

Genetic Alliance
L. Wise, E. Alfano, J. O’Leary, A. Dodd, S. F. Terry
www.geneticalliance.org

Mission: Genetic Alliance increases the capacity of advocacy organizations to achieve their missions and leverages the voices of millions of individuals and families living with genetic conditions. We build communication and mentoring networks, design and sponsor rigorous training courses, and provide infrastructure that strengthens and empowers our 600 member organizations. We are committed to capacity building in underserved and underrepresented communities.

History: For almost 20 years Genetic Alliance has successfully assisted advocacy organizations that serve individuals and families with genetic diseases. Over the years, the Alliance has employed both traditional and innovative methods to increase capacity in its members—from our annual conference and regional trainings, to an interactive website and a variety of listservs. Recently, Genetic Alliance has renewed its focus on excellence in leadership and governance.

Membership: Membership with Genetic Alliance is free. By becoming a member, an individual or an organization gains access to a variety of important resources. Among the resources offered by Genetic Alliance are: a number of web-based tools aimed at pooling and distributing our collective resources; technical assistance that results in measurable growth—increased funding, research, services, and membership; and training programs that prepare consumers for service on advisory committees, for work with policymakers, and for interaction with members of the media. To join, Genetic Alliance, register on our website at <http://www.geneticalliance.org>.

Outreach: A primary component of our outreach efforts is to ensure access to critical genetics resources across all populations, particularly within those communities that have traditionally been underserved and underrepresented. Our partnerships encourage the development of tools that allow advocacy organizations to more effectively engage diverse communities. Additionally, our work with underserved and underrepresented communities allows us to explore new models of advocacy and build advocacy skills among their members.

Keys to Success: Sitting at the crossroads of the genetics community, Genetic Alliance provides a rich nexus of advocacy and community organizations, government officials, industry leaders, and private entities. These interactions accelerate translational research; improve the climate for research and development of new technologies; encourage participation in clinical trials; increase the availability of linked, annotated biological resources; and ultimately lead to improved human health. In our central position in this, the genetics community, Genetic Alliance empowers individuals and advocacy organizations to better the lives of their constituents: individuals and families living with genetic conditions.