# Communications



**Stephanie Lucas**  
Communications  
Director



**Mollie Utting**  
Senior Communications  
Coordinator



**Tanoa Thomé**  
Communications  
Coordinator



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# Growth in Fundraising = Growth in Services Offered

- **4,335** Donors – a record-breaking year for NAF!
- **\$242K** Raised by Walk N' Rolls
- **New Walks:** Jacksonville, Milwaukee, St. Louis, VTech, and Denver
- **Passion Fundraisers:** Comedy Shows, Challenges, Community Events, Artisan Auction, plus more!



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# Development



**Joel Sutherland**  
VP, Development



**Jon Wegman**  
Development Manager



**Rich McCutchen**  
Development Manager



**Meg Hanna**  
Development  
Coordinator



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# We're Proud of Our Work

- **Charity Navigator**

- **4 Star Charity** – Top rating available.
- **99% Rating** – Based on Accountability & Finance, Culture & Community, and Leadership & Adaptability

- **Candid**

- **Platinum Transparency Seal** – Top rating available.



Platinum  
Transparency  
**2024**

**Candid.**



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# Operations



**Andrew Rosen**  
Chief Executive Officer



**Kyle Billadeau**  
VP, Operations &  
Community Services



**Patricia Morel**  
Controller



**Sue Baker**  
Senior Accountant



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# Thank You!

Our donors and members make our work possible.



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