



GNB1 AWARENESS MONTH & DAY CELEBRATION KIT

A Guide for Families, Friends, and Supporters



ABOUT

April is **GNB1 Awareness Month**, and **April 21** is **GNB1 Awareness Day**, a special time when families, friends, advocates, and supporters around the world come together to raise awareness, share stories, and celebrate the strength of our community.

This year is especially meaningful as we celebrate 10 years of being Connected by GNB1. Throughout April, we are working together toward an important goal: raising **\$50,000** to support GNB1 research and awareness. These funds will help advance scientific understanding, support the work of researchers and clinicians, and expand awareness so more families can find answers, resources, and community.

This kit was created to make participation simple, meaningful, and fun. Whether you share a social media post, make a donation, start a fundraiser, or organize a local event, every action helps move us closer to our goal and strengthens the connections that make our community so powerful.

There is no “right way” to participate; choose what feels comfortable for you and your family. Together, we are **Connected by GNB1**.

WHY AWARENESS MATTERS?

- Helps families feel less alone
- Encourages earlier diagnosis
- Supports research progress
- Builds understanding and inclusion

Download the [GNB1 Informational Page](#) and [Pamphlet](#)



Celebrating **10** years
CONNECTED by GNB1

The Connected by GNB1 campaign honors GNB1 Month in April and GNB1 Day on April 21, celebrating a decade of community, collaboration, and meaningful connection

This image represents the heart of the GNB1 community and the strength found in coming together. The circle on the left symbolizes families, caregivers, researchers, clinicians, advocates, and the wider community—each person whose life has been touched by GNB1. The circle on the right represents GNB1 itself, the gene that connects us all, no matter where we are in the world.

Where the two circles overlap is where our shared journey lives. It is a space of understanding, collaboration, and support—where families and the scientific community unite to learn from one another, advocate for progress, and move forward together.

The dashed lines within the circles represent the disrupted communication between cells caused by GNB1 variants. While these disruptions can bring challenges, they also remind us why connection matters so deeply. By strengthening communication between families, researchers, clinicians, and the broader community, we build pathways toward greater understanding, improved care, and meaningful progress.



WAYS TO GET INVOLVED

- **SHARE YOUR STORY**
- **POST ON SOCIAL MEDIA**
- **HOST AN EVENT**
- **FUNDRAISE**
- **SHARE PHOTOS/VIDEOS**
- **EDUCATE YOUR COMMUNITY**

YOU CAN DO ONE SMALL ACTION OR MANY. EVERY VOICE MATTERS.

SOCIAL MEDIA

Social media is one of the most powerful ways families can help raise awareness for GNB1. A single post can educate hundreds, sometimes thousands, of people who may have never heard of GNB1 before. Participate in whatever way feels comfortable for you.

Ways to Participate (Choose One or Many)

- Share a photo-
- Post your story-
- Repost official campaign graphics-
- Change your profile picture frame-
- Share educational facts-
- Post a short video-
- Celebrate milestones-
- Thank supporters or therapists-
- Do a “Day in the Life” to be shared on our social media-

Step 1: Choose Your Content

A message you want people to understand



Step 2: Add Awareness

Include:

- Awareness hashtag
- Mention GNB1 Awareness Month or Day
- Optional graphic or frame

Step 3: Post & Share. Tag the GNB1 Advocacy Group

Post anytime in April — especially April 21.

Suggested Hashtags:: #ConnectedByGNB1, #GNB1Awareness, #GNB1Month
#GNB1Day, #GNB1 Syndrome, #GNB1AdvocacyGroup

SHARE YOUR STORY

SHARING YOUR STORY HELPS:

- Raise awareness about GNB1
- Educate friends and communities
- Support newly diagnosed families
- Build connection across the global community
- Celebrate resilience and progress

You do not need to share everything. Even a few sentences can make a powerful impact.



Ways You Can Share Your Story

Choose the format that feels most comfortable.

- A social media post-
- A short written story-
- A video message-
- Photos with captions-
- A blog or newsletter-
- A school or community presentation-
- Anonymous submissions (The GNB1 Advocacy Group will post)-

[Story Writing Guide Link](#)

HOST AN EVENT

Events can be small, simple, and meaningful. Every event helps grow awareness and connection.

