

Community Days as a Means of Promoting Health Equity

A Presentation by GBS|CIDP Foundation International
for the National Health Council

Presentation Objectives

- ❖ Introduction to the Foundation and How We Can Help
- ❖ Explanation of GBS, CIDP and MMN
- ❖ Review of Policy Initiatives Designed to Support Our Community
- ❖ Defining GBS CIDP Community Days
- ❖ How We Identified Communities that Could Benefit Most from a Community Day
- ❖ Defining a Center of Excellence in Treatment for Peripheral Neuropathy
- ❖ Community Day Outreach Efforts and Outcomes in 2025
- ❖ Lessons Learned and Best Practices Moving Forward
- ❖ 2026 Community Day Locations

GBS|CIDP Foundation International

Our History

- Founded in 1980 by Estelle & Bob Benson
- Bob was diagnosed with GBS before any treatment existed and spent many months in ICU & rehab.
- Estelle vowed that no patient would ever go through this journey alone.
- It began with eight people at a dining room table & has now spread globally with a 50,000-person database.
- Estelle went on to help create NORD & continues her patient-driven mission.

GBS|CIDP Foundation International

Our Vision

Every person affected by GBS, CIDP, MMN or related syndromes will have access to early and accurate diagnosis, appropriate treatment and knowledgeable support services.

GBS|CIDP Foundation International

Our Mission

- We support patients by nurturing a global network of volunteers, healthcare professionals, researchers and industry partners to provide them with critical, timely, and accurate information;
- We educate doctors, clinicians, patients and caregivers to increase awareness and understanding;
- We fund research through grants, establishing fellowships and other appropriate avenues to identify the causes of and discover treatments;
- We advocate at the federal, state, and grassroots levels to educate policymakers and help them make informed decisions that benefit our patient community.

How The Foundation Can Help

- Library of free Educational Materials
- Volunteer led peer-to-peer support
- Free Monthly Virtual Support Calls
- Biennial Patient Symposium
- Doctor to Doctor consult
- Financial Assistance Program
- Research Grant Program
- Ask the Experts Monthly Webinars
- Quarterly Newsletter
- Medical Centers of Excellence worldwide
- ...and so much more!



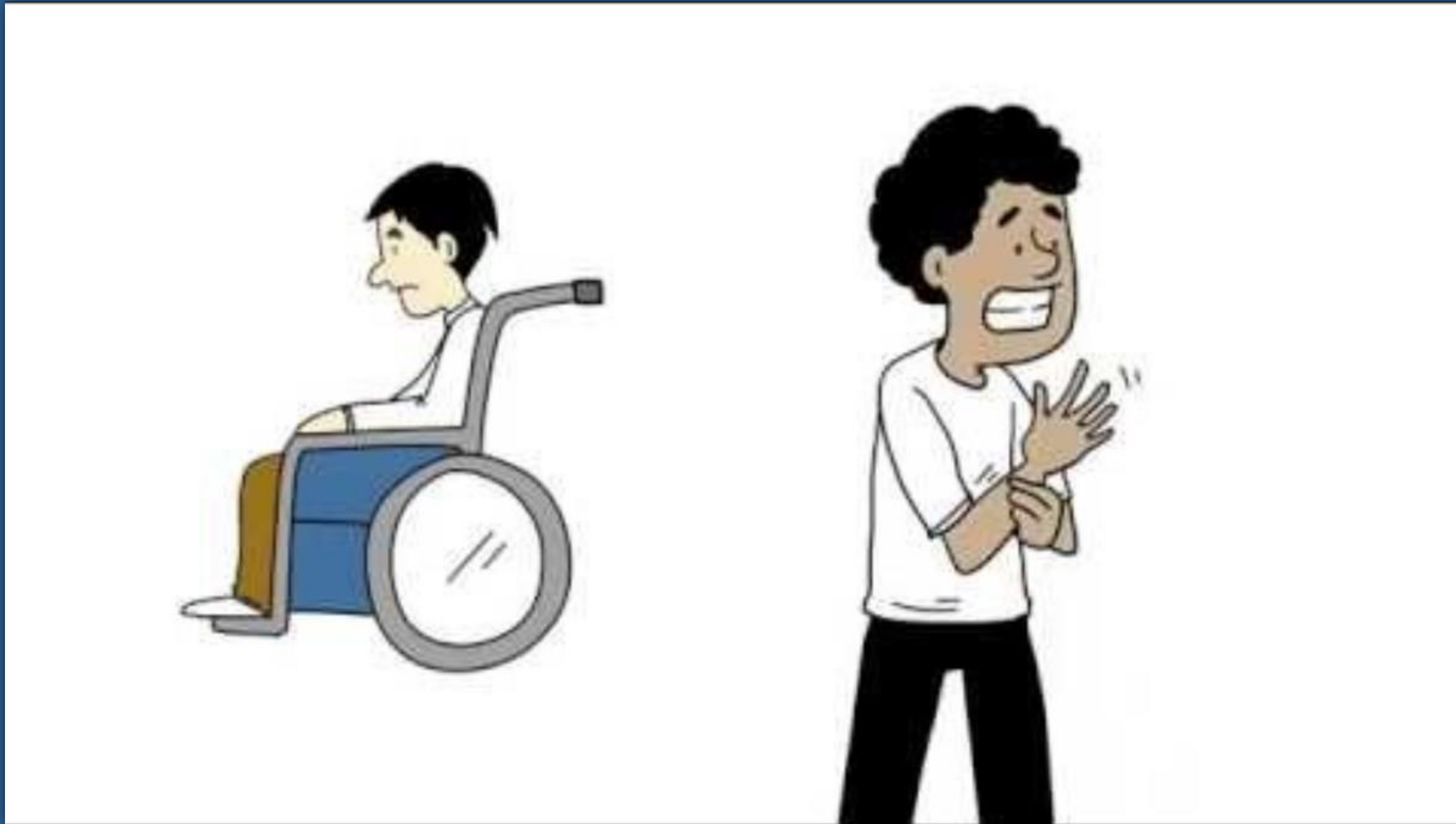
Guillain-Barré Syndrome (GBS)

