



2021

IMPACT REPORT






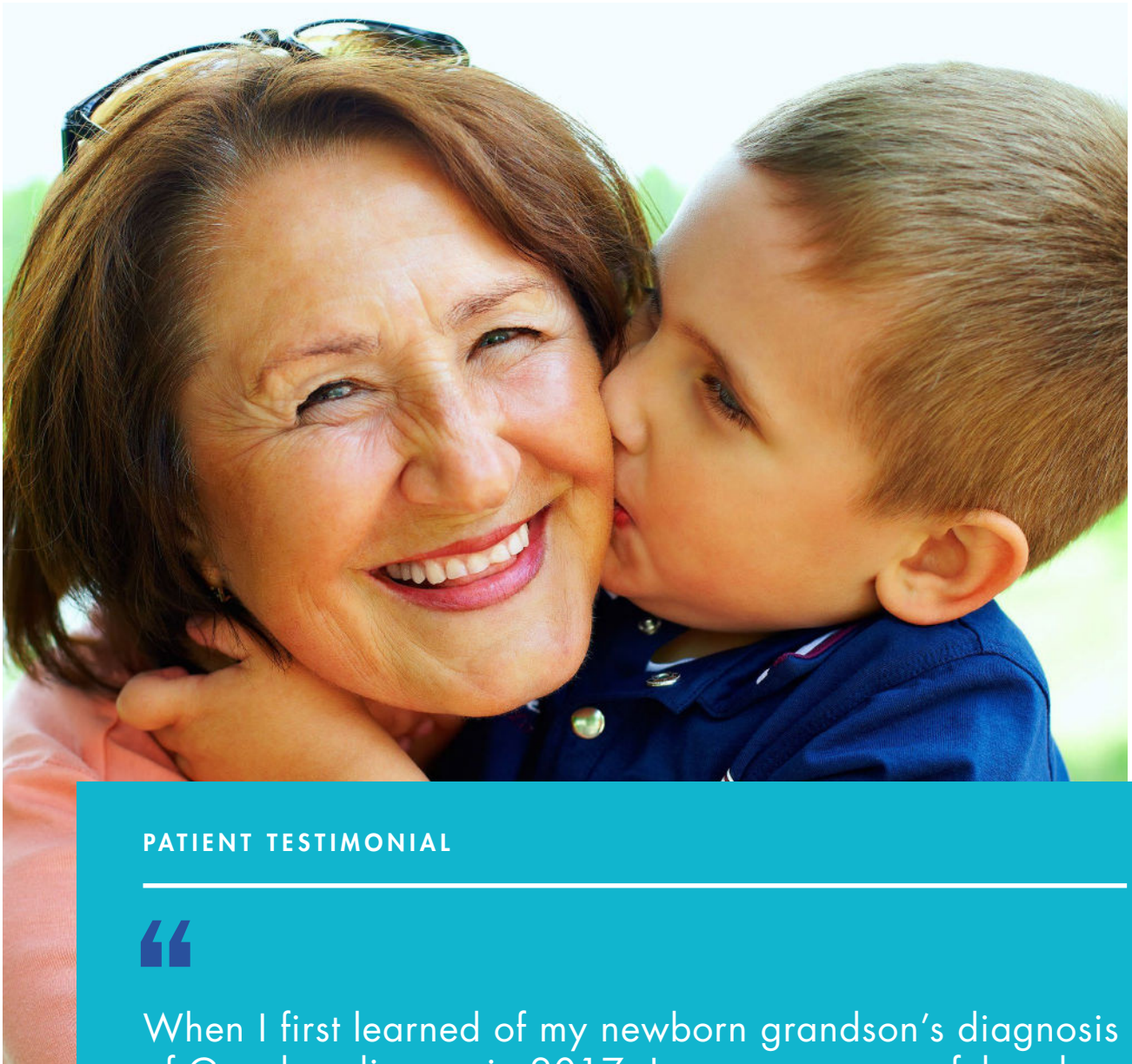
National Gaucher Foundation 2021 Impact Report

The National Gaucher Foundation (NGF) is an independent nonprofit dedicated to serving U.S. patients with Gaucher disease and their families. Through financial support, educational programming, patient services, and collaboration with medical professionals, the NGF empowers Gaucher patients to live a better today.

