

LUPUS™

FOUNDATION OF AMERICA
PACIFIC NORTHWEST CHAPTER

Volume 25, No. 3

Page 5

People with Antiphospholipid Antibody Syndrome Can Now Seek Support Through New American Foundation

Christine Pohlman, Heidi Ponagai, and Todd Ponagai, Co-Founders, are pleased to announce the APS Foundation of America, Inc. The APS foundation of America, Inc. is a non-profit organization founded in June of 2005 and dedicated to fostering and facilitating joint efforts in the areas of education, support, public awareness, research and patient services in an effective and ethical manner for those affected by Antiphospholipid Antibody Syndrome (APS). We are a volunteer run, community based 501(c)3 non profit Public Charity organization. It is the only one in the United States and one of only two in the world.

The major goals of this first ever APS non-profit group in the United States are education for both the medical community and general public, to provide patient support and referral to services and help with research. We have successfully had a TV segment on the Discover; Health Channel; Mystery Diagnosis; Falling through the Cracks.

Antiphospholipid Antibody Syndrome (APS) is the major cause of young strokes, many miscarriages both arterial and venous thrombosis, and heart attacks. It has been estimated by some doctors that one third of all young strokes (defined as under age of 50) are due to APS. Some doctors believe that 1 in 5 of all Deep Vein Thrombosis (DVTs), Pulmonary Embolisms (PEs), and even worse, amputations are due to APS. And it is believed that 10-15% of patients with Lupus also have APS.

Women are more likely than men to be affected by APS. Some estimates say that 75% to 90% of those affected are women. In obstetrics, it is estimated by some doctors that up to 25% of all women with 2 or more spontaneous miscarriages have APS.

Still with these statistics, APS rarely is discussed as a women's health issue and is misdiagnosed often. Therefore the total number of people affected are unknown.

Antiphospholipid Antibody Syndrome (APS) is an autoimmune disorder in which the body recognizes certain normal components of blood and/or cell membranes as foreign substance; and produces antibodies against them. There are two known forms of APS. APS may occur in people with systemic lupus erythematosus, other autoimmune disease, or in otherwise healthy individuals. Sadly, when most people hear about APS and it being referred to as autoimmune disease, they incorrectly confuse the terms autoimmune with acquired immune deficiency syndrome (AIDS); or they think this is a form of cancer.

This lack of knowledge and awareness results in needless suffering for persons with APS. Misdiagnosis and/or delayed diagnosis usually result in damage to vital organs. The need to bring a national attention to APS as a common factor in multiple miscarriages, thrombosis, young strokes and heart attacks is a vital in order to bring a joint effort to research, funding, early detection, and eventually, prevention and cure for APS.

APS Foundation of America, Inc.
Phone: 608-782-2626
Website: www.apsfa.org
Email: apsfa@apsfa.org

