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Nano-rare Patient Colloquium 2025

Creating Connectivity: Building a Community for the Nano-rare

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Connection Brings the Community Together

Connection

- Emotional
- Personal
- Mutual

Community

- People you know or recognize
- Share experiences or beliefs
- Web of support

You are a member of the nano-rare community



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Our Goals for Community Creation

Laid the Groundwork of Community Creation with Two Ideas

1. Build a **knowledgeable** community
2. Draw **attention** to the *needs* of the **nano-rare**

How are we doing this?



Broad Range of Community Educational Efforts

- Yearly Colloquium
- Patient Empowerment Program podcast series
- Lessons in Antisense series
- Dedicated website – nlorem.org
- Presentations to patient communities








Patient Empowerment Program Podcast



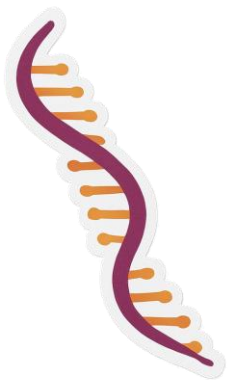
- **Interviews:** Patients/Caregivers, Experts, Physicians, n-Lorem Partners, and Advocates
- **Intro Medical Science:** Provides a masterclass in basic science and how it's related to drug discovery and development

Empowers patients and their families with knowledge as they navigate rare disease.

Provides a forum where voices can come together focused on the nano-rare patient!

2		Hope for Kinsley: Facing TUBB4A with Courage and Care n-Lorem Foundation • 459 views • 3 weeks ago
3		New Insights into Genetically Caused Developmental Delays n-Lorem Foundation • 314 views • 1 month ago
4		Research to Advance ASO Technology at n-Lorem n-Lorem Foundation • 264 views • 1 month ago
5		Commitment to Safety First: The DSMB n-Lorem Foundation • 283 views • 2 months ago
6		Connor Gooley's Story: A First for TUBB4A Treatment n-Lorem Foundation • 462 views • 2 months ago

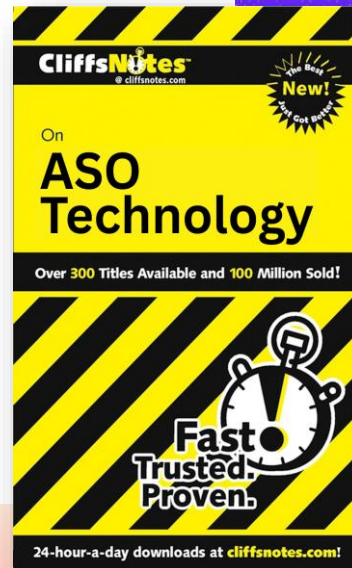
Breaking it Down: Lessons in Antisense for the Community



- Drawn from Dr. Crooke's 35+ years of pioneering work in the field
- Made digestible and publicly shared to meet the growing interest in ASOs
- 20 currently available on LinkedIn & nlorem.org



n-lorem
FOUNDATION





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Results: Evaluating *Success* of Community Creation

