Antiphospholipid Syndrome Alliance for Clinical Trials and International Networking (APS ACTION): 2019 Update

Written by: Joann Vega, CCRC (APS ACTION Lead Coordinator), Amar Mujewic (APS ACTION Volunteer), and Ecem Sevim MD, (APS ACTION Intern)

APS ACTION – Antiphospholipid Syndrome Alliance for Clinical Trials and International Networking (www.apsaction.org) – is an international research network with a commitment to prevent, treat, and cure antiphospholipid antibody (aPL)-associated symptoms. The network was created in 2010 by 25 international physician scientists; currently there are 59 members from 34 centers worldwide.

Since our last update in the Spring/Summer 2013 issue of this newsletter, APS ACTION has made important strides toward our goal of international research collaboration and data sharing. Through the dedication and hard work of APS ACTION members collaborative international projects are currently underway, which include:

• A multicenter web-based APS ACTION Clinical Database and Repository (“Registry”) of over 800 persistently aPL-positive patients; this registry helps us conduct both observational clinical research and mechanistic laboratory research studies to further our understanding of APS. Table below provides the list of APS ACTION centers recruiting patients for this registry.

• Standardization of antiphospholipid antibody (aPL) testing through the use of APS ACTION Core Laboratories worldwide located in Brazil, Japan, Italy, the United Kingdom, and the United States.

• Designing, conducting, endorsing, or participating in APS Clinical Trials, sometimes in collaboration with other organizations.

• Collaboration with other organizations such as APS Foundation of America, APS Foundation of Australia, and APS Support UK to increase APS Awareness and Patient/Physician Education.

APS ACTION Young Scholar Exchange Program (YSEP) with the goal of incentivizing young physicians and/or scientists to get involved in APS-related basic or clinical research by increasing their integration to our community and by enhancing their connections.

As demonstrated by 13 peer-review publications and 40 podium/poster presentations at international scientific meetings (the full list is available at https://apsaction.org/publications), nine annual summits, and six workshops, APS ACTION members are working very closely to further our understanding of APS. Conclusions drawn from a small pool of people in a limited area only gives us an obscure fragment of the picture, hence why we have established an international collaborative effort to expand our pool of patients as well as make our conclusions more definitive. Every piece of information gathered through our research helps us piece together the puzzle, and develop better diagnostic and treatment strategies.

To receive regular updates on APS ACTION, you can follow-us on our website https://apsaction.org/news/ or twitter (@APS_ACTION).

Please contact APS ACTION for full members & centers list.
Letter from the President

Wow, June is upon us in Wisconsin and we are first really having warm weather. It has been a very cold and wet spring with a late snow in May!

A lot has happened since our last newsletter. It is hard for me to do this most of this alone while having Lupus and APS. I delegate tasks and people do not follow through. So, I have decided to hire out on some tasks. If you want to volunteer, please message me at apsfa@apsfa.org

With that, we have redone the website thanks to Alinart, Inc. We still have things to touch up but we think you will like it. We will be re-writing a few pages and adding a few pages, like Pediatric APS.

We have been busy networking with other organizations like the Lupus Foundation of America, Inc, CARRA, AARDa, and the Arthritis Foundation. We have been working with coalition groups to get more research for autoimmune disease in general and more awareness for maternal death and loss for example. We are also networking with Corporations who can help fund professional videos, CME/CE creation, and distribution.

To get this newsletter back on track, we are in need of patient stories to feature in our newsletters. Every APS patient has a story to tell and yours could be shared with the entire APS community. We also need related articles such as book reviews, poems, interest articles, quotes, etc. If you are interested in sending us your story, please write to articles@apsfa.org and we will send you our guidelines. Without your help our newsletter cannot be a success!

We are trying to keep most of our services online to reduce print cost until we find a solid sponsor for printing and a place to store all of it. I simply do not have room for bulk printing in my apartment. If you have suggestions, please email me.

