

Genetic Support Foundation

2025 Impact Report



Our Mission

In a world where genetic technologies are advancing faster than access to care, most people still can't afford life-saving genetic testing for conditions like hereditary cancer or support for their child with a genetic condition such as cystic fibrosis or Down syndrome. Genetic Support Foundation (GSF) is stepping in to bridge these gaps, providing compassionate care and free educational resources and increasing public awareness of ethical standards and access in genetics.

At GSF, we are committed to ensuring patients have access to sensitive, high-quality genetic counseling and comprehensive resources about genetics. We are also a national advocacy leader at the intersection of genetics, ethics, and disability rights.

Top 10 Accomplishments of 2025

Thanks to the generosity of our donors, partners, and community, we continued to expand our impact throughout 2025. Read on to learn how we have made the world a better place this past year and our goals moving forward!

1 High-Quality Genetic Counseling

We provided genetic counseling to more than **5,000 patients** and their families across the US, with **95% of patients** seen through GSF Direct reporting their session improved understanding of their genetic risks and options.

I live in a state that doesn't offer genetic counseling services for neurological conditions. It made a huge difference to me not to have to travel.

I've never heard that the male cancers could be linked to female cancers... The general public just doesn't have that information and doesn't know. And it could really save lives.

2 Financial Assistance for Patients

~**40% of patients** seen through GSF Direct received genetic counseling services at no-cost through our financial assistance program—supported by donors and grant funding. This ensures all patients can access quality genetic care regardless of income.

3 Expanding Digital Tools

Our digital resources reached record audiences in 2025, with over **15,000 GSF** website visitors and over a **quarter of a million** visitors reaching [Lettercase](#) and [Down Syndrome Pregnancy](#) resources—connecting patients and providers to trustworthy, evidence-based information.

2025 At a Glance

5,000+	patients counseled
40%	GSF Direct visits at-no cost
300	providers trained
120	partner collaborations
1,500	free resources provided
550	podcast downloads
8	peer-reviewed publications
5	new grant awards

4 Education & Training

We trained over **300 health providers** and **140 students** from 12 genetic counseling and disability studies programs, helping shape the next generation of compassionate providers.

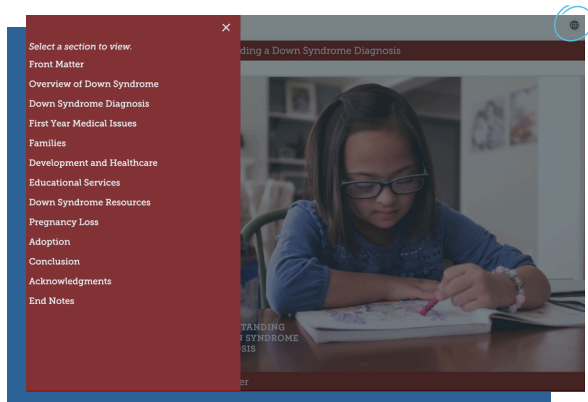
5 Community Partnerships

We collaborated with over **120** community-based clinics, support organizations, advocacy groups, and members of our Alliance for Disability Justice and Ethics in Reproductive Genetics to improve care and policy surrounding genetics and disability.

Top 10 Accomplishments of 2025

6 Free Resources

We provided nearly \$5,000 worth of free, printed resources on genetic conditions to **over 1,500** new and expectant parents and medical providers. We updated our free, online resources to a more accessible digital format, added Spanish translations to all resources, and added 5 new languages to our Down syndrome resource.



8 Research and Publications

GSF staff published **8 peer-reviewed articles** in journals such as the *American Journal of Medical Genetics*, *Journal of Genetic Counseling*, *Journal of Community Genetics*, *Nature Reviews Endocrinology*, and *International Review of Research in Developmental Disabilities*. Our research amplifies disability voices and advocates for more equitable diagnostic practices and ethical standards in genetics.

9 Conference Leadership

GSF staff presented at **6 national** medical, advocacy, and bioethics conferences and **dozens of local conferences**, sharing insights on topics ranging from disability-informed reproductive genetics to patient advocacy partnerships.




7 Media and Public Engagement

We published **9 articles** on our blog, viewed by over 5,000 people around the world. We released **7 episodes** of our new CODED: Genetics podcast, with nearly 550 downloads. Through this engagement, we brought genetic issues to the forefront and raised the voices and perspectives of advocates and experts.