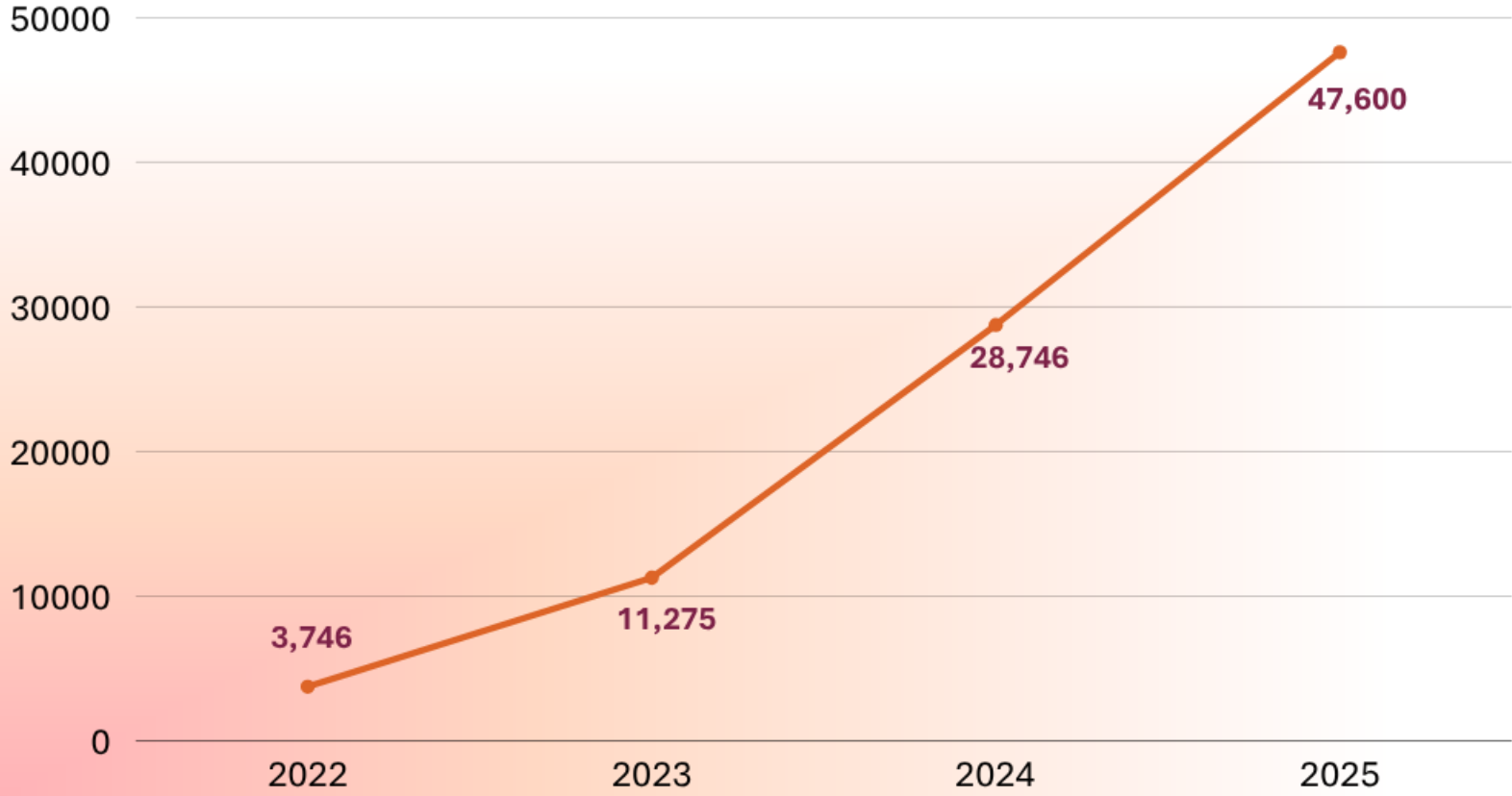
Evaluating Success in Creating a Community: Patient Empowerment Program Podcast



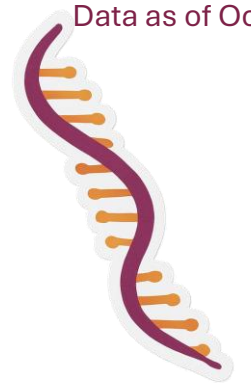
>47,500
Cumulative
Streams

- **154%** growth in 2024
- Goal to hit 50k by the end of the year
- Find the PEP Podcast on YouTube, Spotify, Apple Podcasts

● Episode Streams by Year



Evaluating Success in Creating a Community: Lessons in Antisense



Since April 2025, >5,000 individuals have read lessons

Popular Lessons

- How ASOs Are Made and Why
- Nucleic Acid Hybridization
- How siRNAs and ASOs Differ
- & many more

What people are saying:



Alex Fulton • 2nd

PhD student- University of Cambridge: MRC Toxicology Unit

3mo ...

Thank you for providing these lessons! It's useful to understand the history behind introducing these modifications, as I start to write the introduction to my PhD thesis :)



Dr. Manoj Khavate • 1st

The healthcare market research expert who helps business owners...

3mo ...

Thank you for sharing your expertise-your passion for advancing science truly inspires the community!