Guillain-Barré (Ghee-yan Bah-ray) Syndrome is an inflammatory disorder of the peripheral nerves outside the brain and spinal cord.

GBS is characterized by the rapid onset of numbness, weakness, and often paralysis of the legs, arms, breathing muscles, and face. Paralysis is ascending, meaning that it travels up the limbs from fingers and toes towards the torso. Loss of reflexes, such as the knee jerk, are usually found.

Although GBS is a rare condition, it is also widely considered the most common cause of acute flaccid paralysis worldwide.

Guillain-Barré Syndrome (GBS)



Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)

Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) is a rare disorder of the peripheral nerves characterized by gradually increasing sensory loss and weakness associated with loss of reflexes.

Many people with CIDP benefit with treatment. Although there is a wide spectrum of how severely people with CIDP can be affected, some with the condition require assistance to perform daily tasks. In the more severe cases devices like wheelchairs or walkers may be needed for mobility. One of the goals of early diagnosis and proper treatment is to avoid this level of disability and to improve the long-term outlook.

Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)



Multifocal Motor Neuropathy (MMN)

MMN (Multifocal Motor Neuropathy) is a rare disorder in which focal areas of multiple motor nerves are attacked by one's own immune system. Typically, MMN is slowly progressive, resulting in asymmetrical weakness of a patient's limbs. Patients frequently develop weakness in their hand(s), resulting in dropping of objects or sometimes inability to turn a key in a lock. The weakness associated with MMN can be recognized as fitting a specific nerve territory. There is essentially no numbness, tingling, or pain. Patients with MMN can have other symptoms, including twitching, or small random dimpling of the muscle under the skin which neurologists call fasciculations.

MMN has many features similar to CIDP in that its onset is progressive over time, causing increased disability that reflects the greater number of nerve sites involved. However, unlike CIDP, MMN is asymmetric and affects the right and left side of the body differently. Unlike other forms of chronic nerve inflammation, it is thought to never remit. However appropriate treatment that is FDA approved does limit progression and improves function.

Policy Initiatives
Designed to
Support Our Community

Policy Initiative:

Improve Home Infusion Access to IVIG

- Currently, IVIG infusions must be performed at a clinic, in-person, for Medicare Part B to cover the treatments
- Infusion centers may be hours away - especially in rural areas. Infusions are lengthy and exhausting for the patients, often spread over 2 days
 - Access to vehicle and ability to drive are also factors, patients may need to rely on caregivers and/or the Non-Emergency Medical Transportation Program (NEMT) to support with getting to and from appointments
- The Foundation is working to expand Medicare Part B coverage for home infusion of IVIG to be covered by Medicare Part B

Policy Initiative: Grassroots Advocacy with Under Supported Groups

- Recently launched Disability Task Force within the Foundation to identify areas where policy fixes may be necessary and take proper steps to address them, including through coalition work
- A recurring Veterans Group also identified access gaps that may be addressed with policy

Policy Initiative: Research Funding

Ongoing appropriations work to support National Institutes of Health (NIH), Center for Disease Control (CDC), and the Department of Defense Peer Reviewed Medical Research Program (DOD PRMRP) research programs to advance research for improved, and hopefully more personalized, treatment options.

