



ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter

Antiphospholipid Syndrome Alliance for Clinical Trials and International Networking (APS ACTION): 2022 UPDATE

Written By: JoAnn Vega (APS ACTION Global Lead Coordinator) on Behalf of the APS ACTION Executive Committee*

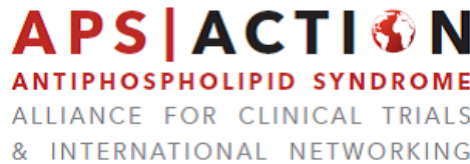
APS ACTION – Antiphospholipid Syndrome Alliance for Clinical Trials and International Networking (www.apsaction.org) – is an international research network with a commitment to prevent, treat, and cure antiphospholipid antibody (aPL)-associated clinical problems. The network was created in 2010 by 25 international physician scientists; currently there are 77 members from 34 centers worldwide.

Since our last update in the Spring/Summer 2019 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 and activities are currently underway, including:

- **APS ACTION Clinical Database and Repository (“Registry”)** with approximately 1,200 aPL-positive international patients with or without APS classification. This registry helps us conduct both observational clinical research and mechanistic laboratory research studies to further our understanding of APS (for centers participating in the registry, visit <https://apsaction.com/research/>)
- **APS ACTION Core Laboratories** worldwide located in Brazil, Japan, Italy, the United Kingdom, and the United States, with the goals of: a) confirming aPL-positivity for our registry patients; b) standardizing aPL testing amongst our core laboratories with the goal that we can later help standardize testing amongst other international laboratories; c) improving diagnosis of APS, and d) providing patient samples for APS

ACTION mechanistic laboratory research studies.

- **APS Clinical Trials** have been endorsed or conducted, sometimes in collaboration with other organizations.



- **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.

- **APS ACTION SCIENTIFIC INTERACTION** when members meet virtually every two months to discuss ongoing or potential future projects.

- **Collaborations with other APS Organizations**

After more than 10 years of hard work and many publications (full list is available at <https://apsaction.org/publications>), we are still learning more every day about APS. Conclusions drawn from a small pool of people in a limited area only gives us an obscure fragment of the picture, hence 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 with the ultimate aim of developing improved diagnosis and optimal treatment strategies.

To receive regular updates on our research you can follow us on our website <https://apsaction.com/news/> or twitter [@APS ACTION](https://twitter.com/APS_ACTION). For more information, you can contact JoAnn Vega (Hospital for Special Surgery,

Click Below to Follow APSFA



Patient Stories & Articles Needed!

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, recipes, 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!

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Letter from the President



November is upon us in Wisconsin and we are first snow. With a healing broken ankle, I am not looking forward to this winter.

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. If you want to volunteer, please message me at apsfa@apsfa.org.

We have been busy networking with other organizations like the Lupus Foundation, CARRA, Autoimmune Association, ITSH, World Thrombosis Day, ICAPA and the Arthritis Foundation to name a few. We have been working with coalition groups to get more research for autoimmune disease in general, medication coverage 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. So far there is one video made by Stago Diagnostics with one of our volunteers on APS. Watch it here: <https://youtu.be/B6qPRciOADs> We also need a new one for our website, if anyone would like to make a professional one.

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!

As a reminder 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 are also with Target and Front Door. We are working of Walmart's SparkGood.

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 did you do to spread awareness and fundraise? What are your plans for next year? Will you hold a fundraiser or awareness event?

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

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How to Establish a Successful Journey for Personal Growth

By Peter Arnold

In our quest for personal growth, we often seek out advice from others. We read books, articles, and blogs on the subject, and we talk to friends and family members about it. And while all of this can be helpful, at the end of the day, it's up to each individual to figure out what works best for them.

There are a few key things to keep in mind when pursuing personal growth. First, it's important to be patient. Change doesn't happen overnight, and it takes time and effort to see results. Second, don't compare yourself to others. Everyone is on their own journey and is moving at their own pace. And finally, don't be afraid to ask for help when you need it. There are plenty of people out there who are more than happy to offer guidance and support.

