

APS Foundation of America, Inc.

Post Office Box 801 La Crosse, Wisconsin 54602-0801 Office: 608-782-2626 Fax: 608-782-6569

2022 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
- ♦ Joined the Defense Health Research Consortium
- 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 2022
- ♦ Attended Thrombosis UK and International Society on Thrombosis and Haemostatis (ISTH) round table virtually in London
- **♦** 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 EURORDIS
- ♦ Continued collaboration with CARRA on APS and Lupus
- Continued collaboration with National Coalition of Autoimmune Patient Groups

www.apsfa.org apsfa@apsfa.org

- ♦ Participated in Pregnancy Loss and Stillborn Awareness Month
- Supported various legislation through a national coalition of patient organizations
- ◆ 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
- Attended ICAPA 2022 Virtually also manned a both. Attended many sessions of interest
- Donated funds for translation services for ICAPA 2022 totaling \$1500.00
- Donated funds for 8 scholarships for ICAPA 2022 totaling \$5000.00
- ♦ Spoke at the ICAPA 2022 Patient Session Virtually
- 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 \$4,000.00 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: 2,656 Average Tweet Impressions per month: 15,000
- ♦ Maintained Instagram Account. Followers: 2,187 Average Reach: 2,788
- ♦ Maintained Pinterest Account. Followers: 588
- Maintained Facebook Business Account. Likes: 11,529 Follows: 10,696 Average Reach: 6,500
- Maintained Facebook Support Group: Number of Participants: 2,536
- ♦ Maintained LinkedIn Group: Follows: 204
- Fundraisers:
 - o Shopify Gift Shoppe
 - o Facebook Gift Shoppe
 - o AmazonSmile
 - o 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
- The Beatles Network (APS Awareness month worldwide awareness.)
 unknown how many people benefited
- o Dr. Oz, MD
- o The Good Doctor
- o <u>APS Foundation of America and IMD Health Announce Partnership to</u> Improve Quality of Patient Education
- o Perri is raising awareness about #Antiphospholipid Syndrome (APS)
- o My family were told I may not survive the night when I got blood clots at 22 and now it's too dangerous for me to get pregnant
- o Daily Inspiration: Meet Dr. Allison Quirin
- o <u>As schools begin new semester, omicron variant brings concerns for</u> educators, parents
- 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 that will be willing to do social media from their homes.
- ♦ Find pro-bono Wisconsin Attorney

♦ Find volunteer professional graphic designer / webmaster

Unusual Year:

2022 the pandemic continued and led to an economic slide. Fundraising was affected due to people being laid off / furloughed from their jobs, costs of basic goods, rent, gas, etc went up. In general, the priorities were not donating.

Professional Growth:

- ♦ 2021-2022 Meta Nonprofit Growth Program Completion (Tina Pohlman)
- ♦ Conducting Surveillance For Venous Thromboembolism Using Traditional and Novel Methods (Tina Pohlman)