

2023 - 2028



# STRATEGIC PLAN



# Welcome



Dear Friends,

On behalf of the GRIN2B Foundation's Board of Directors, I am pleased to present you with our first (five-year) strategic plan! Developing this plan was a labor of love that we hope provides you with a detailed framework of how we will operate over the next five years and where we will be focusing our attention.

When I founded GRIN2B Foundation in 2017, it was several years after my 18-month-old daughter received her GRIN2B diagnosis. I was frustrated by the lack of information and resources available to me. The goal behind GRIN2B Foundation was to increase awareness, fund research, and provide support for the small but growing community of individuals - and their families - affected by GRIN2B Neurodevelopmental Disorder.

Since then, the landscape of GRIN2B has vastly changed. More and more researchers are becoming interested in studying the GRIN2B gene, and our growing community has been paving the road for increased awareness, support, and research. We have led several efforts around these areas, which you will read more about in the following pages.

In 2017, we were the first GRIN-related organization to form. I am thrilled that we now have numerous GRIN and GRI organizations all over the world. I have had the pleasure to meet and collaborate with many of the leaders in these organizations. Collaboration has been an important part of our growth since day one and I know that our community is going to move mountains by working together.

The GRIN2B Foundation Board of Directors is a 100% volunteer, parent-led board. We dedicate our spare time to advancing the mission of the organization and ensuring that all GRIN2B families feel empowered - and never feel alone. We are committed to you, your children, the researchers, and the clinicians who are working diligently to help those affected by changes in the GRIN2B gene.

Thank you for your continued support of GRIN2B Foundation!

Sincerely, Liz Marfia-Ash  
Founder and President  
GRIN2B Foundation



# About



## OUR MISSION

GRIN2B Foundation is a parent-run organization dedicated to furthering research on the GRIN2B gene and providing support and education to the small, but growing community of individuals and families impacted by a GRIN2B diagnosis.

## OUR VISION

Our vision is a world where every family impacted by a GRIN2B diagnosis feels empowered and supported.

## ABOUT THE GRIN2B GENE

GRIN2B is a gene located on the short arm (called "p") of the 12th chromosome at 12p13.1. It is one member of a family of 7 genes: GRIN1, GRIN2A, GRIN2B, GRIN2C, GRIN2D, GRIN3A, and GRIN3B. These genes encode proteins that together form a receptor that is responsible for sending chemical messages between neurons in the brain. GRIN2B Neurodevelopmental Disorder is a syndrome characterized by low muscle tone, developmental delays, seizures, and lack of speech.

# OUR

# Programs



Since 2018, GRIN2B Foundation has stewarded numerous programs intended to empower and support families while increasing research opportunities in GRIN2B Neurodevelopmental Disorder. These programs have been developed by the GRIN2B Foundation board of directors and informed by data collected by the community.

## ● Patient Support Programs



- Financial Assistance Program
- Comfort Items
- Memorial Gifts
- Letters of Support

## ● Meet-Ups

## ● Online Support Groups

## ● Newly Diagnosed Packets

## ● GRIN2B Awareness Week

## ● Celebrating Rare: The GRIN2B Podcast

## ● Bee Active Campaign

## ● Education



- Family Education
- Physician Education

## ● GRI Centers of Excellence

## ● Patient Registry

## ● Research Grant Program

## ● Family / Scientific Conference



# OUR Strategy



In 2023, GRIN2B Foundation embarked on our first strategic planning process. Through this process, **three strategic objectives**, or “pillars” were identified that will help to guide our organizational direction over the next five years. These pillars were informed by data collected from an organizational needs assessment, a community needs assessment, and a three-part strategic planning meeting attended by the GRIN2B Foundation’s Board of Directors.

*Support*

*Awareness*

*Research*

For each **strategic objective**, key measurables have been identified. The GRIN2B Board of Directors is committed to measuring and reporting the progress of these objectives on an annual basis through strategic planning community updates.



HOW WE'LL

# Get There



## Support

*Provide and create opportunities for GRIN2B families to feel supported and empowered.*

1

Evaluate and strengthen existing GRIN2B Foundation support programs offered to GRIN2B families across the globe.

2

Increase the avenues for social support to ensure that all families faced with GRIN2B worldwide have access to a community of support and never feel alone.

3

Empower the GRIN2B community through educational initiatives, research participation, and community connection.

4

Increase outreach to newly diagnosed families through a newly diagnosed packet to ensure that they feel empowered and supported.

HOW WE'LL

# Get There



## Awareness

*Raise awareness of GRIN2B Disorder while engaging families in advocacy efforts.*

1

Raise global awareness of GRIN2B Neurodevelopmental Disorder through strategic communications, increased partnerships, and involvement in GRIN2B research projects.

2

Increase the engagement of the community during GRIN2B awareness week by creating new involvement opportunities for families to participate in research, awareness initiatives, and fundraising.

3

Increase awareness and education of GRIN2B within the larger provider and IDD communities.



HOW WE'LL

# Get There



## Research

*Accelerate and facilitate research of GRIN2B Disorder through collaboration and community engagement.*

1

Increase the number of GRI Centers of Excellence across the United States.

2

Support efforts behind natural history studies and registries by recruiting and retaining GRIN2B families through empowerment and education.

3

Identify strategic research priorities that directly relate to GRIN2B Foundation's mission statement and what matters most to families.

4

Provide up-to-date information on our website of all current GRIN2B research opportunities and biorepositories.

5

Prepare the GRIN2B community for potential clinical trials to ensure that we, as a community, are "clinical trial ready".



# FIVE YEAR

# Key Results



Over the next five years, GRIN2B Foundation will hold ourselves accountable for the strategy and key measurable goals we've laid out. We will report annual progress reports to the community to hold us accountable and keep us transparent.

## KEY RESULTS INCLUDE:

1

Develop a succession plan to ensure long-term success of the organization.

5

Continue to lead the charge in providing patient and family support and awareness in GRIN2B Neurodevelopmental Disorder.

2

Build capacity by growing our team of volunteers, board of directors, and contractors.

6

Expand education of GRIN2B Neurodevelopmental Disorder to patients and providers.

3

Diversify revenue streams and create new fundraising opportunities for the community.

7

Improve research strategy and increase the number of Centers of Excellence.

4

Measure and evaluate programs on an annual basis to ensure efficiencies.

8

Increase enrollment in the GRIN2B patient registry and natural history study.

# HOW YOU Can Help



This strategic plan provides us with a laser focus on what we need to do as an organization to meet our goals over the next five years. We feel energized and optimistic for the future of our loved ones with GRIN2B Neurodevelopmental Disorder and for the future of GRIN2B Foundation.

We are hopeful that you will join us in meeting our mission and carrying out the objectives set out before you. There are a number of ways to get involved with GRIN2B Foundation; here are just a few ways to get started.



**DONATE**



**VOLUNTEER**



**PARTICIPATE  
IN RESEARCH**



**HOST A  
FUNDRAISER**

To learn more about getting involved, please email [info@grin2b.com](mailto:info@grin2b.com)



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