So if you're looking to make some positive changes in your life, remember that it's okay to take things slow and steady. And don't forget to ask for help when you need it! Here are some other tips to guide you on your journey toward personal growth, courtesy of [The APS Foundation of America](#).

Maintain a Self-Care Routine

One of the most important things you can do for your personal growth is to maintain a self-care routine. This means taking care of yourself emotionally, mentally, and physically. When you're taking care of yourself, you're able to show up as your best self in all areas of your life.

Self-care looks different for everyone, but there are a few basics that everyone should make sure to include in their routine. First, get enough sleep. Most people need around eight hours of sleep per night.

Second, eat healthy and nourishing foods. Third, make time for physical activity every day. And fourth, find ways to relax and de-stress. This could involve things like yoga, meditation, or spending time in nature.

It's also important to find balance in your self-care routine. You don't want to neglect your physical health in favor of your mental health



or vice versa. Instead, focus on finding activities that will help you feel good all around. When you're taking care of yourself, you're giving yourself the best chance for success in all areas of your life.

Set Goals and Make a Plan

Another important step in pursuing personal growth is to set goals and make a plan. This will help you stay focused and motivated as you work towards making changes in your life.

Start by thinking about what you want to achieve. What are your long-term goals? What are some things you want to change in the short term? Once you have a general idea

of what you want to accomplish, you can start making a plan.

Break your goals down into small, manageable steps. Then, create a timeline for each goal. For example, if your goal is to lose weight, you might want to commit to working out three times per week for the next month. Or, if your goal is to start a business, you might want to start by learning how to write a business plan and researching what you need to do to register your new endeavor with the state. While there are re-

sources and formation services that can help you with these steps, learn all you can so you'll always have that knowledge — or at least know where to look for any answers.

It's also important to be realistic with your goals. If you're setting

goals that are too challenging, you're likely to get discouraged and give up. On the other hand, if your goals are too easy, you might not see the results you're hoping for. Find a balance that feels right for you, and remember that it's okay to adjust your goals as needed.

The APS Foundation of America is dedicated to fostering and facilitating joint efforts in the areas of education, public awareness, research, and patient services for Antiphospholipid Syndrome (APS) in an effective and ethical manner. If you have any questions, don't hesitate to reach out!



Navigating Antiphospholipid Syndrome (APS) Treatment Options: Patient Education Brief and Black Box Warnings

Written by: Margaret Schumacher, PA-C

Antiphospholipid Syndrome (APS) can be challenging to manage. You have experienced a "blood clotting episode". During the investigation for the cause, APS was diagnosed: persistently positive antiphospholipid antibodies (aPL) present in your blood tests (confirmed on separate blood testing 12 weeks apart). Blood clotting conditions may range from a venous clot in the leg; an arterial clot causing a mini-stroke or several small vessels clotting resulting in poor circulation issues. There are three specific APS blood tests: anticardiolipin, beta-2 glycoprotein I (β 2GPI), and lupus anticoagulant (LA). Understanding that one or all three of these antiphospholipid antibodies may be **persistently positive** is a key component to understanding treatment options.

First of all, asymptomatic individuals in whom blood test findings are positive do not require specific treatment. The presence of symptoms (e.g. lower leg blood clot) or risk factors for increased blood clotting risk - such as smoking, use of oral hormonal birth control, elevated lipids and cholesterol - may require treatment to prevent a future blood clot. Whether you have primary APS or Lupus with secondary APS, treatment options are available. Our goal today is to provide a summary of treatment considerations - including an established black box warning to allow you to make the best and most informed treatment decisions for yourself with your clinician.



Treatment Terminology:

Anti-coagulation: A medication which delays the time it takes for a blood clot to form. Examples include warfarin or Heparin.

Anti-platelet: A medication which delays platelet's role in forming a blood clot. Examples include aspirin or clopidogrel. For patients allergic to aspirin, clopidogrel may be helpful.

Anti-thrombotic: A medication which prevents or reduces the formation of a blood clot.

