Genetic Alliance strategy

At a high level: we strive to find the places in the biomedical research and services system can be transformed in the short and long term to meet the needs of those who suffer.

Long term we look toward where “the puck will be” and create tools that will be useful when we arrive in a place of consumer engagement and involvement like we see in other industries. We are not there yet. However, we have proof that creating these tools ahead of the need will allow the flourishing we need. For example, we created a cross-disease registry, biobank, and ethics review board in 2003. Now they flourish as more communities drive their own research.

Short term we have several concrete and practical programs that will give communities (geographic, religious, Facebook, and advocacy organizations of all kinds) the tools they need to unleash the power and capacity they rightfully own. This is not about enabling or empowering – these communities own this right, and so it is simply aiding them in releasing the power and capacity.

**iHope Genetic Health**: This program, supported by more than $120M of in-kind instruments, reagents, cloud storage, data management, and other tools is diagnosing the undiagnosed in low to middle income communities and countries.

**2022-2023 Strategy**: Raise the operating capital need to run 4 programs in the US, Africa, and India.

**Disease InfoSearch**: A directory of more than 10,000 diseases, with up-to-date information about the condition or disease and support, curated by advocacy organizations. Newly diagnosed individuals can find info about their condition and organization.

**2022-2023 Strategy**: Rebuild the structure and move to a newer server. Contact the 2000 advocacy organizations that have contributed to it and ask them to update it. Complete and launch GaugeRx, the tool that will allow researchers to find diseases ready for further study by overlaying an algorithm on the data in Disease InfoSearch and scoring it in four domains: Biology, Translational Research, Clinical, and Market Opportunity.

**ClinWiki**: A crowdsourced long-tail annotation of clinical trials from the clinicaltrials.gov database. Annotations are made by advocacy organizations to provide clearer, more relevant information for their members.

**2022-2023 Strategy**: Continue to build the UI and add more organizations to ClinWiki.
**Advocacy ATLAS**: A toolkit created by Genetic Alliance, Parent to Parent USA, and Family Voices for individuals with special healthcare needs and their families. The interactive map provides individuals and families with tools and strategies to advocate for whatever they need.

**2022-2023 Strategy**: Rebuild and expand this resource, mindful of advances in many of the resources available to families.

**WikiAdvocacy**: A guide for advocacy organizations to operationalize everything from general management to complex research. This 2000 page compendium of practical wisdom from your peers will offer you resources for every aspect of running a research and support foundation.

**2022-2023 Strategy**: Continue to maintain this and periodically call the communities' attention to it.

**GA registry**: Luna provides infrastructure for engagement, establishing a registry, and/or conducting studies for all Genetic Alliance’s needs. Demos:
- Platform Demo: [https://youtu.be/aLQkLrE2dVU](https://youtu.be/aLQkLrE2dVU)
- Member Experience Demo on Luna: [https://youtu.be/FW16qrfTN1c](https://youtu.be/FW16qrfTN1c)

**2022-2023 Strategy**: Double the number of communities gathering data. Increase the number of communities analyzing and presenting the data.

**Research Bootcamp**: Research Bootcamp is designed to help advocacy organizations launch a successful research strategy and plan. Resources offered in the Bootcamp are wide-ranging and provide intensive hands-on training. The first module is Registry Bootcamp.

**2022-2023 Strategy**: Continue to expand the modules in the Bootcamp in response to demand. Create worksheets to allow for asynchronous learning. Hold synchronous workshops throughout each year both multi-advocacy organization and for single entities as requested.

**Genetic Alliance Biobank**: This is a biobanking service available to any nonprofit. Genetic Alliance provides shared infrastructure and services. Biobank members manage their collections through an online interface, with new services added as various members request them.

**2022-2023 Strategy**: Continue to add new members, doubling the current membership.

**Genetic Alliance IRB**: Fosters research and discovery through a people-centered approach to reviewing research protocols. Under Genetic Alliance's IRB, protocols are reviewed with an eye for harm and burden to a participant, without the authoritative paternalistic regulation of other institutions. We value protecting people by ensuring that review occurs in a timely manner, with low costs and minimal restrictions.

**2022-2023 Strategy**: Advertise the IRB. This will be a new activity, and could dramatically expand beyond the 200 or so protocols we consider each year.
**Genetic Alliance Community Forum:** A space to connect with leaders of other advocacy organizations and ask questions and/or share information. Simply use the form on our website to sign up, then join the conversation directly from your inbox.  
**2022-2023 Strategy:** Continue high-quality useful community interactions.

**Genetic Alliance Weekly Bulletin:** Genetic Alliance will alert you to important action items, announcements, and deadlines, including Genetic Alliance-specific material as well as information from the genetics, health, and advocacy communities.  
**2022-2023 Strategy:** Continue offering the 6 or 8 announcements a week to help busy leaders see what is critical for their limited time and attention.

**Webinars:** Genetic Alliance hosts a webinar series to showcase expertise and emerging topics. From newborn screening to genetic testing regulation, family health history, and tips for running an advocacy organization, the collection of recorded webinars offers a wide array of knowledge.  
**2022-2023 Strategy:** Hold pertinent webinars on an as needed basis. Plan a series for 2023 to showcase our various tools.