Request for Applications (RFA):
Clinical Sites to offer Genomic Testing for Low- and Middle-Income Communities

Notice Number: IGH-RFA-003

Release Date: May 23, 2025
Response Date: Accepting responses on a rolling basis until July 1, 2025
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Issued By: Genetic Alliance
Audience: clinics, community health organizations, advocacy organizations
Application Link: https://forms.gle/VxFekaUkhnc4KUwv6

Timeline

May 23, 2025 – RFA released
Rolling – Applications reviewed upon receipt
June 20, 2025 – Final deadline for application submission
July 11, 2025 – Applicants notified
August 1, 2025 – Onboarding deadline

iHope Genetic Health

iHope™ Genetic Health (iGH) eliminates barriers to genomic testing by offering access to clinical genome sequencing (cGS) and exome sequencing (cES), as well as other genomic diagnostic tests, at no cost to eligible families with suspected pediatric-onset rare genetic diseases (RGDs).

For more than 10 years, the program has established a worldwide network of genomic testing laboratories, clinical partners supporting low- and middle-income patients, and advocacy groups, and supported the testing of more than 2600 individuals and their families. The impact of the program has been documented in both the news media and peer-reviewed literature, including a 2024 American Journal of Human Genetics article that was recognized by both the AJHG editorial board and NHGRI as one of the most impactful publications of the year. In 2024, iGH supported nearly 600 children and their families from largely low- and middle-income countries (LMICs), achieving diagnoses in ~50% of the cohort. In 2025, iGH aims to sequence a minimum of 1,000 more children each year and expand its network of laboratories and clinical partners.

Supported by philanthropic contributions from Illumina and other sponsors, iGH supplies partner laboratories with material awards to facilitate testing, including flow cells, reagents, sample preparation materials, cloud storage, and analysis software. Currently, four laboratories offer pro bono testing, and clinical sites send samples to a location we match them with. This infrastructure enables partner clinical sites to provide in-kind clinical genome and exome sequencing at no cost to eligible children and families who would otherwise lack access to these life-saving technologies.

Request for Applications

iGH releases this Request for Applications (RFA) to identify clinical sites that will join the existing network and refer patients with suspected genetic diseases who remain undiagnosed. We invite medical care facilities, community health organizations, and advocacy organizations, or their equivalents, to apply. Awards will be prioritized for clinical sites/communities that lack access to comprehensive genomic testing and have the infrastructure and experience to refer eligible families and provide them with appropriate follow-up support and care.

Clinical sites (broadly defined to include community and advocacy organizations) are essential to the iGH ecosystem. They are the first point of care for undiagnosed children and families seeking answers. Sites will:

- Identify and refer pediatric patients who meet the eligibility criteria
- Provide informed consent, conduct clinical assessments, and collect samples
- Collaborate with assigned partner labs for testing and result interpretation
- Support families post-diagnosis with counseling, clinical follow-up, and navigation
- Participate in peer learning, mentorship, and shared case reviews across the iGH network.

Priority will be given to organizations with:

- A demonstrated commitment to underserved populations
- Experience in rare disease, pediatric care, and genomic medicine
- Capacity to collaborate with sequencing labs and support diagnostic pipelines

The application requests:

Contact Information:

- Email address
- First and last name
- Institution's name
- Street address
- State/Province (if applicable)
- Country
- Postal code (if applicable)
- Phone number

Institution and Patient Population:

- Description of your institution or organization, including the types of individuals/patients you serve and your role in their care journey.
- Description of your total patient population, including geographic location, socioeconomic status, patient volumes, and general health needs.
- Percentage of patients meeting iHope criteria (residing in rural, low-resource, or medically underserved areas and lacking affordable access to genome or exome sequencing).

Clinical Workflow and Experience:

- Evaluation and management approach for patients with suspected rare genetic conditions, including clinical workflow, diagnostic methods, involvement of subspecialists or referral networks, and current access to genetic testing.
- Prior experience with ordering from labs outside of your country/region.
- Prior experience delivering clinical genomic testing results to low- and middle-income families.

Data Management and Technical Capabilities:

- Policy on returning data to patients and providers, including processes, file types, and systems used.
- Confirmation of internet access and ability to register participants in an online portal.

Operational and Contracting Details:

- Description of how associated expenses (beyond no-cost testing and sample shipment covered by iHope) would be managed.
- Contracting process and average time to contract execution, with a goal of signing contracts within three weeks of award.

Additional Information:

- Any other details that could support your application to iHope Genetic Health.