Just so you know, we are on AmazonSmile. You can donate money to the APSFA just by shopping. Just set the APSFA to your designated charity. smile.amazon.com/ch/20-3085295

We encourage you to follow us on Facebook and Twitter to get the latest APS news. Twitter has a great exchange with medical professionals interested in APS.

June is APS Awareness Month and June 9th is World APS Awareness Day. What do You plan to do to spread awareness and fundraise?

That is about all the news I have to report. Once again, I hope this newsletter finds you in the best of health and with a perfect INR level.

Sincerely,
Tina Pohlman
President & Founder

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The information in this newsletter is not intended to replace standard doctor-patient visits. All information should be confirmed with your personal doctor. Always seek the advice of a trained physician in person before seeking any new treatment regarding your medical diagnosis or condition. Any information received from the APS Foundation of America, Inc. through this newsletter is not intended to diagnose, treat, or cure and is for informational purposes only.

If you have a medical emergency, please call your doctor or 911 immediately.

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Those of us in the autoimmune disease world like to think that “It’s all in your head” is a comment of the past, but is it? A recent article in the Los Angeles Times suggests that we may need to be alert to such a quick dismissal from some physicians.

TV personality Marie Menounos was fortunate when symptoms of her nonmalignant brain tumor quickly caught the attention of a physician. The operation was successful and she has had a good recovery.

However, LA Times reporter Emily Dwass was not so fortunate. It took four years and several doctors before she was diagnosed with the same condition experienced as Menounos. The delay caused permanent problems and made surgery more dangerous than it would have been with earlier attention. Also, after surgery, she still met with “dismissive, condescending doctors.” When she was experiencing muscle spasms, a doctor said, “We don’t know what’s wrong with you—but we think the problem is all in your head.” A nurse correctly suggested that Dwass was having a bad reaction to post-surgery steroids giving to reduce brain swelling.

Doctors may fail to appreciate woman’s symptoms partially because medical research has focused historically on men. A 204 John Hopkins University study found that women having a stroke were 30% more likely than men to be misdiagnosed in the emergency room.

In a study conducted by the American Autoimmune Related Diseases Association (AARDA), the number one concern among women with autoimmune disease is that doctors don’t listen to them. AARDA President Virginia Ladd state that some 40% of women who eventually are found to have serious autoimmune diseases have been told by a physician that they are complainers or simply to concerned with their health.

As Dwass points out, “Elderly women have to contend with ageism on top of sexism.” Her mother-in-law, in her 80s, went from doctor to doctor, trying to find an answer to her severe abdominal pain, which eventually turned out to be widespread cancer. One doctor, making a note of her age, had flip-tantly asked, “What do you expect? It should be pointed out that the ageism/sexism sometimes occurs with young females whose complaints may not be taken seriously.

Is there a perfect answer to this problem? What can we do? Remember “the patients themselves.” We are individuals first, patients second. As such, we need to take charge of our health as much as possible.

- Observe and chart your symptoms. It’s easy to forget some symptoms on a good day. Prepare an organized list to take to the physician. Even the seemingly insignificant, easily forgotten symptom may be the important one.

- Dress the part. Studies have show that a neatly groomed person gains more respect of the physician and office staff alike—the whole team.

- Act the part. See yourself as the “client,” not the “patient.” You are paying for professional advice, not begging. Be polite but self-respecting.

- Keep your mind on the reason for your visit. It’s easy to be too chatty—probably nerves! Write down your questions in advance.

- Be honest. Don’t say, “Just fine,” when the physician asks how you are. Look at your symptom list.

- Take an advocate with you if you are likely to be forgetful or shy. Let that person see your lists of symptoms and questions, but emphasize that s/he should be a silent observer unless you ask for help. That friend could take notes for you.

- Expect the doctor’s attention. If s/he is concentrating on the laptop instead of giving your full attention, try to find a way for full eye-to-eye contact. Many doctors still are not comfortable entering information on their computers.