Coagulation Cascade/Pathway: The coagulation cascade: a series of steps in response to bleeding caused by tissue injury, where each step activates the next and ultimately produces a blood clot.

Direct-acting oral (by mouth) Anticoagulants: This group of medications block blood clot formation (thrombin formation). These drugs have a predictable response requiring no monitoring with INR blood tests. Examples include apixaban (Eliquis®), betrixaban (BevyxXa®), dabigatran (Pradaxa®), edoxaban (Savaysa®) and rivaroxaban (Xarelto®).

Hydroxychloroquine: This medication may assist in lowering antiphospholipid antibody levels and preventing recurrent clots in patients with Lupus.

Hypercoagulable State: Blood clotting occurs "too fast" in response to

presence of antiphospholipid antibodies, genetic blood clot factor deficiencies or medications (such as birth control pills).

International Normalized Ratio (INR): This is a blood test measuring the amount of time for the blood to clot when a patient is on warfarin. INR range will be monitored for a target level of 2.0-3.0(venous or arterial clots) above 3.0 for recurrent thrombosis.

Injection Anticoagulants: Intravenous (IV) Heparin or subcutaneous (sq) heparin are medications given to prevent extension of and formation of new blood clots.

Statins: These drugs lower your cholesterol. They work by blocking a substance your body needs to make cholesterol. Lowering cholesterol isn't the only benefit associated with statins. These medications have also been linked to a lower risk of heart disease and stroke. These drugs may help stabilize the plaques on blood vessel walls and reduce the risk of certain blood clots. Examples include atorvastatin and pravastatin.

Thrombosis: Thrombosis occurs when blood clots form and block veins or arteries.

APS Treatment Options:

Treatment for APS must be individualized. Managing hypertension and elevated cholesterol, avoiding smoking and oral hormone medications are options which decrease clot formation. For a Lupus patient with secondary APS, low-dose aspirin or hydroxychloroquine may be recommended.

Treatment of thrombosis:

When a blood clot has been detected, treatment with Heparin (intravenous or subcutaneous) followed by warfarin therapy is recommended. Usually, an INR blood test is performed weekly until target treatment levels are met. Clinicians will typically use a level of 2.0-3.0 as adequate for venous clots, 3.0 for arterial clots and 3.0-4.0 for recurrent clotting events. For severe cases, a combination of warfarin and aspirin may be used. Lifelong anti-coagulation medications may be recommended in severe cases too. In May 2019, the European Medicines Agency (EMA) issued a guidance statement **recommending against the use of direct-acting oral anticoagulants** (including rivaroxaban, apixaban, edoxaban, and dabigatran etexilate) for patients with a history of thrombosis who are diagnosed with APS, in particular those that are triple positive.

Black box warnings: What does that mean - Don't Take! Direct-acting oral anticoagulants (DOACs), are not recommended for use in patients with triple-positive antiphospholipid syndrome (APS); for patients with APS (especially those who are triple positive [positive for lupus anticoagulant, anticardiolipin, and anti-beta 2- glycoprotein I antibodies]), treatment with DOACs has been associated with increased rates of recurrent thrombotic events compared with vitamin K antagonist therapy (e.g. warfarin)



How To Qualify For Social Security Disability Benefits with Antiphospholipid Syndrome

Written by: Molly

If you have been diagnosed with Antiphospholipid Syndrome (APS) and you have worked in the past but can't work now because of APS you may qualify for Social Security disability benefits. As long as you expect that you won't be able to work for at least 12 months because of APS you can apply for Social Security disability benefits.



What Is APS?

APS is a rare autoimmune disorder where the body creates antibodies that attack the normal healthy tissue in the body as if it is some kind of threat or invader. This disorder leads to increased clotting of the blood and that can lead to serious, even deadly, side effects. Some of the symptoms of APS include:

- Blood clots in legs
- Repeated miscarriages or stillbirths
- Stroke
- Transient ischemic attack (TIA)
- Rash
- Neurological symptoms
- Cardiovascular disease
- Low blood platelet counts (thrombocytopenia)

Some of the risk factors for developing blood clots are:

- Diabetes
- Hypertension
- High Blood Pressure
- High Cholesterol
- Obesity
- Smoking
- Estrogen Therapy
- Some kinds of contraception

If you have been diagnosed with APS you will need to submit a letter of diagnosis and other proof of disability with your application for Social Security disability benefits. The qualifications for SSDI for rare disorders are strict but

having medical documentation really helps.

