

Genetics Advocacy: Opportunity and Obligation

Advocacy is defined as *supporting, pleading, or giving voice to the cause of another*. Genetics advocacy, through communication with elected officials and policy makers, is critical to the passage of legislation and the implementation of policies that support basic research, enhance translation of research, and improve genetic services. The future of genetics research as well as the translation of genetics findings into clinical care rests in large part on the successful advocacy by its proponents—both scientists and consumers. It is no exaggeration to state that successfully educating policy makers, the public, providers, insurers, and others is one key to actualizing the potential benefits of genetics for humanity and to enabling continued research. Scientists who understand genetics and its potential are well positioned with both information and credibility to serve as advocates.

Reasons

Congress, state legislatures, and policy makers at all levels have numerous important competing issues and priorities. Whereas scientists deal with subjects in depth and (sometimes excruciating) detail, policy makers must approach a multitude of topics from a perspective of breadth rather than depth. Elected officials are expected to have working knowledge of a wide variety of complex and essential issues, including everything from billion-dollar budgeting and tax systems to defense and foreign policy, travel and communications infrastructure, and medical and other public support programs.

To elevate and highlight science, support of research- and genetics-related issues on the agendas of policy makers is the responsibility of our community. Geneticists have the knowledge and understanding to communicate to decision makers the importance of human genetics research to human health.

Issues and Partners

The American Society of Human Genetics (ASHG) has been active in tracking, promoting, and educating legislators and regulators about several current issues that are of critical importance to the genetics community. ASHG partners with other organizations through several national coalitions to enhance its effectiveness, visibility, and clout.

ASHG has been working with the Coalition for Genetic Fairness, including a primary partnership with the Genetic Alliance, to succeed in the passage of federal genetic-nondiscrimination legislation. In the 108th Congress, the Senate passed a bill of this type 98–0, the second time such legislation has been unanimously passed by the Senate. The most recent genetics-related House of Representatives bill (HR 1227) has had strong bipartisan support, with >150 cosponsors. Current in-

formation regarding the legislation is available at the ASHG Web site (<http://www.ashg.org/>) and the Coalition for Genetic Fairness Web site (<http://www.geneticfairness.org/>). Additional support will be needed, and ASHG members may be called on to contact their elected representatives.

In collaboration with the Federation of American Societies of Experimental Biology (FASEB), Research!America, and the Association of American Medical Colleges (AAMC), the Society also works each year to enhance federal funding for research, with a special (but not exclusive) focus on National Institutes of Health (NIH) funding. The economic situation in the United States is such that the genetics community must not only continue but also greatly increase its activities to ensure that research support is not further diminished. During the next months, ASHG will also maintain vigilance and provide appropriate input as the reauthorization of the NIH is considered by Congress.

Additional issues that will involve policy and possibly legislative processes include but are not limited to stem cell research; intellectual property issues, including patenting and licensing; translation of genetic testing into practice; and the regulation and quality control of genetic tests.

Methods

There are many ways, both proactive and reactive, to be a genetics advocate. You may contact policy makers directly or express your views through other public venues in writing or by speaking. All forms of communication are important to successful advocacy. The policy process can be slow and unpredictable, so it is essential to be steadfast and always prepared to capitalize on opportunities with regard to timing and access.

First, one must understand the issues as well as the political or policy (e.g., regulatory) process. This knowledge is essential to recognize how one may impact the decision-making process. An advocate must have a clear and concise message and a clear request for action. Every approach should be accompanied by thanks for the listeners' time and commitment to public service. Possible actions include timely letters, e-mails, or phone calls related to a specific issue, debate, meeting, or vote. Visits to elected officials or their staff can be made at their legislative or home-district offices. Often, visits merely to thank an individual or to provide background information on specific issues, genetics, or scientific research may pave the way for topic-specific visits or requests at a later date. The ASHG Board of Directors is holding its spring meeting in Washington, DC, and they will be visiting their own representatives and other key legislators.

Obligation

It is the obligation of citizens to become involved in meaningful issues, especially those for which they have unique and essential knowledge to educate and inform the elected and selected leaders. If we do not participate, the issues important to our lives will not be on the agenda. Constituents count! If we do not speak, they cannot hear our voices. We must make ourselves heard and be sure that our messages are clear and concise.

The officers and Board of Directors of ASHG will continue to lead the organization in the development of messages, activities, and specific calls to action for the membership on urgent issues. If at any time there is a question about these activities, you may contact Joann Boughman, ASHG Executive Vice President (jboughman@ashg.org).

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