- Ask questions. Make sure they are answered before you and the doctor leave the room. Don’t let the “one hand on the door knob” intimidate you.

- Remember your mother’s advice to say “thank you” at the end of your visit—which YOU have ended.

- If all else fails, seek a second opinion or change doctors.

These are not foolproof suggestions but ones that may help your to avoid the “all in your head” flippancy. It’s hard to take charge when you are feeling really bad, but forming a bond of mutual respect with your physicians—with adults working together—can benefit both of you.

Source:
Includes excerpts from the op-ed “the it’s all in your head” diagnosis is still a danger to women’s health,” Emily Dwass, Los Angeles Times, July 26, 2017
2019 CARRA Annual Scientific Meeting  
Written by: Tina Pohlman

Myself and Caitlin Griffin had the pleasure of being invited to attend and speak at the 2019 CARRA Annual Scientific Meeting that was held in Louisville, KY in April 2019.

Childhood Arthritis and Rheumatology Research Alliance (CARRA) seeks to facilitate, accelerate and perform research that is driven by academicians, clinicians, and patients and families to understand the epidemiology, outcomes, etiology and biology of pediatric rheumatic diseases. Their mission is to conduct collaborative research to prevent, treat, and cure pediatric rheumatic diseases.

While there we attended patient and family sessions to help build CARRA.

We also were a part of the scientific sessions and committee meetings, such as Lupus, Lupus Nephritis, Mental Health Workgroup, Lupus Dermatology and Antiphospholipid Syndrome.

I spoke at the Antiphospholipid & Lupus meetings. These are ongoing work groups and work year-round. Sadly Caitlin was unable to give her patient presentation as she ended up in the hospital with sepsis so I had to give my patient story.

The Prisoner In Me  
Written by: Caitlin Griffin

This isn’t what I want. Yelling to the walls that separate me from everyone. Being locked up. Abandoned.

My friends have gone home to their lives. I lie awake, afraid of getting sick and dying. Constantly, BEGGING someone to help me.

Though this nightmare. This jigsaw Puzzle of Disease.

Like a baby in a crib, I throw tantrum. I rail against God and the world SOMEDAYS.

I stand up to fight like the woman I am. Take everything with a smile and with hope. But on nights like this when the thunder crashes. The wind howls. The surety of my living to see another day fades. GONE.

Replaces by an endless barrage of what its and more suffocating than the medicines and treatments could ever invoke within me. I am broken.

In my own body I am a prisoner.

We did leave with assignments. Yes, homework. One, to write the Pediatric APS page for CARRA. Luckily, we needed to write that for the APSFA too and can piggy back most of that. Two, keep up with the workgroups and participate in the conference calls as they arise.

We also learned how to grade poster presentations for scholarships and are on a committee to do that on an ongoing basis.

We also got to hear oral abstracts presentations. To be honest, those could get a little dry.

It was a great chance to meet doctors, researchers and fellow patients from around the United States and Canada.

We were asked to put in pediatric APS research ideas to the Lupus Committee. Under CARRA, APS falls under Lupus. This may change over time.

It was a fast paced 4 days. We were hosted to great food, the North American’s largest firework display kicking off the derby and a air show. Next year we will be at New Orleans.

If you would like to learn more about CARRA or you like to register your Pediatric APS or Lupus child in the registry: https://carragroup.org/
Faces of APS ~ The APSFA Needs Your Help!
Written by: Heidi Ponagai

The APS Foundation of America, Inc (APSFA) is collecting photos for the Faces of APS Slideshow. Photos may also be used to post on our website, future newsletters, or advertisements if a patient story is included. All pictures must be submitted to the APSFA electronically in accord to the specifications outlined here: https://tinyurl.com/yy4pf9xj previously.

Many APS patients find it comforting to read other patients’ stories and find out that they are not alone in their disease. We always include at least 2 patient stories in our quarterly newsletters.