How to Medically Qualify for Disability with APS

Most of the time in order to be approved for disability benefits you need to show that you have a condition recognized by the SSA and listed in the SSA's Blue Book. However, there is no listing in the Blue Book

for APS because it's so rare.

So to medically qualify for Social Security disability benefits due to APS you will need to submit a letter of diagnosis from a doctor and any medical records that you have like MRIs, X-Rays, or other proof of your condition. You will also need to show that you meet the Blue Book listing requirements for a condition associated with APS.

For example, since APS isn't listed in the Blue Book but Chronic Venous Insufficiency, which is a symptom of APS, is listed you can qualify for benefits by proving you have:

Incompetency or obstruction of the deep venous system in a leg

AND one of these two:

Extensive brawny edema involving at least two-thirds of the leg between the ankle and knee or the distal one-third of the lower extremity between the ankle and hip.

OR

Superficial varicosities, stasis dermatitis, and either recurrent ulceration or persistent ulceration that has not healed following at least 3 months of prescribed treatment.

If you don't meet the listing requirements for any condition in the Blue Book you may be able to qualify for disability benefits with an RFC.

Qualifying For Disability Benefits With An RFC An RFC, or Residual Functional Capacity evaluation, is used to qualify for disability benefits when you don't meet a Blue Book listing. Your doctor needs to fill out an RFC evaluation sheet and use as much detail as possible to describe your symptoms and how they limit your ability your work. You can download a blank RFC form

Patient Education Continued

Additional Considerations:

Diet: If your management plan involves frequent INR blood tests - be consistent with your diet, especially foods which may contain a lot of vitamin K. Consider seeing a nutritionist to review diet and potential habits which may interfere with your anticoagulation plan. Also, long term heparin use may result in weakening of bones (osteoporosis), calcium and vitamin D supplementations are encouraged.

Travel: Be mindful of reducing your chance of blood clot in the leg (deep vein thrombosis): hydrate, walk around every 2 hours; consider compression stockings, keep your medication with you in your carry on; arrange for your blood work (INR testing) before and after your trip.

References:

- Antiphospholipid Syndrome Treatment & Management: Medical Care, Surgical Care, Consultations. eMedicine. Published online October 17, 2021. <https://emedicine.medscape.com/article/333221-treatment>

- Antiphospholipid Syndrome Follow-up: Further Outpatient Care, Inpatient & Outpatient Medications, Transfer. eMedicine. Published online October 17, 2021. Accessed June 16, 2022. <https://emedicine.medscape.com/article/333221-followup#e8>

- Eliquis (apixaban) dosing, indications, interactions, adverse effects, and more. Medscape.com. Published July 11, 2019. <https://reference.medscape.com/drug/eliquis-apixaban-999805#5>

This content was created as a patient education support reference and should not be used as a substitute for the advice and care of a medical professional.





APS ACTION Continued

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SSDI Continued

from the SSA's website.

The SSA will consider your work history, your age, your skill set, and other factors including the RFC form to determine if there's any kind of work that you can do. If they find there's no work you can reasonably be expected to do with your condition they can approve your application for disability benefits.

Starting The Application

You can start an application for disability benefits on the SSA's website right now. But you may have to go into your local SSA office to complete and submit the application and your supporting documents.

Sources Found Via:

- <https://www.ssa.gov/disability/>
- <https://apsfa.org/aps/>
- <https://www.disabilitybenefitscenter.org/how-to/qualify-for-ssdi-or-ssi>
- https://www.ssa.gov/disability/professionals/bluebook/4.00-Cardiovascular-Adult.htm#4_11
- <https://www.disabilitybenefitscenter.org/how-to/how-to-file-the-residual-functional-capacity-rfc-form>

The Affordable Connectivity Program (ACP)

Written by: Tina Pohlman

What is the ACP?

