

APS Foundation of America, Inc.

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2021 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.
- ♦ Donated & Mailed Brochures & Booklets —benefited at least 50,000 people.
- Invited to several large professional medical conferences.
- Represented at the Annual Venous Disease Coalition Meeting.
- Represented at the American College of Rheumatology Annual Meeting
- Partially funded Research for APS ACTION
- Promoted APS iBook published by Laurent Phialy, Stephane Zuily, and Dourk Erkan
- Networking with other Non-Profit Organizations and medical professionals.
- Maintained HONCode Certification on APS Foundation of America, Inc.
- ♦ Earned the GuideStar Exchange Seal: Platinum Participant. Only 0.5% of organization have this rating.
- ◆ Attended via Digital due to COVID-19 & Spoke at CARRA Annual Scientific Meeting / ACR PRYSM 2021
- ♦ Continued June 9th as World APS Awareness Day.
- ♦ Continued June as APS Awareness Month.
- Participated in Deep Vein Thrombosis Awareness Month
- ◆ Participated in Lupus Awareness Month
- ♦ Participated in Stroke Awareness Month
- Participated in Heart Disease Awareness Month
- ♦ Participated in Autoimmune Awareness Month
- ♦ Participated in Rare Disease Day
- Participated in World Thrombosis Day with APS Awareness
- ♦ Continued collaborations with MoMMA's Voices
- ♦ Continued collaboration with Rare Disease Legislation
- **♦** Continued collaboration with EURODIS
- ♦ Continued collaboration with CARRA on APS and Lupus
- Continued collaboration with National Coalition of Autoimmune Patient Groups
- Participated in Pregnancy Loss and Stillborn Awareness Month
- Supported various legislation through a national coalition of patient organizations

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- ♦ Attended National Coalition of Autoimmune Patient Groups Meeting in September hosted by American Autoimmune. (Topic: COVID-19 Vaccines)
- ◆ Invited to and Participated in Chat with Thrombosis Experts, Medscape & Everyday Health on World Thrombosis Day
- ♦ Attended & Hosted a Booth the Inaugural Autoimmune Summit presented by the Autoimmune Association
- ♠ Collaborative work with Stago Diagnostics
- ♦ APSFA Medical Advisors posted COVID-19 Vaccine Statement
- Started publishing Constant Contact Newsletter News Briefs
- ♦ Launched press releases benefited at least 500,000 people.
- ♦ Launched Radio Public Service Announcements benefited at least 2,000,000.
- Donated \$14,000 to APS ACTION for their ongoing needs in research.
- Shared reputable articles pertaining to APS at lay and professional level, as well as disease related such as DVT, PE, stroke, Raynaud's for example.
- Shared reputable disease prevention articles.
- Shared inspiration and motivational posts.
- Maintained Twitter Account. Followers: 2,466 Average Tweet Impressions per month: 14,952
- ♦ Maintained Instagram Account. Followers: 1,837 Average Reach: 1,042
- ♦ Maintained Pinterest Account. Followers: 494
- Maintained Facebook Business Account. Likes: 10,475 Follows: 10,696 Average Reach: 19,050
- Maintained Facebook Support Group: Number of Participants: 2,211
- ♦ Maintained LinkedIn Group: Follows: 154
- **♦** Fundraisers:
 - o Facebook Gift Shoppe
 - o AmazonSmile
 - Giving Tuesday
 - o CafePress
 - o Amazon Shop
 - o Zazzle
 - o Individual Fundraisers by Volunteers and Supporters
- Made Press in 21 different media venues that we are aware of − at least 5 million people benefited
 - O House, MD "Instant Karma" (original air date, 10/15/09) benefited at least 16,000,000 people.
 - o Mystery Diagnosis "Falling Through the Cracks" (re- aired several times, original air date, 3/6/2006) unknown how many people benefited
 - o Travelers on Netflix, Season 2, Episode 9
 - o The Beatles Network (APS Awareness month worldwide awareness.) unknown how many people benefited
 - o Dr. Oz, MD
 - o The Good Doctor
 - o Pregnancy loss delayed dreams, the strength to fight, and future hope

- o Antiphospholipid Syndrome (APS) Patient Story
- o Never say die: Woman vows to keep on trying after losing 8 babies
- o <u>Sitti Navarro is pregnant with baby number 2!</u>
- o <u>'How could this happen to a baby?': Cape Town mom on how her eightmonth-old suffered a stroke</u>
- o <u>Car dealership raising funds to help with medical expenses of employee hit</u> by a stroke caused by APS
- o Deceived from Within: Living with APS and Lupus
- o <u>APS Foundation of America takes aim at the antiphospholipid knowledge</u> gap
- o Nadine Samonte, husband expecting a baby girl
- o <u>Carrie Ann Inaba Has Temporarily Left 'The Talk' to Manage Her</u> Autoimmune Conditions APS
- o Woman gives birth to her own nephew after becoming surrogate mum for her sister
- o <u>Top 10 Points Patients Should Know About the Potential Role of the Gut</u> Microbiome in Antiphospholipid Syndrome
- o <u>San Antonio woman with rare clotting disorder awaits COVID-19 booster</u> approval for immunocompromised
- o <u>Top 10 Series: Pediatric Antiphospholipid Syndrome</u>
- o Mirriam shares Joy of having 'miracle babies' after 40
- o "I became grateful for everything I have and lived"
- o Various Articles in various medical and newspapers.

Recommendations:

- Continue to find more avenues for fundraising.
- ♦ Consider publishing quarterly newsletters instead of Constant Contact Newsletters.
- 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 medical advisors.
- Continue to attempt APS mentioned in more publications, including magazines.
- Continue to make more videos and learn how to make podcasts.
- **♦** Considering doing Facebook Live Chats through Zoom.
- Consider going to a Board of Directors of 7, including one medical advisor & one public non-APS person.
- Consider making June 9th World APS Awareness Day 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.
- Consider working with the FDA and getting legislation making a Black Box Warning regarding the Finger Stick Machines and APS since the vendors and manufactures do not openly disclose this.
- Find dedicated volunteers
- Find pro-bono Wisconsin Attorney
- Find volunteer professional graphic designer.

Unusual Year:

2021 the pandemic continued. Fundraising was affected due to people being laid off / furloughed from their jobs. In general, the priorities were not donating.

Professional Growth:

- ◆ Professional Grant Writing Certificate Program from University of Wisconsin Eau Claire (Tina Pohlman)
- ◆ PACE CE Stago Webinar on Lupus Anticoagulant (#LAC) and Women's Health: Part 1 (Tina Pohlman)
- ◆ PACE CE Stago Webinar on Lupus anticoagulants and antiphospholipid syndrome: Resolving confusion, providing new guideline updates (Tina Pohlman)
- ♦ PACE CE Stage Webinar Patient w/ Venous Thrombosis Practical Points for the Laboratorian & Clinician (Tina Pohlman)