We strive to bring you the best newsletter that we can each quarter. In order to do so, we need patient stories and stories of interest from APS patients and their loved ones.

Topics can be from how APS affects you, poems you have written, tips and tricks that help you get through your day, to your favorite recipe. We are also taking book reviews of publications listed on our suggested reading page at: http://www.apsfa.org/publications.htm

Please follow our current guidelines when submitting an article:
• Send your story/article to articles@apsfa.org
• Patient stories and most articles should be approximately 500-750 words long
• Articles should be written at a 5th-8th grade reading level
• Please try to include a picture when submitting a patient story
• Patient stories should read like an autobiography—generally from diagnosis to present time, but it doesn’t have to
• Please also include a title of your story

Please use previous patient stories as your guideline. They can be found here: http://www.apsfa.org/newsletters.html

If you have ideas not listed here and are not sure if it would be appropriate? Drop us an email at articles@apsfa.org.

16th International Congress on Antiphospholipid Antibodies
Written by: Tina Pohlman

The International Congress on Antiphospholipid Antibodies occurs every three years and they have an exciting program that will review, discuss and debate many exciting and evolving topics that are of great relevance across a range of medical sub-specialties including rheumatology, hematology, obstetrics and neurology.

A key focus of the congress will be to involve young investigators and the next generation of leaders from clinical and non-clinical disciplines. We believe that capacity building and encouraging new investigators will help us drive this area forward over the next few years. They also have an exciting patient program in the congress to help us better understand fully the unmet needs and plan and prioritize future research.

The 16th International Congress on Antiphospholipid Antibodies 2019 taking place from 17 – 20 September 2019 in Manchester, United Kingdom. The patient program will be on September 20th.

The APSFA will be providing several scholarships under the Silvia Pierangeli Young Scholarship Award.

We are currently fundraising to attend this Congress in person. Please see that article in this newsletter.

For more information on this Congress, to get registered or submit abstracts: http://icapaconference.com/
World Thrombosis Day and APS Awareness
Written By: Kim Nault

The APSFA did something different in 2018 for World Thrombosis Day and the weeks leading up to it.

Normally, we spread traditional thrombosis prevention awareness. This year we were approached by APS ACTION to help them spread APS awareness during World Thrombosis Day and did we think we decided to get several other APS organizations involved to spread APS awareness during World Thrombosis Day.

The APS Support UK, APS Foundation of Australia, and the APS Foundation of America, along with APS ACTION created a campaign. We made global APS Awareness and fundraising effort. Also, all fundraising generated via APS patient organizations was used specifically to support the research equipment in APS ACTION Core laboratories located in Brazil (University of Sao Paulo, Sao Paulo), Italy (University Hospital, Padova), Japan (Hokkaido University, Sapporo), United Kingdom (St Thomas Hospital and University College London, London), and United States (University of Texas Medical Brach, Galveston, Texas).

Together we were able to raise about $2500.

We had a nice poster that was posted on all of our websites: http://apsfa.org/new/wp-content/uploads/2018/09/World-Thrombosis-Day-e-leaflet.pdf

In addition, we had professional graphics prepared to discuss topics that we want to make points about statistics, what APS ACTION is about and what APS is. For example, did you know that Antiphospholipid Antibodies are tested positive in 17% of patients with stroke under the age of 50 or 9% of patients with pregnancy loss? Those graphics can be found on our apsfa.smugmug.com

APS ACTION members answered medical questions sent to us by patients during the campaign. Those questions and answers can be found here: http://apsfa.org/new/wp-content/uploads/2019/05/WTD-Campaign-QA.pdf

We are planning a similar World Thrombosis Day campaign this year to increase APS awareness. Please stay tuned.

June Is APS Awareness Month!

June is APS Awareness Month and June 9th is World APS Awareness Day. What do You plan to do to spread awareness and fundraise?

Watch our social media feeds for our awareness and fundraising events!
I think my story is atypical of what I read about folks who have APS. For the longest time that caused me to think my condition wasn’t really APS. I’ve been diagnosed for 11 years, and I now see how it’s affected me years before that.