The ACP is a federal initiative to help Americans access affordable, high-speed internet. It replaces the Emergency Broadband Benefit (EBB) enacted during COVID-19 pandemic.

What is the Benefit?

- ⇒ Up to \$30/month discount for high-speed internet services per household.
- ⇒ Up to \$75/month discount for high-speed services per households on Tribal lands.
- ⇒ A one-time discount up to \$100 for a laptop, desktop computer or tablet purchased through a participating provider per household.

Do I qualify?

Households with an income at or below 200 percent of the federal poverty guidelines may be eligible for the ACP. Households who also qualify for the following programs may be eligible

- ⇒ Qualify for the Lifeline program and those who participate in certain federal assistance programs, such as Medicaid, SNAP and SSI benefits.
- ⇒ Households that already use discounted internet services from a high-speed internet provider.

- ⇒ Receives benefits under free and reduced lunch program or the school breakfast program, including through the USDA Community Eligibility Provision, or did so in the 2019-2020 school year.



- ⇒ Households that participate in the Tribal specific programs such as Bureau of Indian Affairs General Assistance, Tribal TANF, or Food Distribution Program on Tribal lands.

How Do I Sign Up?

Eligible households will enroll through participating high-speed internet providers or directly with the Universal Service Administration Company (USAC).

Where Can I Go To Learn More?

Get the latest information and participating providers in your state:

Website: <https://www.fcc.gov/acp>

Text: INTERNET to 22777

Call: 1-833-511-0311



When Lightening Strikes Written by Margaret & Steve Schumacher

That's what other Moms who experienced a stillbirth told me. You have to figure out how to live with this shock and trauma. I never thought this would happen to Steve and me, I never thought that I would grieve the loss of having a "normal" pregnancy forever, and I never expected to be grateful for challenges too. When you lose a pregnancy, a piece of your heart - just shatters! You never forget it or really get over it. Others love and my acceptance of it provided a "glue" so that I could function with this piece of my broken heart. My acceptance of my Antiphospholipid Syndrome and high risk pregnancies allowed me to block out other people's pregnancies and just focus on ours. This is our story .

March 1, 1997 - I married my best friend Steve. By April we were pregnant and on Mother's Day in May 1997 - we put an offer in on our first home - small 2 bedroom Georgian in the suburbs. We

were starting our family after years of enjoying ourselves in downtown Chicago. My first pregnancy - excitement and nervousness abound. First trimester - typical - second trimester more of same - belly still growing. Somewhere between 18-20 weeks my "belly growth" had slowed down.

We went to our 20 week ultrasound - don't worry - everything is ok - here is your new due date... Feb 6th. Then the office called - your recent blood work - alpha feta protein level was elevated - no signs of spinal bifida on your ultrasound - let's just monitor. I have an uneasy feeling - I see fellow pregnant friends - my belly is smaller for the same stage....I start to prepare

myself that maybe I am having a special needs childmy instinct tells me something isn't right.

Oct. 2, 1997 - **lightening strikes!** At my appointment - no heart beat; ultrasound still beautiful baby boy. I wish I could tell you that - the medical community was supportive - some were and some were not. I didn't receive any post-partum care instructions, somehow I didn't realize that my breast milk would come in - that week was awful. I still feel that is a really cruel piece of this - come back to your home with no baby to feed. The subsequent months - I was convinced that I had something which caused this. My OB - "you are grieving - these things just happen sometimes". I look back at my instinct, and I knew that



what I experienced wasn't normal. I knew as I

watched other people experience pregnancy at the same time as me - there was something wrong. I had to figure this out.

I am a Physician Assistant - I had knowledge - I had to explore why this happened so late in my pregnancy. Lupus - I pushed my doctors to screen me for Lupus. I didn't have Lupus but APS. Small blood clots in my placenta which limited blood supply to my son, and eventually it was unsustainable.

