Archived Policy Statement

Genetic Alliance Position Statement on Earmarking

March 18, 2009

Disease advocacy has changed significantly over the past 20 years. From small self-help organizations, many disease advocacy groups now provide support, education, research funding and coordination, and in some cases initiate and conduct research[1]. Further, these organizations work together to drive transformation through policy: for example, passage of the Genetic Information Nondiscrimination Act of 2008, the Newborn Screening Saves Lives Act of 2008, and the recent lifting of the ban on federal funding for stem cells.
These achievements teach us that working together toward a common goal is key to success. Indeed, it is becoming increasingly clear that the transformation of basic science to services, which so many of us seek, will require deep and meaningful collaboration. Working together in the policy realm appears to be easier for disease advocacy organizations than collaborating for research funding and service delivery. Yet, all types of collaboration require removing boundaries to share infrastructure and resources and create and support networks for all disease-specific interests to systematically address their needs—e.g., to electronically aggregate disease-specific natural history data, share methods for establishing best practices for standards of care, and build shared technology resources.

Many disease advocacy organizations move forward in an isolated manner to address their specific issues and needs. Although there are achievements attributable to this model, these achievements are not proceeding at a pace commensurate with advances in other areas of technology and social change such as in the financial services industry. Historically, progress has been made, and tightly maintained, in silos; lessons learned are never shared with the community at large. This impedes the development of better health. Biology is systems-based. Prior to the genomic age in which we work, perhaps it made sense to study diseases based on an organ or location within the body. However, since sequencing the human genome, we know that there are gene families, pathways, and other more effective ways to understand disease. Many examples of treatments and cures for diseases coming from an unexpected direction. We work to inspire the disease advocacy community to reflect the interactive, interconnected nature of science and seize the energy inherent in networks.

Congressional earmarks for specific diseases have contributed to this siloed effect and have ultimately stifled progress for the greater good and the collective community. It is possible, given the systems structure of science, that they also stymie research on the very disease for which an earmark is sought. It is time to move away from earmarking as a solution, a change echoed by the Obama administration.

Genetic Alliance strongly supports policy, systems, funding mechanisms, partnerships, and collaborations that benefit all stakeholders. This includes tools, technologies, and resources

that are developed or designed for a specific cause, as long as those developments are freely available to all who can use, adapt, or benefit from their existence. Every effort must be made to disseminate success and learn from failures.

We acknowledge that the budget and appropriation process at any level must include prioritization and differentiation, but disease-specific earmarking must no longer be part of this process. There is not enough time, funding, or resources to study and develop treatments for each disease individually, yet there are millions of people waiting for our help.

Now is the time to strengthen our collaborations, as there have been significant advances in science, technology, knowledge of diseases, and processes for developing treatments. We must collectively share success and mine our failures in developing systems, practices, and initiatives to study diseases and get treatments to those in need. We call for a culture shift in the relationship between advocacy, research, services, and policy. We are poised to synergize efforts to benefit all stakeholders.

Our long-term needs will no longer be best addressed by earmarking for one organization or disease. We can go much further together. Let us step into the future as collaborators who build shared infrastructure and solutions that accelerate our work beyond what anyone can do alone.

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Genetic Alliance is an organization that transforms health through genetics. As a network of more than 10,000 organizations, including 1,000 disease advocacy organizations, we actively engage all stakeholders to create novel partnerships, improve health systems, and revolutionize access to information to enable translation of research into services. We represent the interests of millions of stakeholders in healthcare, including industry professionals, researchers, healthcare providers, and public policy leaders, as well as individuals, families, and communities.

1 Terry, S. F., Terry, P. F., Rauen, K. A., Uitto, J. & Bercovitch, L. G. Advocacy groups as research organizations: the PXE International example. *Nat Rev Genet* **8**, 157-164 (2007).