

Thursday, October 31 | 4:00 – 4:10 pm

Patient Empowerment Program: Creating a Community for Nano-rare

PRESENTER

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n-Lorem Foundation



Nano-rare
Patient
Colloquium
2024

Hosted by:



n-lorem
FOUNDATION

Nano-rare Patients Need a Community and a Voice

- Nano-rare patients are isolated in their disease
- Nano-rare patients struggle to be heard
- Nano-rare patients have limited healthcare options

***Nano-rare patients are pioneers.
We believe that nano-rare means you are unique - not alone.***

Nano-rare Patients Need a Community

- Share their stories and raise awareness
- Lift each other and their communities up
- Advocate for individualized care and early diagnosis
- Support for families and loved ones
- Network to engage more physicians and institutions
- Inform about health and disease

Holistically Meeting the Needs of Nano-rare Patients

- Annual Nano-rare Patient Colloquium
- Patient Empowerment Program Podcast Series
- Social Media Outreach on Multiple Platforms
- Information-rich and Accessible Website
- Presentations to Scientific and Patient Communities
- Publishing Learnings in Peer-reviewed Journals for the Entire Community
- Treat the patients we can today while expanding to treat more tomorrow
- Apply Learnings from One Patient to a Community

Multiple Ways to Reach the Community

Social Media Outreach
Multiple platforms, singular purpose



Podcast series on topics relevant for
nano-rare patients and others

Website packed with useful information
and resources

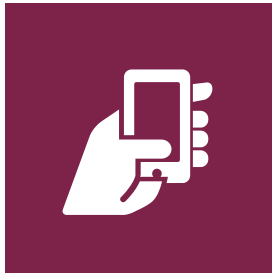
Sharing learnings through publication,
presentations and conference participation

Creating a Community for Nano-rare

Social Media



>1.2 MILLION impressions



Multiple platforms : Singular purpose
Raise awareness by providing information to our patient communities

Join and Connect!



Creating a Community for Nano-rare

Podcast Series

Podcast Series

Patient Empowerment Program

Creating a Community of Care

We are providing a forum where the voices of patients, advocates and experts can come together focused on the nano-rare patient



>25,500 Downloads
>60 Episodes Released



Podcast series on topics relevant for nano-rare patients and others

Listen and Learn!



Interviews



One Year Anniversary: It Takes a Rare Community

Celebrating one year of the Patient Empowerment Program podcast! May marks a year of podcasting for us, and we're [...]



Coming Together for the Nano-rare Patient



Intro to Medical Science

The basics put in simple terms for everyone to easily understand



Medical Science 3

How Drugs are Used

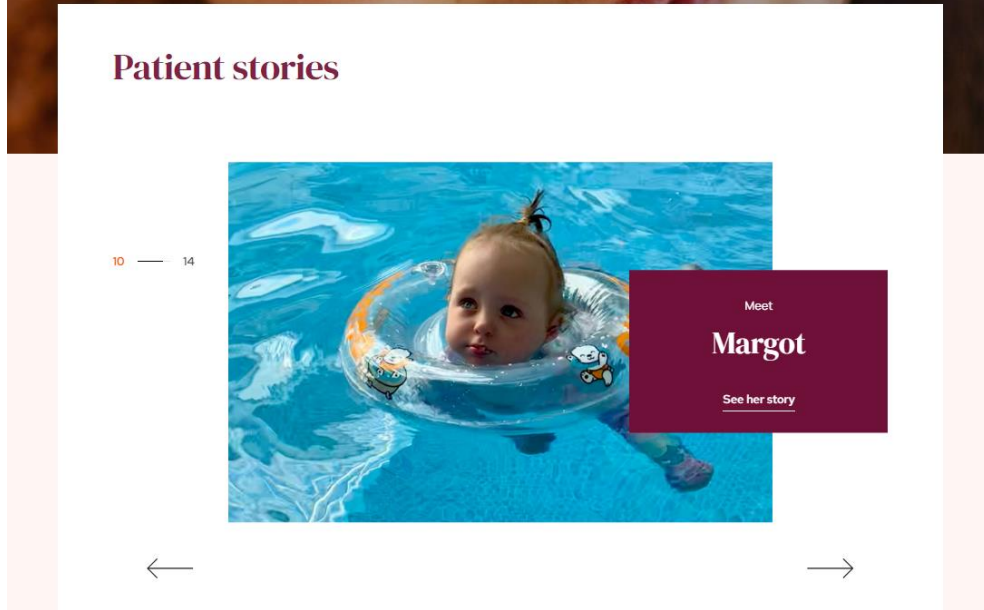
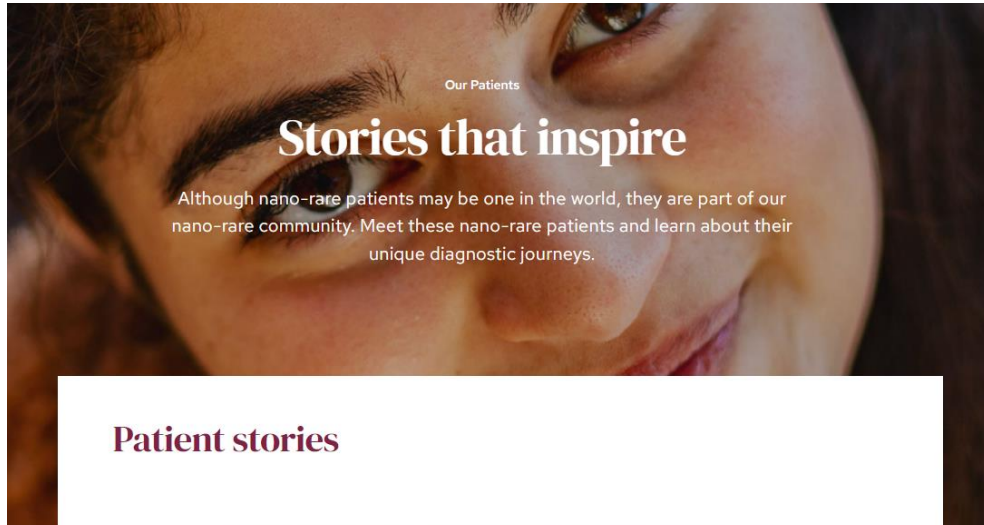