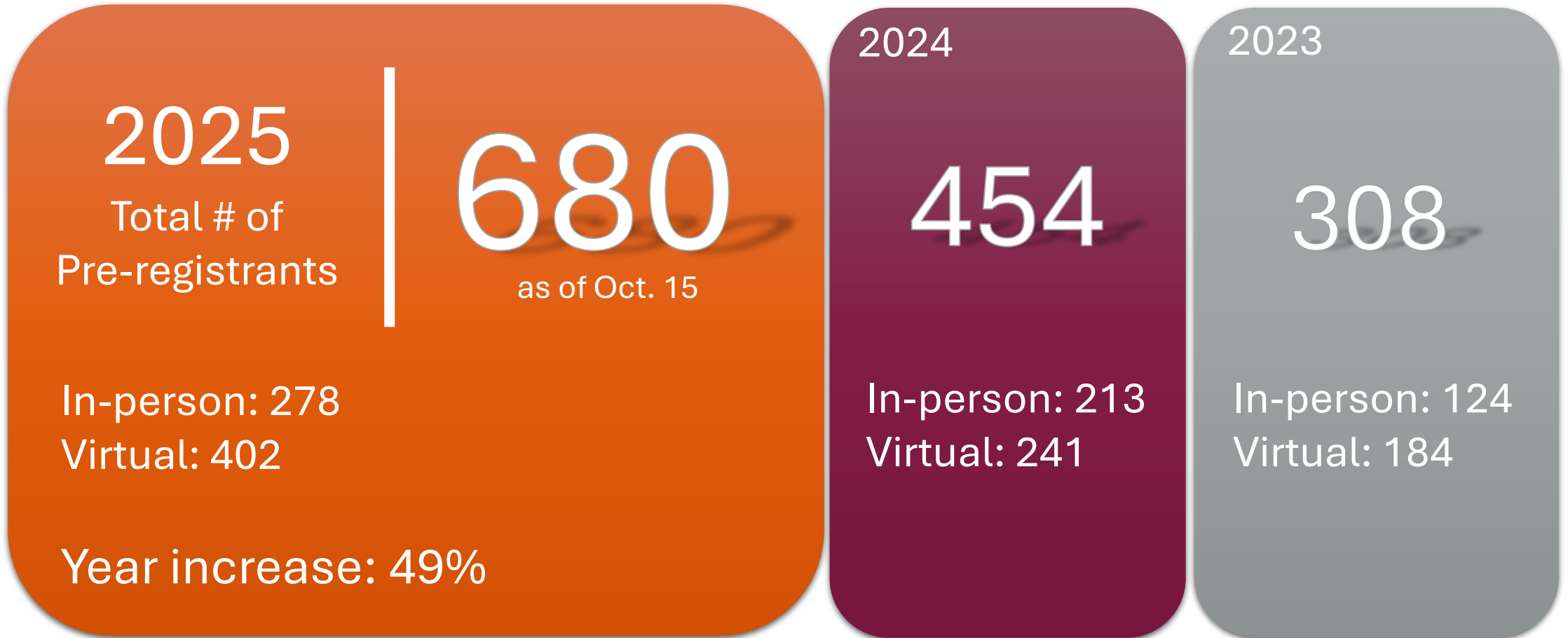


Constantine Linnik, PhD, JD  • 1st

Founder and Managing Partner at IP Supra, PLLC and Lead Couns...

