



## APS Foundation of America, Inc.

Post Office Box 801

La Crosse, Wisconsin 54602-0801

Office: 608-782-2626 Fax: 608-782-6569

### **2020 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
- ◆ Maintained EURORDIS membership
- ◆ Networking with other Non-Profit Organizations and medical professionals.
- ◆ Maintained HONCode Certification on APS Foundation of America, Inc.
- ◆ Earned the GuideStar Exchange Seal: Gold Participant. Less than 2% of nonprofits have this seal.
- ◆ Continued collaborative Effort with the Coordination of Rare Diseases at Sandford (CoRDS) Registry.
- ◆ Attended via Digital due to COVID-19 & Spoke at CARRA Annual Scientific Meeting / ACR PRYSM 2020 in New Orleans – cancelled due to COVID.
- ◆ Continued June 9<sup>th</sup> 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 & Fundraiser for APS ACTION
- ◆ Continued collaborations with MoMMA's Voices
- ◆ Continued collaboration with Rare Disease Legislation
- ◆ Continued collaboration with EURODIS
- ◆ Continued collaboration with CARRA
- ◆ Continued collaboration with National Coalition of Autoimmune Patient Groups
- ◆ Participated in Pregnancy Loss and Stillborn Awareness Month

[www.apsfa.org](http://www.apsfa.org)

[apsfa@apsfa.org](mailto:apsfa@apsfa.org)

- ◆ Supported various legislation through a national coalition of patient organizations
- ◆ Launched press releases – benefited at least 500,000 people.
- ◆ Launched Radio Public Service Announcements – benefited at least 2,000,000.
- ◆ Donated \$4725 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: 2,266
- ◆ Maintained Instagram Account. Followers: 1,516
- ◆ Maintained Pinterest Account. Followers: 450
- ◆ Maintained Facebook Business Account. Likes: 9,940 Follows: 10,354
- ◆ Facebook Support Group: Number of Participants: 2,010
- ◆ Fundraisers:
  - Facebook Gift Shoppe
  - AmazonSmile
  - Giving Tuesday
  - Café Press
  - Amazon Shop
  - Zazzle
  - Individual Fundraisers by Volunteers and Supporters
- ◆ Made Press in 34 different media venues that we are aware of – at least 2 million people benefited
  - 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
  - Travelers - on Netflix, Season 2, Episode 9
  - The Beatles Network (APS Awareness month world wide awareness.) unknown how many people benefited
  - Dr. Oz, MD
  - The Good Doctor
  - [Mum, 36, is left in tears as she is finally able to hug her miracle baby on Christmas Day after suffering 'more miscarriages than she can count'](#)
  - [Solenn says she almost gave birth at just 5 months after complications](#)
  - [THANK YOU for Sponsoring a STAR in aid of the new Sue Ryder specialist neurological care center in Fulwood](#)
  - [Hyderabad-based college dropout makes her designer dreams come true](#)
  - ['I Was Diagnosed with PTSD After Suffering Seven Miscarriages'](#)
  - [Woman who had eight miscarriages gave her husband permission to leave her](#)
  - [Cabaret darling Shannon Turner cheated death three times. She comes alive on stage.](#)
  - [Warwick Rotarians hear about rare condition known as 'sticky blood syndrome'](#)
  - [Patients at Cuerden Hall - Sue Ryder Neurological Care Centre to choose artwork for new specialist center in Fulwood](#)

- [Rare Condition Causes Stroke for Nursing Student](#)
- [APS Foundation of America takes aim at the antiphospholipid knowledge gap](#)
- [County Board Chair Tara Johnson laments Trump's 'broken promises'](#)
- [Wisconsinites Blast Trump for Broken Promises to Women](#)
- [Hours After Wisconsin Democrats Blast Trump for Social Security, Medicare, Medicaid Cuts, He Doubles Down](#)
- [Antiphospholipid Syndrome \(APS\): Young Women are Five Times More Likely Than Men to Have This Rare Disease](#)
- [Wisconsinites Blast Trump for Broken Promises to Women](#)
- [Shilpa Shetty says she has the APLA disease; find out what it is](#)
- [A Friend Taught Her About Her Antiphospholipid Syndrome: Why the Medical Field Needs to Do Better](#)
- [Thousands raised to help man from Deal left with rare Locked-in Syndrome after brain stem stroke](#)
- [6 Organizations Joining the Fight Against Devastating Diseases](#)
- [Biker mum dies suddenly of heart attack aged 50 leaving family devastated](#)
- [Mother who suffered three miscarriages in one year due to an immune system disorder reveals joy after giving birth to triplets](#)
- ['I'm not ashamed anymore'. The heartbreaking effect of the miscarriage taboo on a woman who lost six pregnancies](#)
- [DARKEST MOMENTS: My doctor laughed as I cried in pain during miscarriage & then joked, 'imagine what real labor feels like'](#)
- [Superheroes on track for charity](#)
- [Anti-Phospholipid Antibodies in COVID-19 Are Different from Those Detectable in the Anti-Phospholipid Syndrome - Docwire News](#)
- [John Stapleton says he still has 'bad moments' following wife's death](#)
- [Our clotting disease triggered by the sun - Standard Health](#)
  
- Various Articles in various medical and newspapers.

### **Recommendations:**

- ◆ Continue to find more avenues for fundraising.
- ◆ Get back to publishing quarterly 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 that truly want to help.
- ◆ Continue to attempt APS mentioned in more publications, including magazines.
- ◆ Continue to making more videos and learn how to make podcasts.
- ◆ Considering doing Facebook Live Chats.
- ◆ 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:**

2020 was the year of the pandemic. Fundraising was affected due to people being laid off / furloughed from their jobs. In general, the priorities were not donating.