Information about the Issuing Organization

iHope Genetic Health is a program of Genetic Alliance. Genetic Alliance is a 501(c)(3) organization founded in 1986 that engages individuals, families, and communities to transform health. For over three decades, we have empowered advocacy organizations and health-focused communities to collaborate with clinical, policy, service, research, and other health institutions at international, national, state, and local levels. Genetic Alliance has earned the trust of diverse stakeholders. Consequently, our collaboration with and convening of multidisciplinary entities yield novel, relevant, and practical solutions. Genetic Alliance builds and liberates capacity in networks, enabling each entity to leverage the learnings, resources, and tools of others.

Our work is strongly influenced by and deeply rooted in activism; we have a history of radical advocacy, the early AIDS movement, and social justice activism. We possess a rich heritage in genetics, having been established before the conception of the Human Genome Project. We have participated in and led numerous projects and programs in genetics and genomics, including serving as co-founders of the National Academies of Medicine Board on Health

Science Policy and Roundtable on Genomics and Precision Health, Global Alliance for Genomics and Health, International Rare Disease Research Consortium, the Personalized Medicine Coalition, the Coalition for 21st Century Medicine, Obama's Precision Medicine Initiative, and the Cancer Moonshot. We led the coalition that enabled the enactment of the Genetic Information Nondiscrimination Act as U.S. federal law. Throughout all of this, we have consistently valued the health of all individuals, particularly those in underserved and resource-limited communities, as our guiding principle.

Genetic Alliance Capacity and Infrastructure

Genetic Alliance is a pioneering nonprofit dedicated to advancing health through genetics and patient-led innovation. Since its founding in 1986, the organization has become a global leader in genomics-driven equity, building robust infrastructure, driving public policy, and empowering communities.

Core Tools and Infrastructure:

- **Cross-Condition Registry Platform:**
  Operating since 2003, our cloud-based registry enables people to contribute clinical, genomic, and self-reported data to research across conditions. Built on secure, interoperable systems (now using LunaPBC technology), it gives participants full control over their data and supports rare disease natural history studies and clinical trials.
- **Biobank Services:**
  Genetic Alliance manages a biobank in partnership with Precision for Medicine, linking biospecimens to longitudinal clinical and genomic data. The system honors participant consent and maximizes utility for diagnostics, therapy development, and repurposing studies.
- **Institutional Review Board (IRB):**
  Our in-house, federally registered IRB offers rigorous, efficient ethical oversight for domestic and international studies. It is especially attuned to the needs of underserved and underrepresented populations, enabling streamlined review of iHope's global work.
- **Clinical Research Organization (CRO) Capabilities:**
  Genetic Alliance functions as a mission-aligned CRO. We provide protocol development, ethics and regulatory navigation, study operations, and community-centered recruitment—serving the full research lifecycle with an equity lens.

Advocacy Leadership:

- **Passage of the Genetic Information Nondiscrimination Act (GINA) – 2008:**
  Genetic Alliance founded and led the **Coalition for Genetic Fairness**, a nationwide alliance of more than 500 organizations. Over a 12-year campaign, the Coalition worked across party lines to ensure passage of GINA, landmark legislation that prohibits discrimination in health insurance and employment based on genetic information. This law laid the foundation for public trust in genetic testing and data sharing.

- **Free the Data Campaign (launched 2013):**
  In partnership with academic and industry stakeholders, Genetic Alliance co-founded **Free the Data**, a campaign to encourage individuals to publicly share their BRCA1/2 test results in open-access databases. This initiative accelerated transparency in clinical variant interpretation and promoted patient empowerment in scientific discovery. The campaign directly influenced policy changes in data sharing and catalyzed the formation of global data commons for cancer and rare diseases.
- **Participant-Driven Research and Open Science:**
  Central to Genetic Alliance's mission is the belief that ordinary people—not institutions—should drive the research that affects their lives. Our approach is grounded in transparency, participant ownership of data, and open collaboration. In practice, this means research studies are co-designed with communities and families, and individuals are empowered to recruit researchers—not the other way around. This paradigm was articulated in our landmark publication "*The Study is Open: Participants are Now Recruiting Investigators*", which lays the foundation for initiatives like iHope. We uphold the principle that people are not subjects of research—they are the primary agents, decision-makers, and stewards of their health data and the research agenda.

Through these combined efforts—policy, infrastructure, and community empowerment—Genetic Alliance has proven its ability to not only envision systemic change but implement it at scale. This legacy of advocacy and operational excellence continues to guide the growth and global impact of the iHope Genetic Health program.