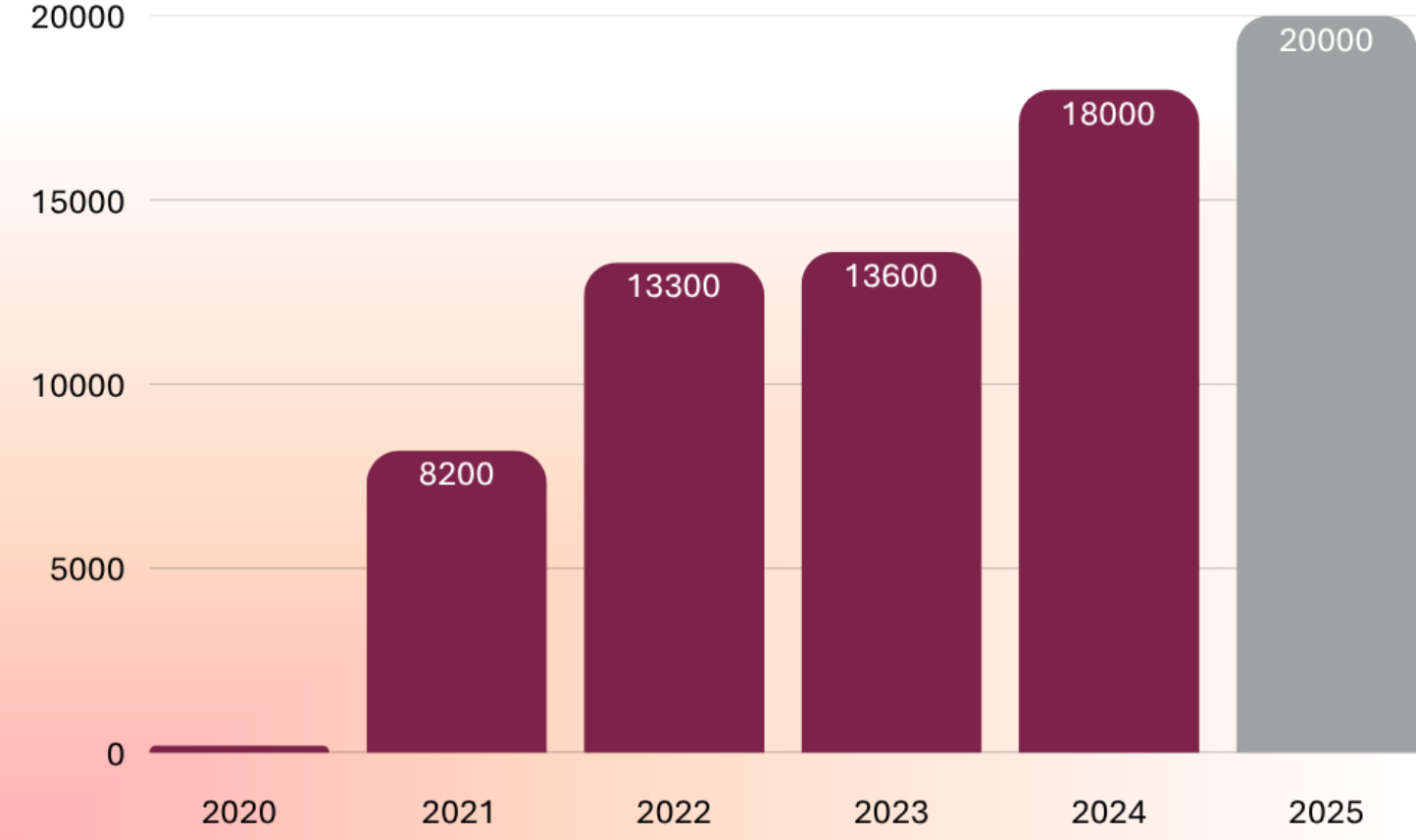
Excellent! Would love to buy a book one day!