GBS|CIDP Foundation International's

2024 – 2026 Strategic Plan

Diversity, Equity and Inclusion: “Over the next three years, the Foundation will be intentional in reflecting the community we serve and understanding their DEI needs, especially those of under-supported communities, resulting in better access to information, resources, diagnosis, and treatment”

Defining Community Days

Community Days are an all-inclusive day, that offers an opportunity for anyone living with these conditions, or their care partners, to connect with highly knowledgeable healthcare professionals, fellow patients and educational resources. These one-day events can offer the vital connections and support that patients are seeking, in their healthcare journeys with GBS, CIDP, MMN and related conditions. They are designed to empower patients and health care providers with the latest knowledge and resources on managing GBS, CIDP and related conditions, and they work to make sure that everyone receives the high-quality care and access to information that they deserve. Topics addressed include Research & Clinical Trials and Resources such as Adaptive Devices, Health Insurance Counselling and Financial Assistance.

Identifying Community Day Locations

SUPPORT EDUCATION RESEARCH ADVOCACY SUPPORT EDUCATION RESEARCH ADVOCACY SUPPORT EDUCATION RESEARCH ADVOCACY SUPPORT

➤ Who is searching for us?

TOP IMPRESSIONS ON GOOGLE ADWORDS,
(past 30 Days)

California - 4165
Texas - 1938
New York - 1660
Pennsylvania 1350
Georgia - 1305
Illinois - 1040
North Carolina - 1036
Ohio - 941
Michigan - 817
New Jersey - 810

➤ How many members do we have in those areas?

These are the top 13 States in Foundation Database:

California - 7308
Pennsylvania - 5699
Texas - 5002
Florida - 4434
New Jersey - 3153
Illinois - 2737
Ohio - 2335
Michigan - 2036
North Carolina - 2380
Maryland - 1544
Georgia - 1510

Identifying Community Day Locations

SUPPORT EDUCATION RESEARCH ADVOCACY SUPPORT EDUCATION RESEARCH ADVOCACY SUPPORT EDUCATION RESEARCH ADVOCACY SUPPORT

➤ *Are there medical professionals and volunteers that can partner and assist in those areas?*

1) OHIO: COE's, OHIO STATE UNIVERSITY; UNIVERSITY OF CINCINNATI – Richard met with at AANEM

2) MICHIGAN: COE's, UNIVERSITY OF MICHIGAN, HENRY FORD HOSPITAL

3) ILLINOIS: COE, UNIVERSITY OF CHICAGO

4) NORTH CAROLINA: COE, UNIVERSITY OF NORTH CAROLINA, CHAPEL HILL

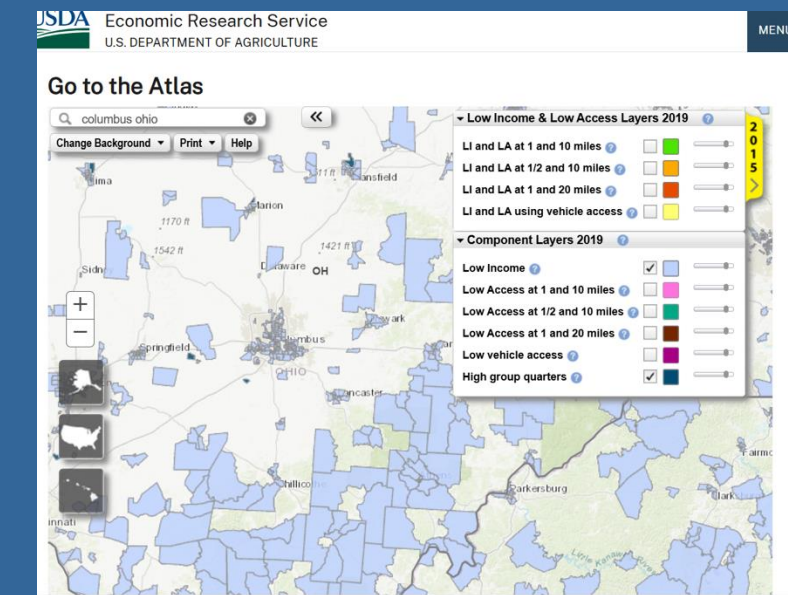
*GEORGIA – NO COE, NO ACTIVE VOLUNTEER: Delayed Community Day until 2026

➤ *Have we held meetings there before?*
Only in Chicago, Illinois.

