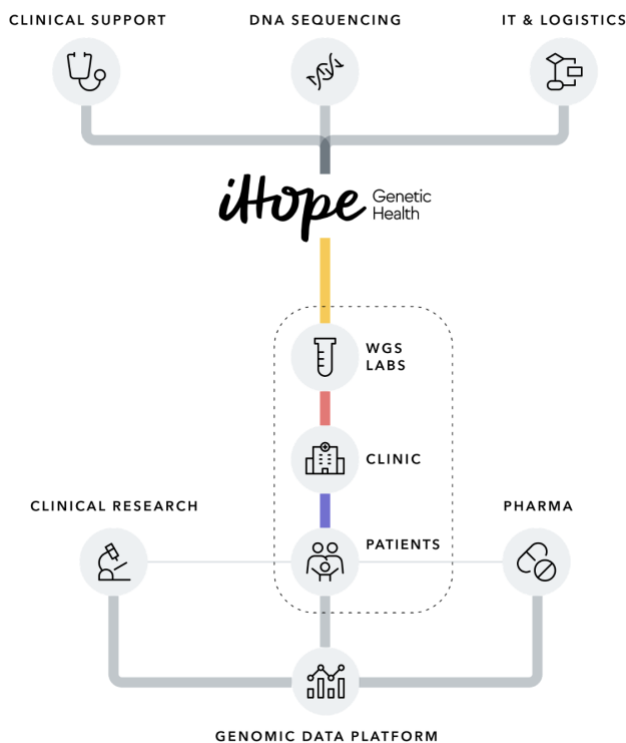




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### Update on Genetic Alliance activities relevant to the National Human Genome Research Institute (NHGRI)

[iHope Genetic Health](#) (iGH), a program by Genetic Alliance, provides patient support services and cWGS for undiagnosed individuals in low- and middle-income countries (LMICs), as well as low-to-moderate income (LMI) households in the US and other high income countries. iGH, utilizes in kind contributions from Illumina for genomic sequencing technology, Amazon Web Services (AWS) for storage and computational support, LunaPBC for patient-centered data control, and donations from philanthropists, technology and logistics partners to provide reagents and consumables, and if needed, sequencers and software to enable clinical whole genome sequencing globally. iGH aims to develop sustainable solutions for communities with little to no access to genomic care within their own countries. By doing so, iGH will revolutionize the offering and acceptance of genomic technologies, services, and therapy development and delivery in resource-limited regions.



**The Model**

We welcome partners for this endeavor. Our first two years of work have yielded a map of the world's sequencing capacity adjacent to areas of need. We still seek funding for administration and direct costs such as shipping reagents.

## **We are commemorating the 20th anniversary of Genetic Alliance's Institutional Review Board (IRB).**

It is with great excitement that we announce a significant milestone for the Genetic Alliance's Institutional Review Board (IRB). We are proud to recognize and celebrate the continued contributions of our IRB to research ethics and participant protection. For the past two decades, the Genetic Alliance's IRB has prioritized a people-centered approach to research protocols, ensuring the safety and well-being of research participants. Our IRB was established in 2003 with the sole purpose of advocating for the interests of research participants. We assess risk and benefit based on what is best for individuals, families, and communities, and we are the only lay-owned and managed IRB. We also encourage lay investigators who are advancing research to benefit their communities.

The benefits of working with the Genetic Alliance's IRB are unparalleled. Our IRB is committed to providing an efficient and streamlined protocol review process, offering researchers lower costs, faster turnaround times, and user-friendly templates that simplify the application process for research protocols.

This milestone is a testament to the dedication and expertise of our team, who have diligently reviewed countless research protocols in a timely manner and with minimal restrictions, ensuring that participants are at the forefront of each research endeavor. We are proud to have earned the trust and respect of researchers and participants alike, having reviewed 121 applications in just the past year. Our turn around time from submission to approval is 1.2 days (not a typo). We remain the only lay led and managed IRB and hold the distinction of being the lowest cost IRB as far as we can tell.

We are immensely proud of our contributions to the scientific community and the countless lives positively impacted by the research conducted under our oversight. The Genetic Alliance's IRB will continue to provide excellent services and advance scientific discovery for years to come.

### **Significant perspectives articles in recent months**

Diagnose Quickly and Effectively: Now. August 29, 2023  
<https://doi.org/10.1089/gtmb.2023.29075.persp>

Who are the experts? May 30, 2023  
<https://doi.org/10.1089/gtmb.2023.29071.persp>