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PATIENT TESTIMONIAL



When I first learned of my newborn grandson's diagnosis of Gaucher disease in 2017. I came across useful and user-friendly information on the NGF's website. I also called and spoke to [staff], who was incredibly kind, sympathetic, and reassuring. My grandson is now almost four years old, and I rely on the NGF when needed. I can't begin to express our gratitude for such empathetic experts at the NGF.

LINDA, Grandparent

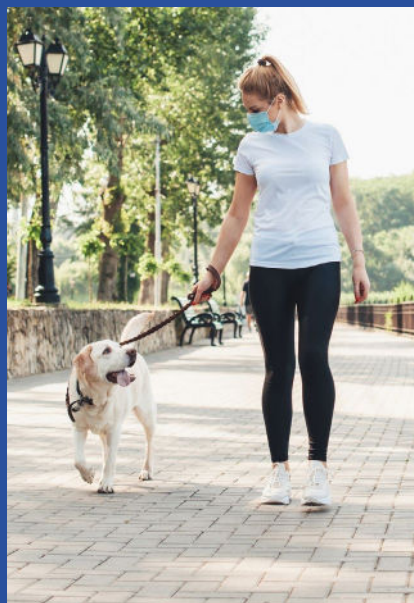
CARE

In 1993, the National Gaucher Foundation recognized the need for financial assistance in the Gaucher community. The National Gaucher CARE Foundation (NGCF) was created to help relieve this financial burden. The NGCF provides financial assistance for people with Gaucher disease and their families through the CARE and CARE+ Programs.

Assistance is available to individuals with Gaucher disease who are US citizens residing in the United States and can demonstrate extraordinary financial hardship in paying for eligible Gaucher-related expenses.



\$2.1 MILLION
in grants awarded to
eligible community members



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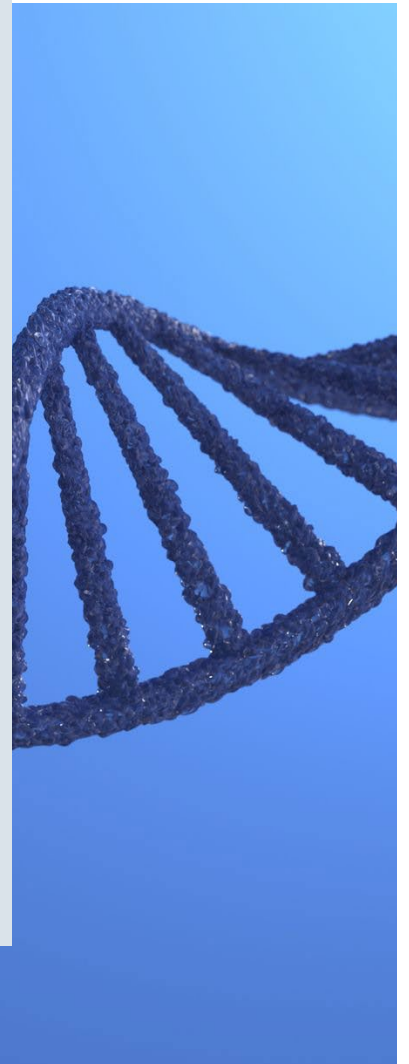
When I found out I had Gaucher disease and knew there was a treatment I couldn't afford, I was brought to tears. Then, miraculously, I found the CARE Programs. I would not have been able to receive treatment and access proper disease management over the years without it. The CARE Programs have been a lifesaver.

MARILYN



The National Gaucher Foundation CARE program positively impacts our lives. From times in our working lives when it was difficult to afford insurance premiums to our current status as retirees, assistance from the NGF CARE program has enabled us to live without fear of losing insurance or having to choose between necessities like groceries or medical insurance. I'm not at all clear what we would have done without it and we are eternally grateful for its existence.

ANONYMOUS



For more than 25 years, the NGF has supported people with Gaucher disease who endure extraordinary financial hardship with financial grants programs.

Care

- Approved OIG Opinion
- Provides financial grants to pay for insurance premiums for eligible Gaucher patients and their families

Care + Plus

- Approved OIG Opinion
- Provides financial assistance for ancillary costs not covered by insurance for eligible Gaucher patients



“

I was laid off during the middle of the Covid-19 pandemic. Loss of income and loss of health insurance increased an incredibly stressful situation. Thanks to the CARE Programs, I was able to continue my healthcare plan and have a big weight lifted off my shoulders. This allowed me to focus exclusively on getting a new job that includes health insurance. I no longer need the CARE grant and, as I appreciate the value of CARE, I am now a recurring donor.