➤ *How do we focus in on the health desert areas?*

USDA Economic Research Service

- Largest population with
- lowest income
- lowest vehicle access
- lowest access to food



Defining a Center of Excellence

Our Global Medical Advisory Board has set standards for what they consider to be excellent medical centers for the diagnosis and treatment of GBS and CIDP, MMN and related neuropathies. Based on levels of expertise, available treatments, facilities, and research capabilities, these are the medical centers that we can unequivocally recommend as “Centers of Excellence.” Centers of Excellence are encouraged to display the seal on their websites.



Defining a Center of Excellence



The Foundation has worked with Medical Facilities around the Globe to Establish 63 International Centers of Excellence.

If you represent a Medical Facility that provides exceptional service, we encourage you to contact us to express interest in becoming a GBS CIDP Center of Excellence

Community Day Outreach Efforts

Expanded Outreach Efforts were made to advertise the Community Days to populations who had never interacted with the Foundation before, this included:

- Outreach to all infusion centers offering IVIG within 100 miles of each Community Day event – Contact information obtained using the National Infusion Center Association (NICA) registry
- Contacting Rural Health Organizations, State Hospital Associations, and entities that Manage Federally Qualified Health Centers and Rural Health Centers in each state where a Community Day was held
- Contacting Non-Profit Organizations geared towards supporting patients with rare conditions in each state where a Community Day was held
- Utilizing the outreach resources of each Center of Excellence where a Community Day was held. This included letters to patients advertising the Community Days, Contacts to the Referral Sources for the Centers of Excellence and more.

2025 Community Day Locations

Columbus, Ohio: June 7th

Birmingham, Alabama: June 14th

Detroit, Michigan: August 16th

The Ohio State University

June 7, 2025



- The Ohio State University has a large event facility which was utilized for the Community Day in Partnership with The Ohio State University Neuromuscular Division
- Doctors from the Center of Excellence spoke during breakout sessions regarding the conditions; and several staff members at the Ohio State University including a physical therapist, a registered dietitian, a social worker and a neuropsychologist gave talks regarding their respective disciplines
- This event was exceptionally well attended with more than 50 patients and caregivers present

The University of Alabama at Palmeto Infusion

June 16, 2025

- Palmetto Infusion allowed the Foundation to use their corporate conference space in Birmingham Alabama to hold the Community Day
- The Director of the Division of Neuromuscular Disease at the University of Alabama gave a talk about GBS, CIDP, MMN and related conditions. Representatives of the Foundation spoke about Adaptive Device Programs, Insurance Counselling Resources and Financial Assistance.
- Described as “Small but Mighty” – attendance at the event was low. However, participants were pleased with the level of individual attention and interaction that the lower attendance level afforded them.



Henry Ford Medical Center

June 16, 2025



- This event was held at the Henry Ford Medical Center in one of their large conference rooms which was intelligently designed to for the purpose of offering educational presentations
- This event was a true partnership, with multiple Centers of Excellence and local medical providers participating. Henry Ford Health, The University of Michigan State University and the University of Michigan all played significant roles outreach and/or content creation for the Community Day
- This event was well attended with more than 20 patients and caregiver present, and generated significant interest in volunteering

Lessons Learned and Best Practices

- Be mindful of local customs and be willing to adjust plans to align with those customs (OSU Football Season)
- Be mindful of your population and their non-medical needs. (If your population is predominantly people over age 40, consider that in accordance with US census data they are statistically likely to be parents)
- Patients, Caregivers and Community Partners need ample time to prepare to attend an event. The more time community members have to prepare for the event, the more likely the event is to be well attended
- Medical providers at expert teaching hospitals tend to want to hold events at the end of a semester or just before the start of a new semester