Evaluating Success in Creating a Community: Nano-rare Patient Colloquium



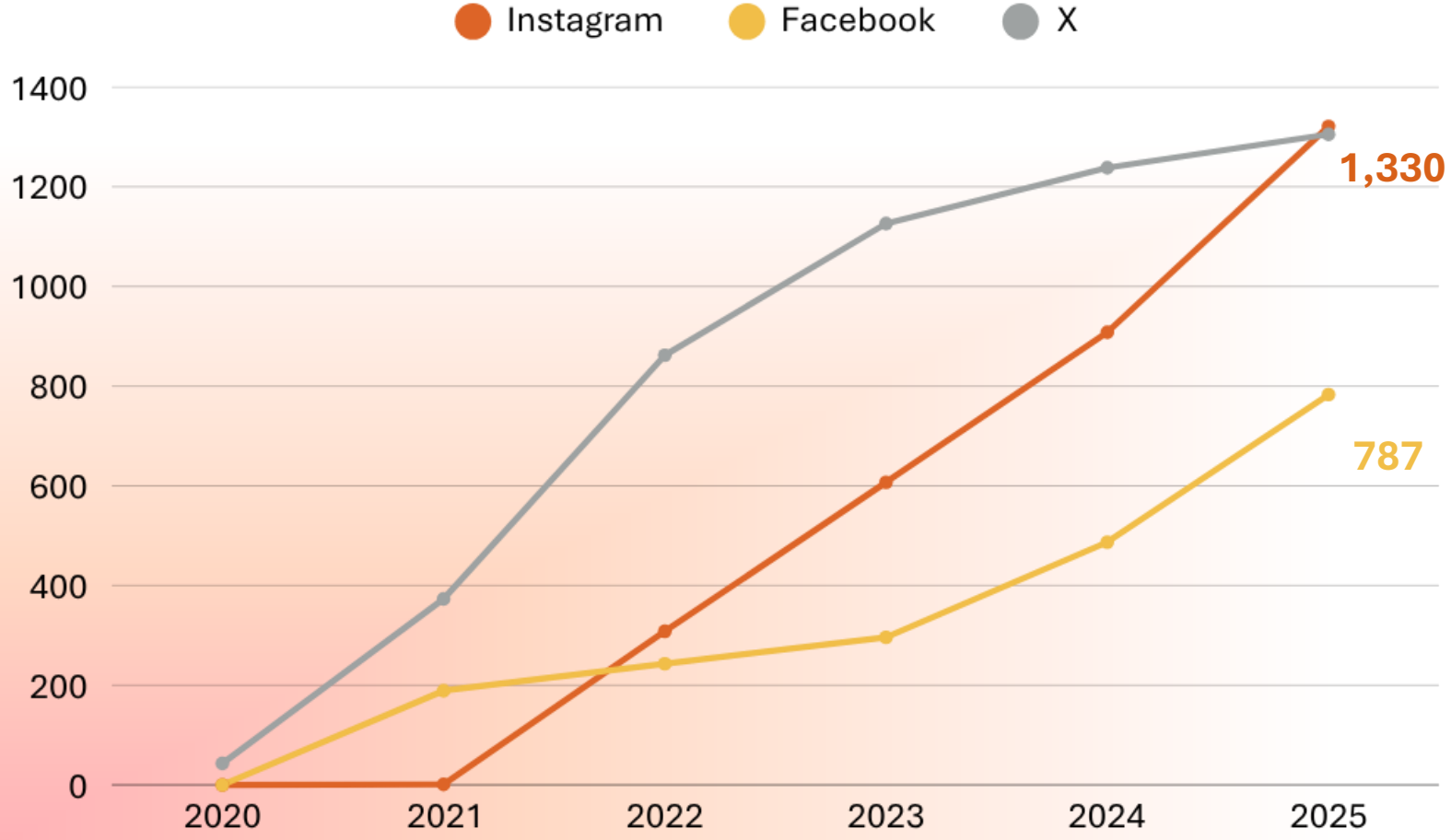
Evaluating Success in Creating a Community: Social Media Engagement

- Engagement = # of likes, comments, shares
- Continued growth
- 2022: 61% increase
- 2024: 33% increase



