ITP, Public Health, and the Centers for Disease Control

This spring PDSA was invited to participate in the first ever conference on Blood Disorders in Public Health, sponsored by the Centers for Disease Control and Prevention (CDC), marking a huge step in PDSA's quest for more public visibility. While PDSA staff has had conversations with CDC officials in the past, this was the first time an official invitation was extended to the group.

The CDC, and its public health mission, includes so much more than warning the public about H1N1. At the conference (March 9 to 11, 2010, near Atlanta, GA) about 400 attendees heard talks on a variety of topics including blood safety, genomics, and quality of life in the four plenary and 47 concurrent sessions.

ITP was not lost amidst all the learning opportunities. Caroline Kruse, Executive Director of PDSA, included in a panel of support group representatives, showed a short and riveting video about living with ITP and introduced the attendees to PDSA's many accomplishments. Dr. Michael Tarantino, a hematologist and one of PDSA's medical advisors, made the case for the CDC to support a more comprehensive approach to treating ITP. After the presentations, the attendees gathered additional information from the posters and exhibits, including a PDSA table-top display.

With the opportunity to learn more about public health policy, and mingle with the public and private sector attendees, the conference was a new and enlightening experience for PDSA's attendees, Caroline Kruse, Nancy Potthast, and Joan Young. Some conference highlights:

Babesiosis – a threat to those without a spleen

Babesiosis, a disease caused by a protozoa (a one-celled organism called *Babesia*), is transmitted by the same deer tick that carries Lyme disease. It is on the rise, mutating, and becoming a more serious threat, especially in northeast and northwest US. Many people who get babesiosis may not notice any symptoms or develop a mild case that resembles the flu. But for people without a spleen, the disease can be deadly.

The CDC has found that red cells in some donated blood are contaminated with the protozoa and have documented a few cases where people receiving whole blood have contracted the disease. Although those with ITP don't usually receive red cell or whole blood transfusions, it is possible for donated platelets to be contaminated by red cells. However, a more pressing problem for people with ITP, especially those without a spleen, is getting the disease directly from the deer tick.

The best defense against babesiosis is avoidance. A deer tick is about the size of a sesame seed and can be carried by mice and chipmunks, as well as deer. Because the tick must be on the skin 24 to 48 hours to transmit the disease, the best prevention is to wear protective clothing and be vigilant in looking for and removing any ticks.

See also: http://www.cdc.gov/babesiosis/

Genetics and ITP

Since the first draft of the human genome was available in 2000, researchers have rushed to look for links between specific genes and diseases, leading to thousands of published research articles. The CDC has created a sophisticated process and database, called the HuGE Navigator, to help sort and organize the myriad studies on genetics and disease. ITP is included and the results are on the Internet.

There are 26 genes that have an association with ITP (listed as Purpura, Thrombocytopenic, Idiopathic) and 123 genes associated with thrombocytopenia. Since ITP is a diagnosis of exclusion, the plethora of genes associated with thrombocytopenia only helps confirm the difficulty in diagnosing low platelet diseases and separating them from ITP. See for yourself at http://hugenavigator.net. But beware, the list you find today may be different tomorrow since the volume of research continues to grow and the database is updated frequently.

For a different view of disease genetics, go to the OMIM database of National Institutes of Health (http://www.ncbi.nlm.nih.gov/omim) and search on 'thrombocytopenia.' You'll find at least 200 low platelet diseases with a genetic link.

The Case for Comprehensive Care for ITP

Is ITP a public health problem? Could support of a comprehensive care program for ITP make a positive difference? Yes, was the take-away answer to both of these important questions in a presentation by Dr. Michael Tarantino. A public health problem is defined by the disease prevalence (how many people have a disease at any one time), the impact on the person's life, and the need for assistance in managing the disease. Dr. Tarantino defined all three for ITP, and then proposed a plan of action.

According to journal articles on the subject, about 70,000 adults and children have ITP in the US and 600,000 - 800,000 have the disease worldwide. Dr. Tarantino cited further data on the fatality rate and general toll of the disease: the rate of fatal hemorrhage is 0.0162–0.0389 cases per adult patient-year at risk; people diagnosed at age 25 lose 15 quality-of-life years; a patient age 70 loses 9; bleeding and infection contribute equally to mortality. He provided more information on the quality-of-life impact and the unmet needs. Then he cited statistics showing that people with hemophilia (about 18,000 in the US), treated at federally funded treatment centers with comprehensive care programs, addressing the medical needs as well as psycho/social needs of the patient, fare much better than those who do not receive comprehensive care. Why not open these centers to a wider population? Why not fund and apply the same standards to ITP? Indeed.

Additional Information about the CDC Blood Disorders Program

The CDC's program on blood disorders:
http://www.cdc.gov/ncbddd/blooddisorders/index.html

The blood disorders conference agenda and speakers:
http://www.blooddisordersconference.com/

Journal articles based on the presentations:
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www.ajpm-online.net

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