

Sponsorship Guide

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About Start Genetic

Too many people spend years searching for the reason a loved one is experiencing unexplained medical symptoms or developmental delays when a simple genetic test could provide critical insight. Start Genetic® is working to change this through a public awareness campaign designed to help families, clinicians and educators understand the importance of genetic testing in shortening the diagnostic odyssey. The campaign was officially launched in July 2025 by CureSHANK, a non-profit accelerating Phelan-McDermid syndrome research.

Genetic Testing Action Day

The annual Genetic Testing Action Day is the centerpiece of the Start Genetic campaign. It takes place each year on July 25 when families impacted by genetic diseases take to social media to tell stories of how critical genetic testing is and the impact it has on care. Lifting our voices collectively, on the same day, amplifies our message to take action and seek genetic testing.

Start Genetic is an opportunity for all genetic disease communities to educate the public about their conditions and how they are diagnosed. While CureSHANK is the fiscal sponsor, all voices are needed.



Our Story

Start Genetic was created by moms and dads. We understand in our bones how life-changing a genetic diagnosis can be. Each of us had walked a long, confusing road toward a genetic diagnosis, so we understand what it means to finally put a name to what our children were experiencing.

From the conversations we had with each other about those personal experiences with diagnostic odysseys, an idea took shape: to raise awareness and to make the journey easier for families who would come after us. That's how Start Genetic was born.

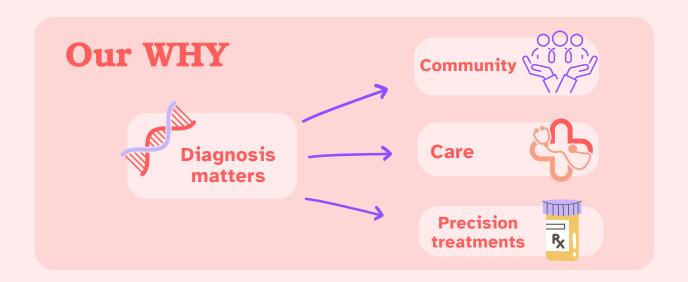
We asked ourselves what we most needed back then, and the answers were simple: better awareness and understanding of the importance of genetic testing as well as a place to learn and feel supported. So alongside our annual Genetic Testing Action Day to increase visibility, we built a warm and welcoming website designed to inform families and build community. You can explore it at www.startgenetic.org.

As we shaped this project, we knew families would need more than information; they would need tools. That's why the site also includes parent and healthcare provider toolkits — created to help parents confidently advocate for genetic testing and to support clinicians in ordering tests effectively. We were fortunate to have genetic counselors, geneticists, and physicians at our side throughout the process. Their expertise shaped every page and ensured these toolkits would truly serve families and providers.

We're deeply grateful to our 2025 sponsors, GeneDx® and Genome Medical®, whose support helped us create a real resource for families seeking answers.

As we look ahead, we know there is still so much more to build. If you or your organization feel called to be part of this work — to stand with families searching for answers and help create the compassionate resources that are so needed — we warmly invite you to join us as a sponsor.

Vision & Mission



Core Belief

Start Genetic was born from the vision and dedication of patient advocates and genetics professionals who share a core belief: everyone with a genetic condition has the right to access genetic testing and receive an accurate and timely diagnosis.

Mission

Our mission is to empower people to think genetic first for the answers they need to move forward.

Goals Educate the **Encourage and** Reduce the **Empower** Grow and normalize public about stigma around people to ask strengthen conversations what genetic genetic testing about genetic genetic disease testing is and testing when communities, around genetic the profound facing fostering testing and impact it can unexplained connection and genetic disorders have symptoms support

Our Impact 2025

First-Year Engagement Results



Press release

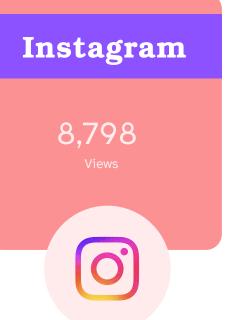
- Picked up by 506 news outlets
- Reached a potential 185.3M readers
- Articles published in <u>AFRO</u> and AsAmNews

Website (<u>www.startgenetic.org</u>)

- 2,234 website visitors
- Toolkit downloaded 419 times



Facebook 13,300 Views





2026 Goals



Goal 1

Double our social media exposure and impressions

Streamline our social media kits for patient advocacy groups and other stakeholders to ensure ease of use.