Event Ideas

- Coffee meetup
- Neighborhood walk
- School awareness day
- Virtual gathering
- Bake sale
- Awareness table

Community Events

- Awareness walk in a local park
- Playground meetup
- Community picnic
- Neighborhood gathering
- Group photo event

Virtual Events:

- Virtual story-sharing session
- Online awareness talk
- Instagram Live conversation
- Virtual Run

Workplace Events

- Awareness email to coworkers
- Breakroom information table
- Casual lunch-and-learn
- Company social media post

Classroom Events

- Wear awareness colors day
- Classroom presentation
- Read a book about inclusion
- Awareness poster activity
- School morning announcement



Planning Checklist

- Pick Something:**
 - Coffee meetup • Park playdate • School activity • Virtual gathering
- Choose a Date**
 - Anytime in April or April 21 (GNB1 Awareness Day)
- Invite People**
 - Text, email, or social media invite
- Add Awareness**
 - Share GNB1 facts or your story
 - Wear awareness colors or use graphics
- Share & Celebrate**
 - Take a photo Tag Us
 - Post using #ConnectedByGNB1

Host an Event Guide

Fundraising Master List Link

FUNDRAISING IDEAS

🍋 Host a lemonade or snack stand.

🧁 Organize a bake sale with awareness treats.

📅 **\$1-a-Day Challenge** — Supporters donate \$1 each day during Awareness Month.

👕 Share the GNB1 merch store

☕ **Skip-a-Coffee Donation:** Invite friends to donate the cost of one coffee.

💻 Share our online donation page with friends and family.

👕 Hold a wear-awareness-colors day at school or work.

🚶 Organize a walk, roll, or movement challenge.

🍕 Partner with a local restaurant for a giveback night.

🎨 Sell handmade art, crafts, or bracelets.

☕ Host a coffee meetup.

🏃 Participate in a race or activity in honor of GNB1.

🎮 Stream a gaming fundraiser online.

📖 Host a community yard or book sale.

🎵 Organize a small music or talent gathering.

🍷 Plan a picnic with a donation option.

✉️ Ask friends/family for small donations via text or email.

🐾 Host a neighborhood dog walk.

🎟️ Run a small raffle or prize drawing.

👨🍳 Cook or bake and share with donation support.

📌 Add a fundraiser link to your social media profile.

📌 Social media challenge encouraging small donations.

💼 **Matching Donation from Local Businesses** — Ask a local business to match the amount you raise, doubling the impact of donations.

INVOLVE YOUR COMMUNITY

Help families invite friends, neighbors, schools, and local groups to learn about GNB1 and participate in awareness activities together.



Ways to Get Started

- Share what GNB1 Awareness Month means to your family.
 - Invite others to participate in a small activity or event.
- Focus on connection awareness grows through conversations.

Email Outreach Template

PARTICIPATION CALENDAR



EXAMPLE

Week	Activity
Week 1	Share Your Story
Week 2	Post a Photo
Week 3	Educate a Friend
Week 4	Fundraise or host an event
April 21	Celebrate GNB1 Day

RESOURCE PAGE

GNB1 INFORMATIONAL FLYER

GNB1 INFORMATIONAL PAMPHLET

GNB1 GIVE BUTTER DONATION LINK

**GNB1 DAY PICTURE TEMPLATE LINK 1
(CANVA)**

**GNB1 DAY PICTURE TEMPLATE LINK 2
(CANVA)**

GNB1 DAY STORY TEMPLATE LINK (CANVA)

GNB1 DAY STORY TEMPLATE LINK 2 (CANVA)

EMAIL TEMPLATE COMMUNITY OUTREACH

GNB1 MERCH STORE



EVERY STORY SHARED, PHOTOPOSTED, AND CONVERSATION STARTED HELPS GROW AWARENESS AND STRENGTHENS OUR CONNECTED BY GNB1 COMMUNITY. THANK YOU FOR CELEBRATING WITH US AND HELPING CREATE A MORE INFORMED AND SUPPORTIVE WORLD.