Back in 1997-1998 - some physicians didn't really believe in APS. That was really difficult - I was brushed aside as "grieving". I searched for a fertility specialist that could

help us. I found one and am so grateful for his guidance. Heparin shots twice a day, daily baby aspirin and close monitoring was our formula for success.

May 1998 - pregnant again - on all meds - following all of orders. End of July 1998 - **lightening strikes again** - miscarriage requiring multiple procedures to manage the bleeding. But our baby girl was destined for Heaven, and my APS didn't have anything to do with it. At this point - our disappointment and sadness is overwhelming - maybe it's time to take a break and explore other options for family.

After several months - we decide that we will try one more time.

Feb 1999 - pregnant. Heparin, baby aspirin, 20 weeks of bed rest, and close monitoring. Dec 17, 1999 - our beautiful daughter born! We had a formula that worked! August 21, 2001 and September 22, 2003 prayers answered again - we welcomed our wonderful sons!

I wish I could spare everyone from finding out through tragedy or "sudden illness" that they have APS, but that's not the way it presents. I wish I could convince you - the process of trying to have a baby with your APS is WORTH IT!

My hope is that you find strength from my story and feel my compassion for you - It's your journey. Trust your instinct, be honest with yourself and be your own advocate! When it's overwhelming, it's ok to not be ok.



Listen To Me

Written by: Kami Morley Schindler



My name is Kami and this is my story.

In Jan 2004 I had to endure watching my Mother lose her battle to

Cancer. I was grieving the biggest loss of my life losing my Mom. I was under tremendous grief & stress. Little did I know then that I would have my own battle to face.

I was 37 years old with 2 little girls & my husband. In Feb 2004 I started to get neck pain, kind of like a pulled muscle. I thought I must of done it at work lifting something. Then it started radiating down my right side by my lung. Me being stubborn dealt with this the best I knew how. I continued to work, refusing to go to the doctor. This went on for a week. Finally I could not catch my breath, I couldn't move. Still wouldn't go to the doctor, stubborn & stupid I know. My family all tried to get me to go, but I refused.

My Dad had a chiropractor friend who came to my house to give me "an adjustment". Stupidest move, that almost killed me. The next couple days I laid on the couch begging the Lord to take me. I was grieving my Mom so much, I just wasn't in my right mind.

Finally after 2 weeks of this pain my step Dad showed up on a Monday and said lets go now. He took me to

the doctor, my blood pressure was crazy high like 195/90 something crazy like that. They did EKG's on me which were off the chart. I was given 2 or 3 nitro pills, which did nothing. The doctor sent me home and was told to stay out of work for 3 days and come back on Wed. Well Wednesday came and now my left leg had the worst "charlie horse" I came limping into the doctor office. The doctor saw me walk in and said, what's wrong, why are you limping? I told her my leg was hurting. She said you have two choices 1) go by ambulance or 2) go to hospital immediately you have a blood clot.

So my step Dad took me home, cause I insisted I wanted to take my shower first.

Then called my hubby to meet us at hospital. When I got to the ER they took me immediately back. My blood pressure was now like 204/101, they ran EKG's, leg doppler, MRI to find out I had 2 DVT's that traveled from my left leg to my right lung. So I had two PE's. I was hours to a day away from dying the ER doctor's told me.

They immediately started me on heparin. I was in the hospital for a week. I did a lot of damage to my lung because I waited so long (2 weeks) to go to ER.

I had all kinds of tests run on me to find out I had this big long word, antiphospholipid syndrome an auto immune disease. I couldn't pronounce it let alone spell it. Later through this fb group I learned the abbreviation of APS. I started out having to take 12mg warfarin for about 2 yrs. Then I was moved to 10mg for another 2 years, now I have been steady at 9mg since then.