Beyond Headlines: Down Syndrome and CRISPR

What happens when scientific discoveries collide with sensationalist headlines? When Japanese scientists published research showing they could remove the extra copy of chromosome 21 in isolated skin cells, media outlets quickly proclaimed: "Cou..."

September 17, 2025 • 42:33



Medicaid and the Devastating Ripple Effect of Budget Cuts on People with Disabilities

The House just passed what President Trump calls the "Big Beautiful Bill," and its implications could be devastating for millions of Americans who depend on Medicare and Medicaid. As this massive budget reconciliation bill heads to the Senate, ...

May 27, 2025 • 32:16



10 Growing Grant Support

In 2025, we were selected to receive **5 new grants** from the Patient Centered Outcomes Research Institute, Cystic Fibrosis Foundation, Compassionate Parents Network/Trisomy Collaborative, and Case Western Reserve University/National Institutes of Health, allowing us to reach more patients, strengthen community partnerships, and shape ethical genetics.

What is Your GSF Why?

A Community Partner Story

"Thank you for all your help with my pediatric patients that I refer to GSF. I didn't realize GSF has been around for over a decade. A family had recently told me about GSF when they couldn't get into either of the [local genetics clinics] for over a year from now due to the waitlists."

-Sam Keblawi, MD

An Advocacy Impact Story

"Thanks to leadership from the staff at GSF and support from our community partners, the voices of people with achondroplasia are being brought to the forefront about treatments for that condition. Between our articles and conference presentations, we are making sure that those with genetic conditions have a seat at the table."

-Stephanie Meredith, MA, DrPH, GSF

Patient Stories

"The information and support I needed came through the Genetic Support Foundation. Today I was able to speak with a qualified expert in this field. She answered all of my questions and put the information into the proper context . . . Genetic testing needs to be handled with the proper level of respect for the permanency of the results. Because you can't change your genetics, you need to really understand what you are about to learn from genetic testing."

-GSF Patient

"If you can catch anything early and deal with it early, the outcome is so much better. You have this [genetic] information so you can make the decisions. Instead of having cancer make the decisions for you, you can choose to make the decisions."

-GSF Patient, BRCA2 mutation carrier

A Board Member Story

"My 'GSF Why' is a story best told with our family photo. Like so many families, our family is made up of people with and without genetic disabilities. We see our disabilities as part of who we are. As we were building our family, we sought healthcare professionals, including genetic counselors, who would also view our genes as part-but not all-of who we are."

Viewing genetic histories through a lens of cultural competence and a commitment to dignity for all is embodied by the Genetic Support Foundation and I was honored to join their board when invited.

I look forward to working with and alongside GSF because there is so much important work in this space to be done."

-Kara Ayers, PhD



Top 5 Goals for 2026

Looking ahead to 2026, GSF is building on this year's momentum with ambitious goals that will expand access, strengthen partnerships, and advance disability justice in genetics.

1 Alliance for Disability Justice and Ethics in Reproductive Genetics

Organize and convene a coalition of over 40 scholars, advocates, clinicians, and community leaders to identify and advance policy priorities that promote **disability justice and ethical practices** in reproductive genetics.

2 Advance Research and Education

Conduct community research and publish educational materials for new and expectant parents learning about conditions such as skeletal dysplasias and trisomies 13 and 18.

3 Expand Access to Genetic Counseling

Expand partnerships with cystic fibrosis and disability advocacy organizations to **increase access to genetic counseling and education** in rural and underserved communities in the Pacific Northwest and across the nation.

4 Strengthen Advocacy

Promote policy changes that **improve access, equity, and ethical standards** in disability and genetic health services. These efforts are particularly important moving into 2026 as we face increasing healthcare cuts and limits on insurance coverage.

5 Deepen Public Engagement

Broaden our outreach through new podcast episodes, blog articles, and multimedia stories to elevate patient and provider voices and **build greater public understanding of genetics and disability**.

Join Us

While genetic testing is rapidly expanding, access to experts who can help patients understand these results has dramatically declined. This is largely due to cost-cutting of genetic services and insufficient insurance reimbursement.

Together—with our partners, donors, and community allies—GSF is advancing a more ethical and accessible future in genetics that prioritizes person-centered care and resources.

Every single donation helps the individual patients we support through services like vital genetic education resources or compassionate conversations with genetic counselors. And large donations help us change systems!



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