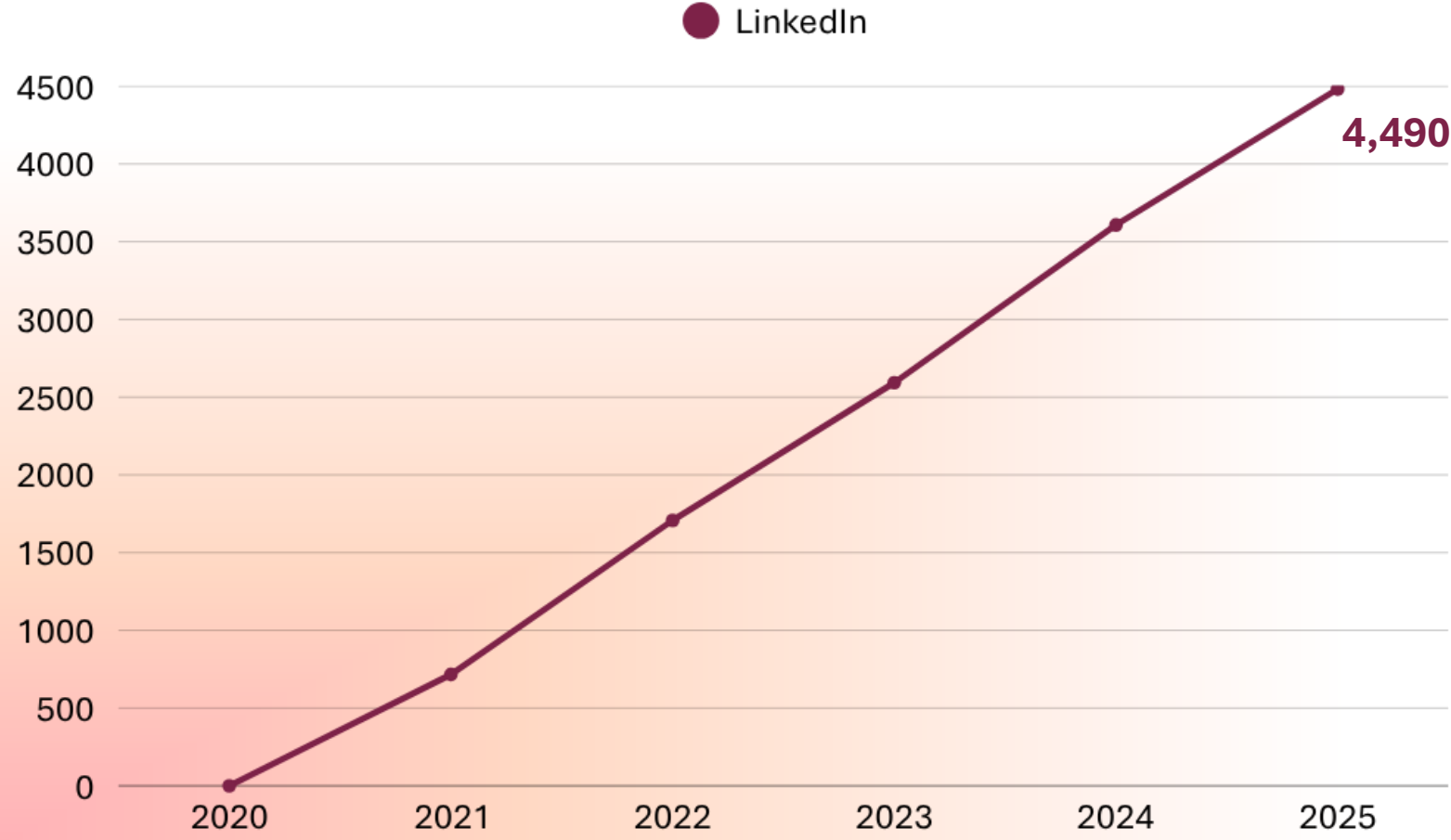
Evaluating Success in Creating a Community: Social Media Followers

- Instagram & Facebook are trending upward
- Patients & families are continuing find us



Evaluating Success in Creating a Community: LinkedIn Followers

- LinkedIn – our fastest growing platform
- Reaching executives, researchers, and healthcare



 **>7,800 followers across SM platforms**





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Nano-rare Patient Colloquium 2025