Medical Science 4

Drug Discovery Platforms

Creating a Community for Nano-rare

Website & Patient Voices



>48,000 Visitors
>20 Patient Stories



Giving Nano-rare a Voice
Sharing creates a community



Creating a Community for Nano-rare

Community Outreach



Hundreds of touch points

Representation and Participation

- Scientific and therapeutic focused conferences
- Rare disease focus
- Patient advocacy meetings
- Patient family meetings
- Partner communications internal and external

Engagement

- Patients
- Partners
- Physicians and institutions
- FDA
- Government funding entities
- Foundations
- Individual supporters



Creating a Community for Nano-rare

Reaching More and Creating a Community

Social Media Outreach
Multiple platforms, singular purpose

210% increase



Podcast series on topics relevant for
nano-rare patients and others

119% increase

Website packed with useful information
and resources

36% increase

Sharing learnings through publication,
presentations and conference participation

120% increase

Progress in 2024 Highlights our Reach

Information is Power: Educating the Nano-rare Community



>25 Intro to Medical Science Episodes

- What is n-Lorem?
- Biological Systems and Chemical Networks
- How Drugs are Used
- Drug Discovery Platforms
- Why ASO Technology?
- Antisense (How we do it at n-Lorem)
- Cardiovascular System: Blood
- Cardiovascular System: The Pump — Heart Anatomy
- Cardiovascular System: The Pump — Heart Diseases
- Cardiovascular System: The Pipes — Arteries and Veins
- Cardiovascular System: The Spigot — Kidney Functions
- Cardiovascular System: The Spigot — Kidney Diseases
- The Energy of Life
- Lungs: Defending Airways
- Lungs: Heavy Breathing — Diseases and Obstructions
- Liver: Metabolic Magic
- Liver: The Master Chemist
- Liver: Diseases
- Autopilot: The Autonomic Nervous System
- How to Think About “Risk” Part 1 & 2
- Advanced Genetics Part 1 & 2
- Why We Dose Intrathecally
- Ion Channel Mutations: The Complexities of Treatment
- Knowledge is Power: Part 1 & 2

Beyond the Numbers

Successful Efforts to Support Nano-rare

- ✓ Created a community for nano-rare patients
- ✓ Unified cohesive patient community coupled to n-LoRem, physicians, institutions, donors, patient foundations
- ✓ Conducted an extraordinary 2023 Nano-rare Patient Colloquium
- ✓ Support for and (*hopefully*) successful 2024 Colloquium
- ✓ Engagement of and support from partners year over year
- ✓ Established educational initiatives through podcast series
- ✓ Created a groundswell of excitement and support of nano-rare
- ✓ Providing access to accurate information

How Can You Help

- Today, a few nano-rare patients have hope and help
- We need to do more, **for more**
- What can I do?
 - **Most importantly, become a donor**
 - Share the word – raise awareness of nano-rare and n-Lorem
 - Advocate broadly for genomic sequencing of newborns
 - Advocate with your institution for treatment
 - Support our mission
 - Fundraise with us
 - Advise us
 - Join our community of care
 - Join us in this important mission



Thank you!

Nano-rare
Patient
Colloquium
2024

Hosted by:  Biogen



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Podcast: Patient Empowerment Program