



APS Foundation of America, Inc.

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2012 Year in Review

(These are in no particular order.)

- ◆ Maintained 501(c)3 Non Profit Status granted under Section 170, 2055, 2106, 2522. We also were granted an advanced ruling as a Public Charity.
- ◆ Filed Taxes.
- ◆ Registered to solicit in the states we were required to do so.
- ◆ Made all brochure & booklets that have bibliographies available – available online.
- ◆ Published three newsletters that are available free to the public on our website – benefited at least 400,000 people.
- ◆ Donated & Mailed Brochures & Booklets –benefited at least 20,000 people.
- ◆ Donated Printed Publications to Public Libraries – Unknown number of people benefited.
- ◆ Invited to several large professional medical conferences.
- ◆ Represented at the Annual Venous Disease Coalition Meeting.
- ◆ Represented at the American College of Rheumatology Annual Meeting
- ◆ Represented at the Lupus Foundation of America, Philadelphia Tri-State Chapter Living Well With Lupus Symposium.
- ◆ Networking with other Non-Profit Organizations and medical professionals.
- ◆ Maintained our Webpage –benefiting 35,284 people based on the index page.
- ◆ Maintained the forum to make it more user friendly – benefiting 90,494 people.
- ◆ Maintained HONCode Certification on APS Foundation of America, Inc.
- ◆ Maintained HONCode Certification on APS Friends & Support Forum.
- ◆ Earned the GuideStar Exchange Seal: Partner in Trust.
- ◆ Searched for more medical advisors.
- ◆ Working on obtaining the Better Business Bureau Accredited Charity Status.
- ◆ Attended a Nonprofit Resources Night to learn more about grant writing, giving trends, and other topics.
- ◆ Became members of EURODIS – Rare Diseases Europe
- ◆ Invited & Attended the 13th Annual Public Interest Organization Meeting, sponsored by the National Heart, Lung, and Blood Institute (NHLBI) in DC.
- ◆ Continued collaborative Effort with the Coordination of Rare Diseases at Sanford (CoRDS) Registry.
- ◆ Maintained several blogs & pages on various social networking sites on various servers to get awareness out – benefited at least 500,000 people.
- ◆ Continued June 9th as World APS Awareness Day.
- ◆ Continued June as APS Awareness Month.
- ◆ Launched press releases – benefited at least 50,000 people.
- ◆ Launched Radio Public Service Announcements – benefited at least 1,000,000.

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- ◆ Participated with ABCs Dr. Richard Besser Twitter chats regarding various topics, including Rare Diseases.
- ◆ Partially funded a project that involved work carried out by a medical student at Dr. Pierangeli's laboratory at the University of Texas Medical Branch in Galveston. The study showed for the first time that affinity purified antibodies directed against domain I of B2glycoprotein I are "thrombogenic" in mice and induce upregulation of tissue factor. The significance of this study is that the investigators are confirming by using state-of-the-art technology a specific subset of Antiphospholipid antibodies may be responsible for the clinical manifestation in humans. Importantly, these findings may lead to the development of new "targeted" treatments for APS. The study was presented as a poster at the American College of Rheumatology meeting in DC in November 2012 and as a manuscript is being prepared with the collaborators at the University College London (Dr. Anisur Rahman, Charis Pericleous, Ian Giles, et al).
- ◆ Published in the Journal of Arthritis & Rheumatism twice.
- ◆ Advocated for clients in person and in writing.
- ◆ Donated funds to purchase a -80°C freezer for the USA Core Lab for APS ACTION
- ◆ Fundraisers:
 - Café Press – approx 676 items sold
 - World APS Day Items – approx 2 items sold
 - Scentsy Fundraiser: 5 participated
 - Holiday Related:
 - Giving Tree – 23 participated
 - Café Press Collectors Edition – 17 participated
- ◆ Made Press in 5 different media venues that we are aware of – at least 100,000,000 people benefited
 - The View – (original air date, 6/1/2012) benefited at least 1,000,000 people.
 - House, MD – "Instant Karma" (original air date, 10/15/09) – benefited at least 16,000,000 people.
 - Mystery Diagnosis – "Falling Through the Cracks" (re- aired several times, original air date, 3/6/2006) - unknown how many people benefited
 - Mystery Diagnosis – "Falling Through the Cracks" (re- aired several times, original air date, 3/6/2006) on iTunes unknown how many people benefited
 - The Beatles Network (APS Awareness month world wide awareness.) unknown how many people benefited
- ◆ Forum Information:
 - Number of Participants: 2,184

Recommendations:

- ◆ Continue to find more avenues for fundraising.
- ◆ Continue to collaborate with more organizations (both lay & professional).
- ◆ Attend or have materials available for more conferences.
- ◆ Apply for more grants.
- ◆ Continue to search for more active medical advisors.
- ◆ Continue to attempt to get APS mentioned in more publications, including magazines.

- ◆ Continue to making more videos and learn how to make podcasts.
- ◆ Consider tapping in more social networking sites.
- ◆ Consider going to a Board of Directors of 7, including one medical advisor & one public non-APS person.
- ◆ Consider making June 9th World APS AwarenessDay formally via a bill through Congress.
- ◆ Consider making June APS Awareness Month formally via a bill through Congress.
- ◆ Consider making a Scholarship fund for those going into the Medical Field.
- ◆ Consider making a formal Scholarship fund for APS Research.
- ◆ Consider spending the money to get professional press releases written and sent out at \$1000+ each. We thought our followers would help us so we could use our donated dollar towards research needs but without awareness we have nothing.
- ◆ Find a way to get a better open rate for newsletters.
- ◆ Consider reducing newsletters to twice a year.
- ◆ Consider working with the FDA on getting a Black Box Warning regarding the Finger Stick Machines and APS since the vendors and manufactures do not openly disclose this.
- ◆ Plan a good June 2013 Fundraiser.