I’m fortunate to have had a primary care doc who would not give up and a supportive husband who wanted me to feel better.

Antiphospholipid Syndrome mostly affects me through symptoms. I’ve had clotting events, but it’s the cluster of symptoms that truly affected my day to day living for 2 years. I was tired, really, really tired, had all over pain, intermittent vision loss and a hefty dose of cognitive confusion.

Like many of you, I was checked for Lupus, and MS. For lack of a diagnosis I was diagnosed with Fibromyalgia. The only thing it didn’t really address was my vision loss.

I’ve been blind in my left eye since I was 8 years old. The fact that I was having intermittent vision loss in my right eye was concerning to my husband and my doctors, however I was done. I just couldn’t see one more specialist. My primary care doc encouraged me to see a neuro ophthalmologist. Turns out it was the same one I saw when I was 8 years old. Although my eye health was fine, he wondered about low blood flow. That brought me to my (now hero!) hematologist who was able to find the root of all my challenges.

Eleven years later I feel great. I still have times of flares which are discouraging, but I bounce back within weeks. For 11 years I have given myself anticoagulant injections; sometimes 2x daily, sometimes daily, and currently every other day. Sure, there are risks and things to be careful with, but my philosophy is that we all have challenges. I’m fortunate that this major challenge was diagnosed and I’m healthy overall!

16th International Congress on Antiphospholipid Antibodies Fundraiser
Written by: Todd Ponagai

The 16th International Congress on Antiphospholipid Antibody Congress will be held in the UK in September 2019. Please consider a donation of $10 or more to send representation from the US to this important doctor/patient conference, which is only held every 3 years. It is vital to share information with APS specialists and other patients worldwide if we are to further knowledge and research that could benefit all patients with Antiphospholipid Syndrome. It is up to everyone to do our part to aid earlier identification of APS, make further advances in treatment options, and ultimately find a cure!

We need $7000 to attend. We are currently at $1700 raised.

To Donate: https://tinyurl.com/yxjztu27
My teenage years dealing with Antiphospholipid Syndrome

Written by: Jessica Spindler

It was the night of a family member’s funeral when my right leg swelled up and started hurting. I could barely put pressure on it. I went into my mom’s room while she was getting ready and told her that I was in pain. When she saw how swollen my right leg was and felt my heated skin, she grew concerned. She called a few people, explained my symptoms, and was told to get to the hospital.

Before I knew what was happening we were in the car on our way. She didn’t want to tell me what it might have been because she was worried that I might get upset. We arrived at the hospital and while the waiting room was a blur I do remember lots of people around me and the nurse forcing me into a wheelchair because I wasn’t allowed to walk. It all went by so quickly. The doctor constantly reassured my mother that the swelling in my leg was not a blood clot.

The doctor told my mom that they would do a few tests to rule out some possibilities. The first test was the ultrasound. I was nervous and uncomfortable. It was explained to me that they would look at my leg and other suspected areas of my body. It was a very uncomfortable 15 minutes. I watched the video the entire time hoping that he wouldn’t find anything. He periodically stopped to record certain spots.

Once the test was over, I was taken to an area to get blood work done. Being terrified of needles, I refused the test. Each time the nurse went to stick me I would move out of the way. At 16 years old it wasn’t something I was used to. The nurse stopped trying and explained to me that if I do have this disease that they suspected that blood work would be a regular part of my life and I would need to get used to it. I allowed her to continue with the blood work as it wasn’t nearly as bad as I had made it out to be.

When the ultrasound results came in, the doctor told us that they found a clot in my right leg, that it wasn’t moving and needed to be dissolved by using a Heparin IV. The blood work came back shortly after and the doctor explained to my mom that I tested positive for Antiphospholipid Syndrome. I remember not being able to mad because I didn’t understand what was happening at the time. I didn’t know what any of it meant, that I had an immune disorder. Somewhere along my family blood lines this disease manifested and transferred to me.

