Venous Thromboembolism: Mechanisms, Treatment, and Public Awareness

Patient Advocacy to Promote Public Awareness About Thrombosis and Thrombophilia

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For the last 22 years I have worked as a lobbyist in Washington, DC representing medical and healthcare organizations on issues ranging from funds for biomedical research to payment for specific medical technologies and services. In that time I have learned that health policy decisions are strongly affected by the organized voice of patients and their families. Whether the issue has been liver disease, hemophilia, inflammatory bowel disease, or juvenile diabetes, Congress and various Administrations have responded to the messages brought by individuals personally affected by these disorders. One only needs to look at the number of targeted treatment and research activities funded by the federal government to appreciate just how potent patient advocacy can be.

These groups may work in different areas, but they have many goals in common. First, they strive to build public awareness about the disease or condition. This is especially important for rare or “orphan” diseases but is no less necessary for common conditions like heart disease or cancer. Second, they seek to translate greater awareness into changes in public attitudes and policy. For example, mental health advocates have worked to eliminate the stigma of mental illness, while seeking improved therapies and insurance coverage. The Juvenile Diabetes Foundation (JDF) has waged a successful campaign to increase federal funding for research into this disease. Cancer survivors have banded together with the scientific community to create federally funded centers of excellence leading to research breakthroughs and improved treatments. Their success is highlighted by the fact that being a cancer survivor is no longer a rarity, but a common reality. Third, they want to create a refuge for people affected by the disease. A singularly important role for patient advocacy groups is patient support. The opportunity for individuals to share their experiences with an empathetic audience has enormous value for both the teller of the story and the listener.

Despite the widespread impact of thrombosis and thrombophilia on patients, families, and the health professionals who treat these conditions, organized efforts to increase public awareness and understanding, impact public policy to advance the standard of medical care in this area, and develop a community of support were limited until recently. I learned this in a most personal way when in late 2002 I was hospitalized with pulmonary embolism. I then found out that I carried the prothrombotic Factor V Leiden variant. As a newly minted “patient advocate” I began a search for the thrombosis equivalent to JDF. Although I found professional societies with interest in the science, websites developed and maintained by people who had experienced thrombosis and thrombophilia, and sporadic efforts at public education, there was no organized patient advocacy group. It was largely the professional medical organizations that were speaking on these issues. Their work is tremendously important, but it is different from the organized efforts of patients. In fact, the greatest successes in influencing public policy have been the result of associations of patients and health care providers working in tandem to support common goals.

At about the same time, the Centers for Disease Control and Prevention (CDC) also recognized that there was no equivalent to JDF in the area of thrombosis and thrombophilia. In 2003 CDC served as a catalyst in the formation of the first national organization of patients and families who have experienced blood clots, the National Alliance for Thrombosis and Thrombophilia (NATT; www.nattinfo.org). Modeled after groups like the National Hemophilia Foundation, NATT is led by a lay board of directors, advised by a strong Medical and Scientific Advisory Board, and dedicated to promoting public awareness of clotting and clotting disorders. This advocacy includes expanding biomedical research, improved therapies, public education, and support for individuals and families affected by clotting disorders. Like most patient advocacy groups, NATT is very oriented to grass roots activities, emphasizing local educational programs, building chapters, and encouraging support groups across the country.

Although NATT is unique in its structure and membership, it is by no means the only voice calling for greater public and governmental recognition of the tremendous impact that thrombosis and thrombophilia have on the nation’s public health. Major medical and professional organizations have come together in an array of coalitions. These include the Venous Disease Coalition, the Coalition to Prevent Deep Vein Thrombosis, and the North American Thrombosis Forum, among others. NATT is a member of many of these coalitions also, ensuring that the patient perspective is represented. Each of these groups has its particular expertise and focus but share common goals like expansion of biomedical research, improved diagnosis and treatment, and greater public understanding of the importance of clotting disorders.
All of these efforts are beginning to have positive results. Media coverage of thrombosis and thrombophilia has increased. March is now recognized as National DVT Awareness Month, and state governments like Connecticut, Massachusetts, and Texas are taking steps to build awareness within their own borders. The CDC recently awarded NATT funds for public and professional outreach and education. This was the first time that CDC had made a significant investment in thrombosis disorders. A prime example of the power of patients and health professionals was the joint meeting in May 2006 where the US Surgeon General announced plans to issue a formal “Call to Action” on DVT. A similar Call to Action years ago resulted in the successful effort to reduce smoking. NATT participated in the recent meeting along with medical professionals and government health policy leaders. The positive outcome is a clear sign that collaboration between patient and provider can be a powerful influence in the development of health policy. Although the Surgeon General’s office has not released details on the Call to Action, we expect a strong push for public and provider education programs, as well as increased efforts by the National Institutes of Health to expand research efforts in thrombosis and thrombophilia.

These successes will launch a sustained national effort that in 5 to 10 years will see expanded research into the basic causes of clotting disorders, leading to more effective preventive measures and therapies. Public education will help people understand the risk factors for clotting and better recognize the signs and symptoms of a clot. The day when a DVT is confused with a sore muscle will be history as patients and healthcare providers become more sophisticated in their understanding and awareness as a result of strong patient advocacy.

Disclosures

None.
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