Goal 2

Engage stakeholders early and often

Create a communication framework to engage patient advocacy groups and other stakeholders in a consistent and sustained manner.



Goal 3

Reach new audiences

Pitch media outlets, including national, regional, and those that reach diverse audiences, and cultivate relationships with select influencers.



Goal 4

Continuously update content to reflect current recommendations for genetic testing

Monitor the literature for updated recommendations. Create connections with professional organizations to ensure efficient knowledge exchange.

Sponsorship Opportunities

SPONSORSHIP	AMOUNT
Megabase-hitter	\$20,000
Kilobase-runner	\$10,000
Gene team	\$5,000

Sponsors can expect

- To have company name and logo and a link to Sponsor's home page listed on the Start Genetic website.
- To be individually tagged in at least one LinkedIn post, providing an opportunity to comment, re-post, or share using #StartGenetic.
- To be recognized in a StartGenetic press release (only for sponsorships received before June 1, 2026).
- To be provided with a social media kit.
- StartGenetic will not provide any inducements to buy a sponsor's products or services nor endorsements of a sponsor's products or services. Sponsors may benefit indirectly from increased awareness of genetic diseases and genetic testing.
- Sponsorship payments meet the definition of qualified sponsorship payments.
 Sponsors will receive an acknowledgment of the sponsorship payment from CureSHANK.

Interested in sponsoring Start Genetic? Complete the **sponsorship form** (page 09).

Sponsorship Agreement & Terms

Introduction

- CureSHANK is the "fiscal sponsor" of Start Genetic, serving as its administrative home.
- Sponsor shall mean the company signing this Sponsor Agreement.
- The individual executing this Sponsor Agreement warrants that they have the authority to bind contractually the organization applying for the sponsorship.

Payment and Cancellation Terms

- · Sponsorships are non-refundable.
- · Sponsorship is not confirmed until full payment is received.
- · CureSHANK will confirm your sponsorship of Start Genetic upon receipt of payment.
- · Confirmation will come via email from sponsorships@startgenetic.org
- Sponsors must pay the total balance by June 1, 2026, to be included in a Start Genetic press release.
- In the event of cancellation of Start Genetic as a result of acts of God, war, terrorism, disaster, pandemic, governmental regulations, power or internet outages, strikes, or other causes that would prevent its occurrence, this agreement will be terminated immediately.
- The sponsor hereby waives all claims against CureSHANK for damages, reimbursement, refund, or compensation.

Sponsorship Fulfillment

- The sponsor agrees that no refund will be given for the loss of benefits or recognition due to missed deadlines by the sponsor.
- A sponsor media kit will be provided upon submission of payment.
- The media kit will provide sharable content and social graphics sponsors may utilize to inform their audience about their participation in Start Genetic.

The sponsor understands and agrees to abide by all terms governing this agreement.

Sponsorship Form



Thank you for supporting Start Genetic.

Personal information	
Name	
E-mail	
Company	
Phone	
I am authorized to contract	ually bind my organization
I agree to the terms in the s	ponsorship packet
What company name/project/ init Genetic sponsorship announceme	tiative name would you like listed in the Start ent?
Start Genetic will tag sponsors in company's LinkedIn page:	at least 1 LinkedIn post. Please share your
Please select your level of support:	How would you like to submit payment?
Megabase hitter \$20,000	We will contact sponsorships@startgenetic.org to arrange a wire transfer
Kilobase- runner \$10,000	We will send payment via check to: Start Genetic c/o CureSHANK
Gene Team \$5,000	11777 San Vicente Blvd, Suite 500 Los Angeles, CA 90049
Please share with us why you dec	cided to support Start Genetic:

Upon completion please save (or print to PDF) and send to abby@cureshank.org.

CONTACT INFO

For more details and inquiries, kindly contact us at:

Address	11777 San Vicente Blvd, Suite 500, Los Angeles, CA 90049
E-Mail	abby@cureshank.org
Website	www.startgenetic.org



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