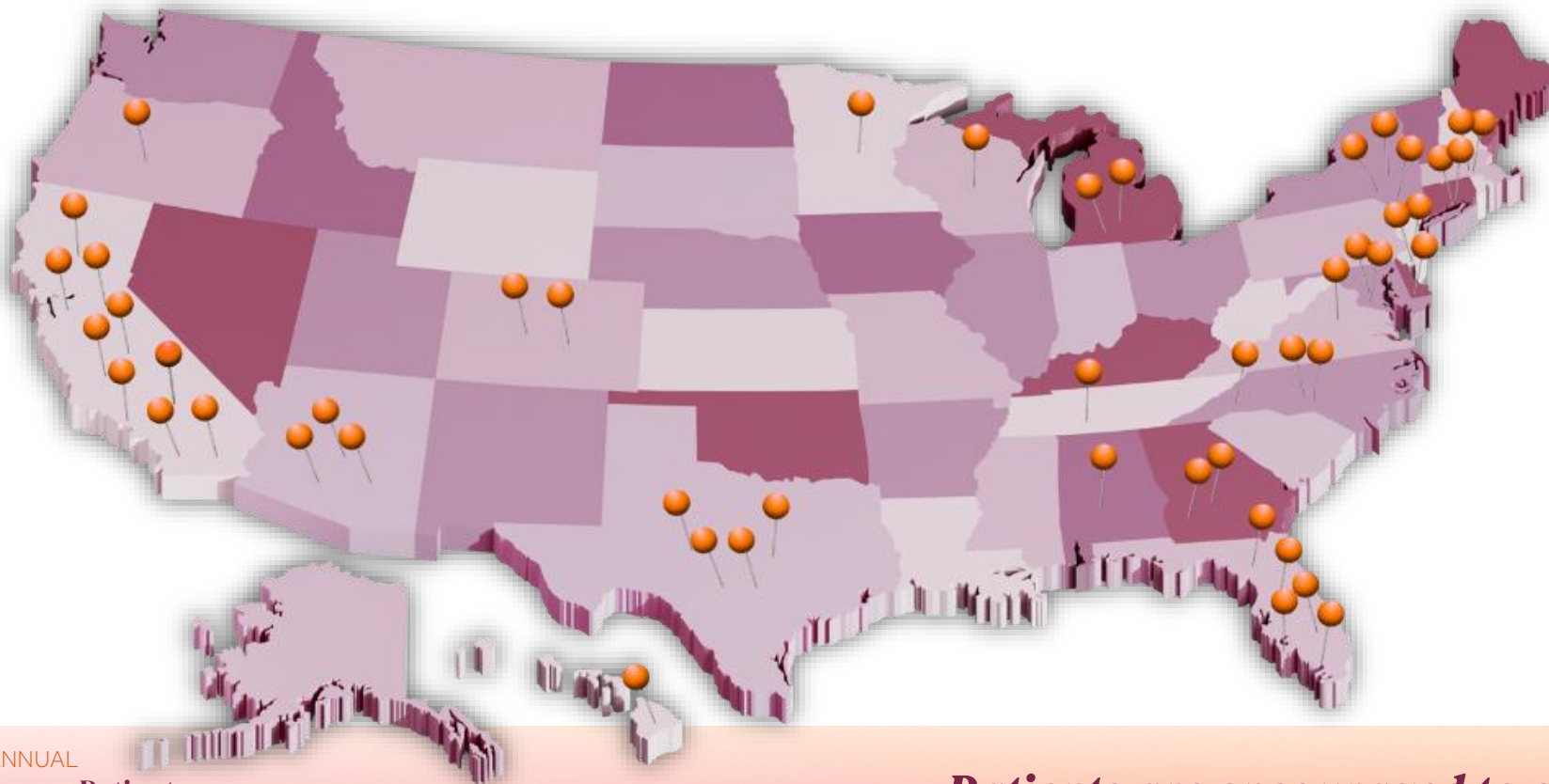
**At the Forefront of Our
Community are Our *Patients*
and Their *Caregivers***

n-Lozem is Blinded to Patient Identity



56 of >200 patients have identified themselves (~28%)

Until... a patient/family willingly chooses to connect with us



= Unblinded Patient



Patient Wall

At n-Lorem HQ, a stark reminder of the lives we're serving



Alya
Anais
Anna
Annie
Beau
Bowie
Camille
Colbie
Connor D
Connor G
Connor L
Emersyn
Emmery

Ethan
Frances
Grace
Gunnar
Heidi
Harlow
Ireland
Jiya
Kinsley
Layken
Lena
Margot
Marley

Mostyn
Nolan
Pyper
Roger
Rosie D
Rosie G
Ryker
Sloane
Susannah
Talia
Tom
Tristan
Turner

