

PDSA Takes Part in NHLBI PIO Meeting

PDSA staff attended NIH's 12th Annual Public Interest Organization (PIO) Meeting of the National Heart, Lung, and Blood Institute (NHLBI) held May 23 and 24, 2011, in Bethesda, MD. The annual event provided unique opportunities to interact with other PIO representatives, meet NIH and NHLBI leadership, and learn more about the NIH.

In the keynote address Dr. Lawrence Tabak, Principal Deputy Director of NIH, discussed rare disease research at NIH. He said what is learned from studying rare diseases will be applicable to other diseases in the future. A 2011 NIH Roundtable explored new uses for abandoned and approved therapeutics, with the pharmaceutical industry open to doing this, he said.

Dr. Susan Shurin, Acting Director of the NHLBI, described research activities at the NHLBI, including information about clinical trials. NHLBI is the third largest of the 27 Institutes and Centers at NIH, with an annual budget over \$3.1 billion. She said most of the NHLBI's research funds are allocated to support research across the US and around the world.

PIO representatives met NHLBI staff members who have expertise in diseases of the airways, lungs, vascular system, blood (including platelets), heart, as well as sleep and sleep disorders. PDSA staff met with Traci Mondoro, PhD, from the NHLBI's Division of Blood Diseases and Resources. Traci, a specialist in transfusion hemostasis, told us of an ongoing NHLBI clinical trial for ITP, "Initial Treatment of Patients with Immune Thrombocytopenic Purpura" with high-dose dexamethasone treatment." During lunch we met Donna DiMichele, MD, Acting Branch Chief of the Thrombosis and Hemostasis Branch of NHLBI.

PDSA's Executive Director, Caroline Kruse and Dr. Paul Coates, NIH Director of the Office of Dietary Supplements, gave presentations in the afternoon session "Dietary Supplements". Caroline/PDSA was one of only two organizations (out of 94 PIO groups who attended) who were asked to give a presentation this year.

Caroline shared her ITP story describing the range of treatments she received including steroids and splenectomy (which did not work). She said ultimately a dietary supplement (folic acid) was key to her overcoming her low platelet disorder. The PIO meeting provided a wonderful opportunity for Caroline to describe PDSA's efforts to support, educate, advocate for, and encourage patients with ITP and other platelet disorders. For more information about research on dietary supplements visit:

<http://ods.od.nih.gov>

In the afternoon session "Collaboration, Resources, and Information Sharing," Dr. Stephen Groft, Director of the Office of Rare Diseases Research, NIH, described their programs for rare disease research and the importance of developing information about rare diseases and conditions for health care providers and the public. Key activities in his Office include sponsoring rare disease-related scientific conferences with NIH Centers, developing genetic tests for rare diseases, setting up patient registries (data bases) for rare diseases, and a new program for undiagnosed diseases at NIH.

For information about NHLBI at NIH, visit their Web page:

<http://www.nhlbi.nih.gov/about/dbdr/>

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