MIKE

Stepping Stones Sustainer

This year, the NGF launched Stepping Stones, a sustainer giving program designed to support our patient advocacy initiatives, focusing upon the CARE Programs. With a monthly gift in any amount, NGF can better focus our efforts to support patients and their families – and less time on fundraising.

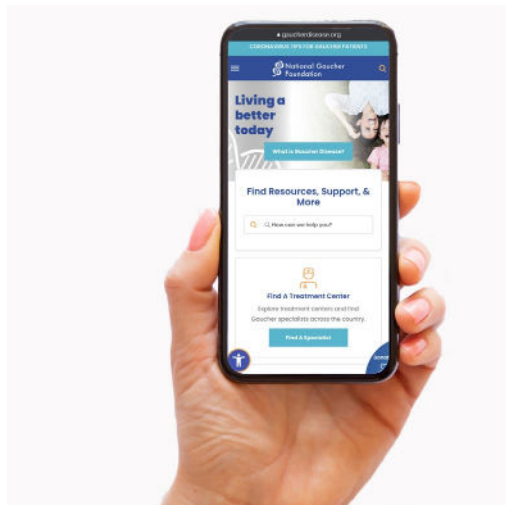
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As a Gaucher patient, I recognize the many types of challenges a patient and their family face. All of the support elements from coping to research to care and treatment require consistent funding to properly budget and plan. Providing a recurring donation, even a small one, is one thing I can do to contribute to the long term support needed for the Gaucher community.

ANONYMOUS

DIGITAL ENGAGEMENT

The National Gaucher Foundation creates compelling content that reaches an international audience and appears among the top rankings in web searches. We redesigned our website this year to best leverage updated technologies and enhance the user experience. This contributed to continued significant growth in our web traffic, which resulted in weekly global inquiries.



New Website

In 2021, the NGF launched a new website to better serve the Gaucher community. We refined our pages to be even more user friendly and accessible. With a new and enhanced search process, users can quickly find the information they need.

Website Engagement

Since the website Relunched in 2016:



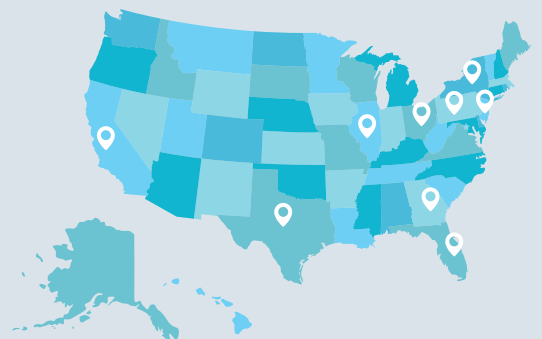
2.8 MILLION
Unique Users



3.2 MILLION
Unique Pageviews

Top Users by State

- California
- New York
- Florida
- Texas
- Illinois
- Pennsylvania
- New Jersey
- Massachusetts
- Georgia
- Ohio



Search Engine Optimization Rankings



#1 RANKING
for 108 keywords
(out of 433 targeted)



#2-3 RANKING
for 116 keywords
(out of 433 targeted)



#4-10 RANKING
for 119 keywords
(out of 433 targeted)



343
number of keywords
ranking on the first page

#1 Ranking Highlights:

- ashkenazi Jewish disease
- gaucher cells
- gaucher's disease diagnosis
- gaucher's type 2
- gaucher type 1
- substrate reduction therapy
- gaucher disease screening
- test gaucher
- history of gaucher disease
- gaucher gene therapy



EDUCATION & AWARENESS

Internationally recognized as an authoritative source, the National Gaucher Foundation provides quality Gaucher education & awareness. In 2021, the NGF's education & awareness endeavors included social media, digital & print campaigns.

Through collaborative endeavors and the steadfast generosity of its supporters, the NGF benefitted the global Gaucher community.

Optimizing your health is the goal of effective disease management. A Gaucher specialist plays a key role in achieving this goal.



13,000
new users for treatment-related pages



5,000
projected unique pageviews for the
treatment finder page for 2021

Social Media

This year we began to overhaul our social media engagement to educate, inspire, and connect with the Gaucher community.



62,000+
Impressions



5,000+
Unique Engagements



19%
Net Audience
Growth

Print Publications



400,000

Print circulation households reached



Public Health Policy

In our effort to better educate the Gaucher community about ever changing public health policies, we continually share relevant and useful information.