Lessons Learned and Best Practices

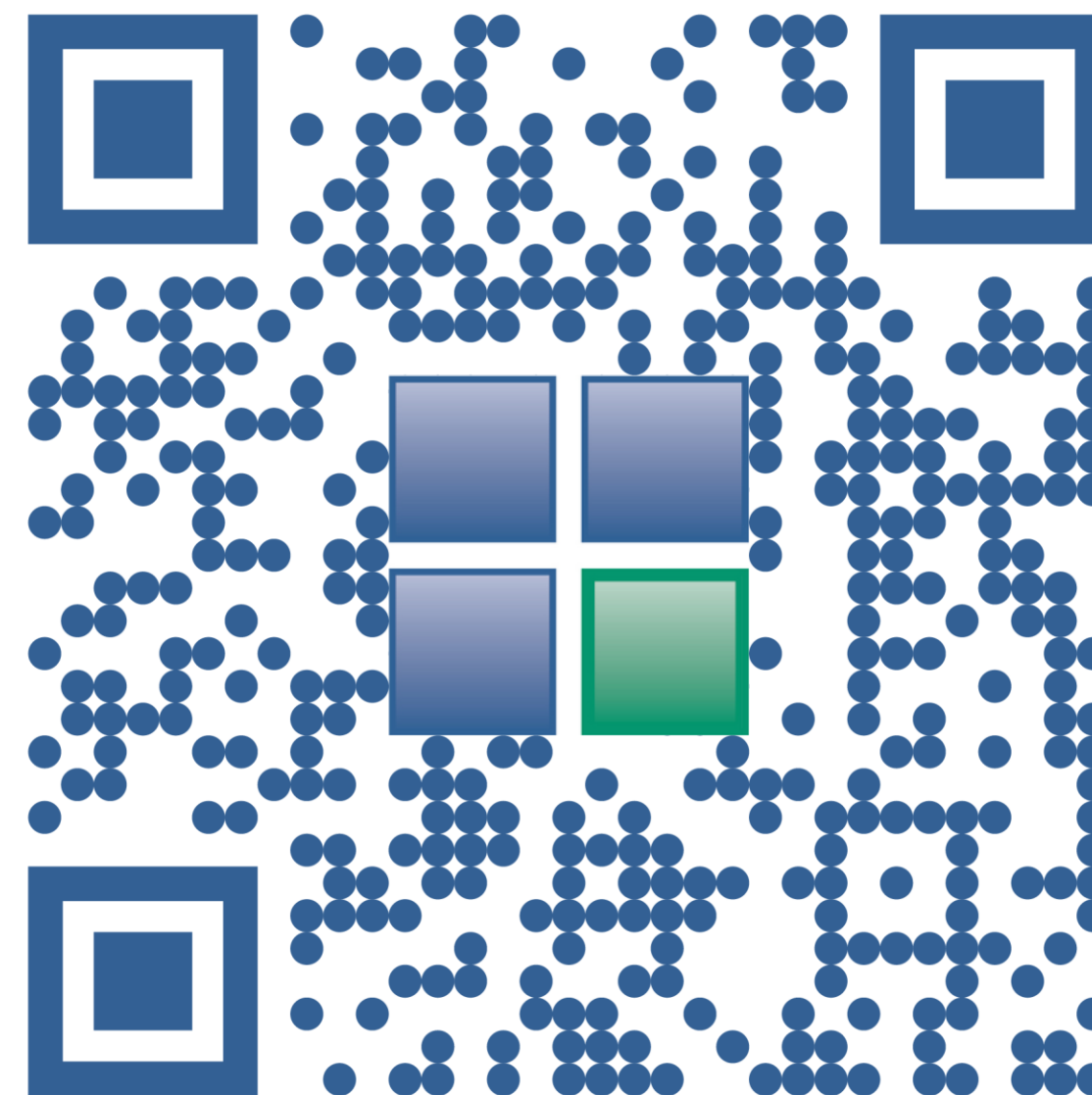
- Community Days tend to generate interest volunteering and interest in holding more local events. It is ideal to be prepared to build on the momentum created by these events. Preparation can include blocking out time to allow for additional activities and follow up conversations to support local communities
- Although expert medical providers are often well-versed in public speaking; medical institutions where experts work have varying degrees of experience in community event planning and outreach
 - Wherever institutional resources exist, it is preferable to utilize those resources to support community outreach efforts
 - In situations where institutional event planning resources are not available; it can be beneficial to supply stakeholders at local institutions with guidance regarding best practices

2026 Community Day Locations

- Philadelphia, PA
- Los Angeles, CA
- Dallas, TX
- Atlanta, GA
- Portland, OR / Seattle, WA
- Staten Island / Long Island NY
- Memphis, TN

References

- ❖ <https://www.gbs-cidp.org/gbs/>
- ❖ <https://www.ncbi.nlm.nih.gov/books/NBK532254/>
- ❖ <https://www.gbs-cidp.org/support/centers-of-excellence/>
- ❖ <https://rarediseases.org/understanding-rare-disease/rare-disease-facts-and-statistics/>



**For more information about
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