I spent the next week in the hospital not being allowed to get up from the bed and walk around or use the bathroom. My mom was always there and several family members came to visit me. At night they all left and I was alone in that dark room trying to sleep twisted in an IV and cords monitoring everything. The day I was able to eat normal food, my mom got me a bagel and chocolate milkshake from my favorite place, which I was only able to enjoy a little bit before vomiting. The nurses rushed in and had realized that they overdosed me on Heparin. Later that day the doctor said they would be taking me off the heparin and I would be going on Warfarin, which was a tiny peach pill. I would soon learn that I would have to take this for the rest of my life.

The hospital referred me to a local hematologist. The first month on Warfarin was difficult and I didn’t make it easy on my mom or the doctor. I didn’t want anything to do with this disease. At times I even pretended that I didn’t have it. I grew up with this disease hanging over my head reminding me daily that I could get a blood clot at any time if I went off of these meds. Since my diagnosis, I’ve become anemic and had to take iron supplements daily. I’ve had a lot of practice managing my disease and the complications from it. Now at, 29 years old I’ve learned that I can’t control everything in my life. APS has given me perspective on things and making every day count is what’s important.
Facebook Gift Shoppe
Written by Armas Cravins, II

We would like to introduce you to our Facebook Gift Shoppe.

We are now offering items that represent APS, Lupus and our mascot, the dragonfly and our color burgundy.

Once the items are out of gone they are gone. So if you see them, order them before they are gone.

100% of the profits from these products will go to the APS Foundation of America, Inc.

Visit our shoppe at: facebook.com/APSFA/shop

Book Review: Drying My Tears
Written by Tina Pohlman

We know that autoimmune disease tends to cluster in people and families, but how you handle all of that when it is your family that seems to be so unfairly impacted?

For Liz Wilkey, author of Drying My Tears, One Family's Journey with Autoimmunity, laughter seems to be the best medicine. At the very least, a good sense of humor has maneuvered her family through their autoimmune disease journey.

Heart warming and down to earth, Liz recounts her talk as again and again a new autoimmune disease diagnosis is added to the list. Start with her daughters and eventually herself, Liz describes how these disease transformed her home and family. From watching the progression of diseases happen to those she loved to dealing with it herself, Liz tells how her daughters have fought their conditions from a very young ages to adulthood as she navigated her own illness as a parent, while and professional, ass while adapting to the new circumstances while still handling the normal demands and delights that life brings.

The struggles of Liz, her three daughters, and her husband are all to familiar for an person or family impacted by autoimmune diseases. However, Liz brings a healthy dose of humor and humility as she describes how her family has continues to grow and thrive despite the challenges and pain of lupus, Guillain-Barre, Hashimoto’s thyroiditis, spondylyarthritis, and Sjogren’s syndrome.

Liz offers up her own experiences and ways that she and her family have lived and cope with autoimmune diseases. She affirms the value of the practical, loving support of her husband; and Liz says of the many physicians in her life, “I have found that the best doctors are the ones who work collaboratively with their patients.”

Café Press ~ APS, DVT & Lupus Awareness Items

We have a number of new products & designs for DVT and Lupus Awareness Items available in our Café Press store. Some of our new products and designs are shown here and many are available in burgundy for APS as well. Our creative team is working on new one of a kind designs and lines and many more will be coming soon. There are even a few new items such as travel mugs, glasses, cellphone & iPad accessories, pillows, and dark colored shirts and sweatshirts. Our Café Press items are high quality and the clothing comes in a variety of sizes from infant to many different adult sizes, including plus sizes and maternity. Many items also come in a variety of colors. The APSFA gets to keep a small percentage of each sale from our store when you buy from it, so not only will you get a quality item, but you will also make a donation to a worthy cause!! Check out our store at the address below and be sure to check back often.

http://www.cafepress.com/apsfoundation