To see an example of the information we share hold your device over this QR Code so that it's clearly visible within your smartphone's camera screen. The phone will automatically scan the code and take you to the website.

Coronavirus

The NGF continued its collaboration with the US Physician Working Group on the Impact of Gaucher Disease and COVID-19. This group of esteemed expert Gaucher clinicians, epidemiologists and immunologists discussed the evolving understanding of COVID-19 and relevant clinical studies to provide the most current information for those who have Gaucher disease.



Follow CDC & Your Local Guidelines.



Get Vaccinated. Find a Vaccine at www.vaccines.gov/search/.



Consult your Gaucher specialist about any concerns.



Continue all prescribed Gaucher medications and treatments. Do not change your treatment without consulting your doctor.



Wash your hands to help stay healthy and prevent the spread of infection.



When in close proximity to others, continue to wear a mask that covers your mouth and nose to protect yourself and others.



If you haven't been vaccinated yet, continue to practice social distancing.



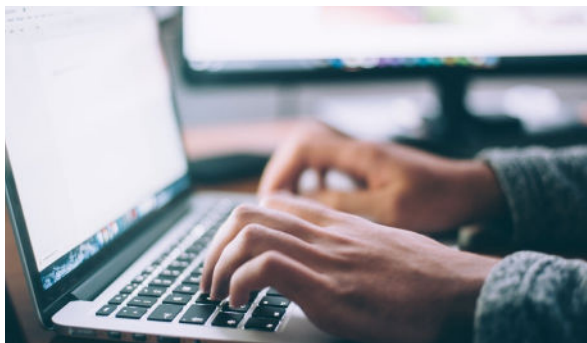
Eat healthy, get enough sleep, and exercise as regularly as you can.



Be kind to yourself and others.

Blogs

In 2021, we continued to publish compelling and useful blogs that saw a 22% increase in organic traffic and a 26% in new users as compared to the previous year.



7 Tips for Selecting Health Insurance When You Have a Pre-Existing Condition

READ THE BLOG:



Hold your device over this QR Code so that it's clearly visible within your smartphone's camera screen. The phone will automatically scan the code and take you to the website.



How Systemic Inflammation Affects Your Brain & Central Nervous System

READ THE BLOG:



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Newborn Screening: What You Need to Know

READ THE BLOG:



Hold your device over this QR Code so that it's clearly visible within your smartphone's camera screen. The phone will automatically scan the code and take you to the website.





9 Myths About Genetic Disease Carrier Screening

READ THE BLOG:



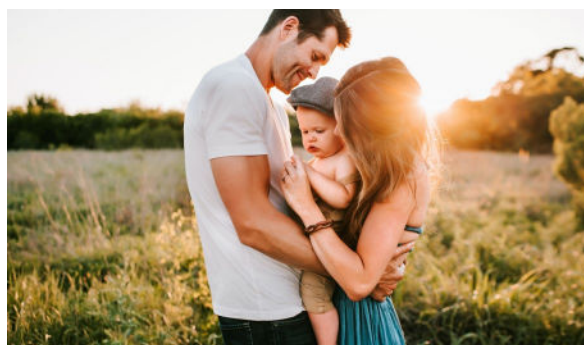
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Gaucher Disease and Reproductive Health

READ THE BLOG:



Hold your device over this QR Code so that it's clearly visible within your smartphone's camera screen. The phone will automatically scan the code and take you to the website.



How the American Rescue Plan and State Health Insurance Laws Affect You

READ THE BLOG:



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ADVOCACY

The National Gaucher Foundation has been at the forefront of advocacy for the Gaucher community for over 37 years. Our trusted reputation developed through being a constant voice on behalf of the Gaucher community, supporting and empowering each individual in the greater Gaucher community.

Lobbying Legislators

This year, the National Gaucher Foundation lobbied congressional and state legislative leaders to continue to raise awareness of the unique health challenges of those who have rare diseases and the impact of legislation on access to the health care essential to disease management.



OUR STAFF



Brian Berman

President & Chief Executive Officer



Amy Blum

Chief Operating Officer



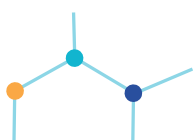
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To go to our website:

SCAN THIS QR CODE



Hold your device over this QR Code so that it's clearly visible within your smartphone's camera screen. The phone will automatically scan the code and take you to the website.