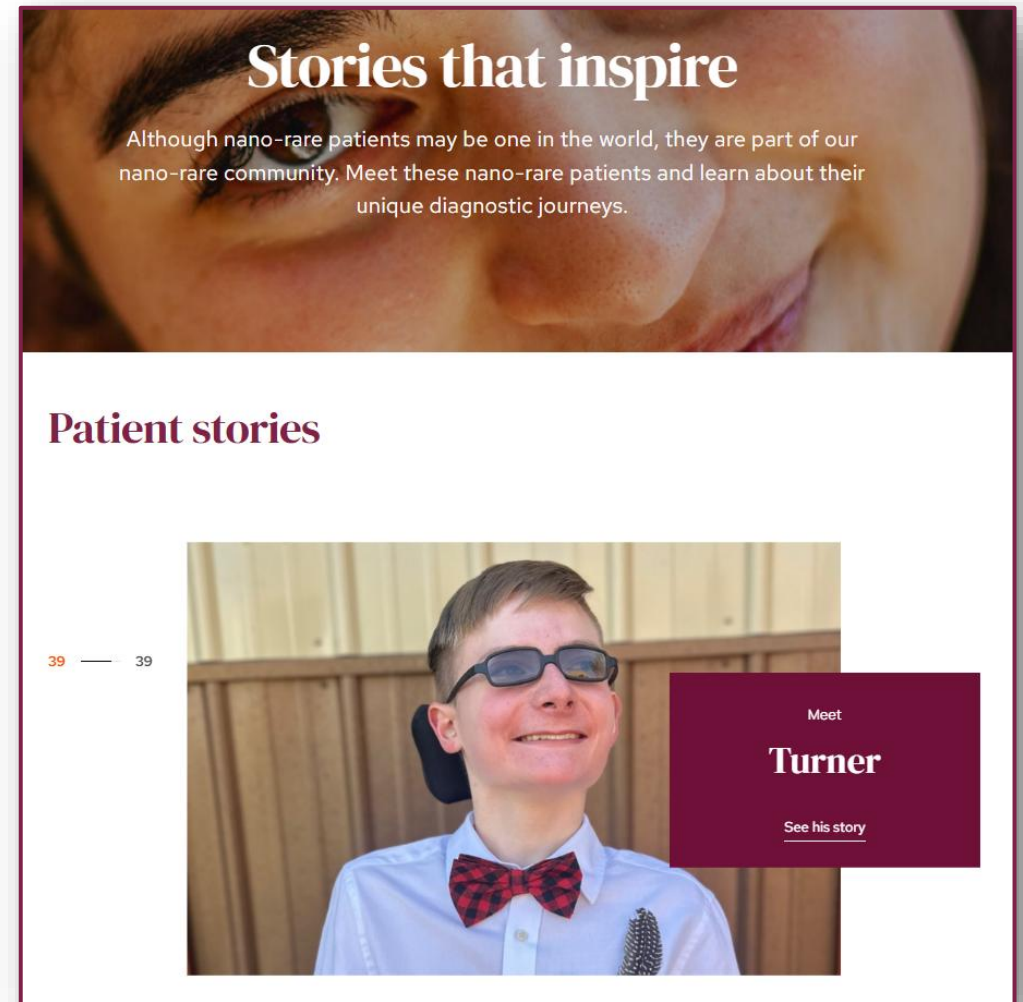


Stories Bind us, Creating a Living, breathing network of shared experiences and personal journeys

Written by patients or their caregivers



- Detailing diagnosis, challenges, triumphs & joys
- Often deeply personal & emotional
- Other patients & families able to relate while navigating through their journey
- Help supporters realize the magnitude of our mission



**~40 Patient Stories
on nlorem.org**

Stay Informed with n-Lorem on Social Media



~20% of NRPC registrants noted they heard about the NRPC on SM

- Follow us for the latest updates
 - Media & articles
 - Podcast clips
 - Celebrate patients
 - Highlighting disease awareness days
- Great place for families find & connect each other
- Tag us – we often reshare posts from the community

Join and Connect!



Taking action to support the community and our mission

Spread the word

- More potential patients and physicians will know we exist
- May help drive more diagnoses
- Increases support for n-Lozem

**More support =
More patients helped**

What else can you do to help?

- Consider approaching local businesses or sports teams for fundraising events
- Introduce us to potential donors
- Become an individual supporter
- Connect with us
- Contact with your local news station



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Media Coverage



The Atlanta
Journal-Constitution



**Let's continue educating, uniting, and
growing OUR community & supporters!**

Thank you

