



PDSA's Executive Director **CAROLINE KRUSE** Talks About ITP, Her New Role and the Association's Mission

CAROLINE KRUSE FIRST GOT INVOLVED

with the Platelet Disorders Support Organization (PDSA) six years ago, when, after being diagnosed with idiopathic thrombocytopenic purpura (ITP), she started a local support group for patients and their families in her hometown of Cleveland, Ohio. ITP is a bleeding disorder in which the immune system destroys platelets, which are necessary for normal blood clotting. At the time, Kruse didn't realize the group she began was the first of its kind in the country.

Kruse later went on to meet Joan Young, who founded the PDSA

12 years ago and heard her story about fighting the severe disorder. Kruse is an award-winning journalist with a background as a radio and television reporter and producer and is the creator and co-host of a nationally syndicated talk radio show, *Family Matters*, that focuses on health and family issues. She invited Young to be a guest speaker and to talk about her experiences with ITP. The two women became friends, and Kruse got more involved in the Association, attending meetings and eventually serving for two years on the Board of Directors. When PDSA developed a need for additional marketing and public relations support, Kruse then joined the Association staff as the director of Public Relations, a position created for her. After founder and mentor Joan Young retired, Kruse was asked to become the executive director, a position she began in January 2009.

PDSA's Focus on Education

PDSA's main goal is to provide support to patients and information on diagnosis and treatment. Most people upon receiving a diagnosis of ITP have never heard of it and turn to the Internet to learn more. PDSA provides on its website, a host of booklets to download or to order free and offers the newly diagnosed and their families a chance

Cleveland, Ohio



PDSA participated as a partner at the first-ever National Conference on Blood Disorders in Public Health presented by the Centers for Disease Control and Prevention (CDC) in March. Pictured from left to right are: PDSA Founder 2010 Joan Young, Marketing Director Nancy Potthast, Executive Director Caroline Kruse, and Medical Advisor Michael Tarantino, MD.

to talk with someone either one-to-one or as part of a discussion group.

Since Kruse started that first local support group, which she continues to co-facilitate, the number has grown to 25 across the country, and the Association has started hosting a teleconference for parents of children with ITP. Kruse notes that they are hoping to start another group for young adults as well.

Other priorities for the year include the launch of a national walk/run in the fall to raise awareness and funding for ITP research and to promote the first National Platelet Disorder Awareness Month in September.

Kruse mentioned a long-term goal to develop criteria in order to designate Centers of Excellence around the country, to establish a comprehensive care model for people with chronic platelet disorders and to institute a national registry.

Living with ITP

Kruse, who has been in remission from ITP for five years, characterizes it as an emotional disease. Physically, she says, the disease changes week to week and it has a huge impact on a person's quality of life. Physical activity is very limited. Kruse could not bike ride or ski and was often severely fatigued. She describes the experience as, "living by your platelet count." Kruse adds that there is a tremendous fear associated with the disease, and that PDSA's work provides support and hope for other patients and their families.

KYM H. KILBOURNE is PPTA's Assistant Director, North America Communications

About ITP

Symptoms of idiopathic thrombocytopenic purpura (ITP) can include excessive bruising, tiny red dots on the skin caused by broken blood vessels (petechiae), purple spots on the skin (purpura), menorrhagia, bleeding gums and nose bleeds. Immune globulin (Ig) and anti-D Ig are among the treatments for ITP. Diagnosis is made through a routine blood test to determine the platelet count.