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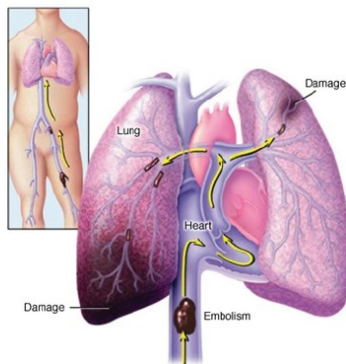
So now it's been 15 years later and I am still on 9mg

and haven't had another blood clot or PE. I did have a couple ER visits with possible TIA's. But ending up diagnosing me with Aura Migraines. I still get migraines a lot. Some where I lose partial vision. I have body/joint aches, no energy & just plain tired most days. But I have learned to live with it.

Most people don't understand because I "look" fine on the outside, but struggle a lot on the inside. I learned to just not tell people about my aches & pains because they don't get it or tired of hearing me complain. So I just go on with life as normal.

(Side note, with both my pregnancies in the 90's I had pre-eclampsia with both but delivered healthy babies.)

So just to educate others, my pain did not start out with the typical "leg pain" it started with neck pain. And because I damaged the bottom part of my lung, I only have half capacity of it. I have trouble holding my breath while I swim. But I am thankful I lived to tell my story. And now I have 2 grandchildren that I am grateful to be alive for.





Third Time's a Charm

Written By: Jennifer Bryant Cowling



I was 21, engaged and we found we were pregnant. Not exactly a shotgun wedding since the wedding date was already set, right?

We had a great wedding and honeymoon. A few months later, we had a wonderful baby shower. The week after the shower, I found out my son had died in utero. I was 28 weeks. I was induced and delivered vaginally. My husband and I got to hold Nathan and we were given photos, his footprints and the blanket and cap he wore.

I started injections twice a day and had Josh at 28 weeks. I'd gone to the OBGYN for a regular checkup and my BP was 185/135 and my kidneys were shutting down (protein in urine). I was started on magnesium to prevent stroke. Josh was 3lbs, 1 oz and born with both lungs collapsed and a small brain bleed.

Today he's a normal moody almost 19 yr old college student.

I really didn't have more issues with APS until 2016. My husband and I were at Disneyworld for our 20th anniversary. The last couple days there I was short of breath, but assumed it was my asthma (had since I was 2yrs old). I went to the ER when we got back and was told I was in severe congestive heart failure and needed surgery.

About 18 months after my heart surgery, I was at work (at a doctor's office) with a horrible migraine. I went to tell my boss I needed to leave. My boss had a doc to check my BP. It was higher than when I had Josh. The doc called 911. By the time they got to me, I couldn't move my left side. That was when I was put on warfarin for the rest of my life.

Throughout the last 20 years, I've been fatigued, stressed, sore. I've been headache-y, but for the most part, I shine it on. I cook and go to work and pay bills because there's no alternative.

Since my stroke, I've recovered 90%. My left hand is significantly weaker and I'm more clumsy. I just work on the weekends, so I can go to all the doctors during the week.

There's been pain and heartache, literally, but I am thankful for my little family and my "third time's the charm" baby.

I didn't bathe or work or eat much of anything for the next 3 months.

Two years later, I was pregnant again. I was at home and started bleeding. I was instantly hysterical. My husband happened to come home for lunch and found me on the kitchen floor. He carried me down the stairs of our apartment and drove me to the hospital on the army base where he was stationed.

I was yelled at for crying too loudly. As a teaching hospital, I must've had 30 ultrasounds, both abdominal and transvaginal and although I knew what was happening, nobody would say what was happening until a doc came and told me a D&E was scheduled for that afternoon. I was in hell again.

It was only several months later I learned I had APS and what it meant. Because we were at an Army hospital, the student doctors and technicians basically did every lab there was and genetic testing on both husband and me. I see other women who have had a half dozen or more losses before their diagnosis and the thought sickens me.

Two years after that, I was pregnant again. After four at-home tests, I called my OBGYN hysterically and demanded an appointment that day. I knew I needed to get on Lovenox injections!

Shopify Gift Shoppe

Written by Todd Ponagai

We would like to introduce you to our **Shopify Gift Shoppe**.

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



dy. 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.

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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

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