



ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter

Volume 18

Summer/Fall 2010

Do You Know What You Need To Know About Autoimmunity?

Written by: Karyn Lombana

I had the privilege of attending the information session entitled "What Every American Needs to Know About Autoimmune Disease." This session was put on by the American Autoimmune Related Diseases Association, Inc. (AARDA) and was held at the Crowne Plaza Hotel in Newton, Massachusetts, which is right outside of Boston.



Karyn Lombana represented the APSFA at the "What Every American Needs to Know About Autoimmune Diseases" session.

I arrived early and was able to help Pat at AARDA with registrations. I also tended to the APS booth, answered questions, and gave out information. We were one of only four booths there; the others being Sjögrens, Myasthenia Gravis, and Addison's disease. There was also a representative from the Feinstein Institute that is doing a research study called SisSLE (Sisters of Women with Systemic Lupus Erythematosus). Although it seemed like I was the only person with APS at the session, being able to meet others with autoimmune disease and discuss some of our similar experiences was encouraging. We are not alone in our fight for awareness. That in itself was comforting and tied in nicely with the overall theme of the program, which was how all autoimmune diseases share common threads.

The first presentation was delivered by Dr Noel Rose of Johns Hopkins University. It was entitled "What is Autoimmunity?" He began by discussing how autoimmunity is a natural part of our immune system and how our autoimmunity can develop into autoimmune disease if our normal regulatory processes fail.

About a third of the chance that one can have an autoimmune disease is thought to be tied to heredity. He also stated that evidence suggests that environment and other outside factors play about 50% of a role in whether this predisposition leads to autoimmune disease. These factors, such as drugs, exposure to viruses, bacteria, foods, hormones, stress, and pollutants, may potentially trigger the development of an autoimmune disease in genetically susceptible people. He also cited two studies that indicate how most types of autoimmune disease generally begin to manifest themselves around age 15 to 20 and kick into full gear during the patient's early to mid-thirties. Furthermore, these studies indicate that the numbers of people with autoimmune disease are on the rise worldwide.

The second part of the program, "Autoimmune Disease in Women" was presented by Rita Baron-Faust, author of The Autoimmune Connection, who is battling the effects of Raynaud's Disease. She discussed how autoimmune diseases tend to cluster and how female hormones (especially during pregnancy) may be a factor as to why 78% of those affected by autoimmune disease are women. She explained that it still takes about 5-7 years to get a diagnosis, and about 45% of all women patients are labeled as hypochondriacs. She noted how doctors may have difficulty seeing symptoms of autoimmune disease in their patients because they may on the surface seem to be unrelated. For instance, about 80% of people with multiple sclerosis presented with fatigue

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Newsletter Articles Needed!

We are in need of APS related articles such as book reviews, poems, recipes, interest articles, quotes, etc. for our newsletters.

We also need patient stories to feature in our newsletters, especially about men or children who have APS. Every APS patient has a story to tell and yours could be shared with the entire APS community.

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



Wow, I woke up this morning and it was in the 50's. I think that is the queue that Fall is on its way with all of its beauty. Summer was certainly a hot, humid and rainy. It was great to shut the air conditioner off and hear the crickets at night.

June was APS awareness month & we did get a lot press about APS. We had a great response this year!! Matt, a participant of the APS Friends & Support forum, started an APS Campaign on the Global Beatles Network. This is a Beatles Internet radio station that is heard in over 50 countries! He ran APS PSAs every hour for the month of June. He asked many of my Beatles related connections to be displaying the APS banners on their web page. We also had the support from Bonnie & the crew from WFLS 93.3 in the Washington DC Metro Area airing PSAs. Last but not least, we had a special APS promoter, Tyler & the All About Kids, who did a classroom fundraiser in memory of his uncle, Jason Strauss. The kids' quotes on what APS is will come in a future newsletter.

Thank you to everyone who celebrated our 5th Anniversary with us and helped us spread awareness during June for APS Awareness Month. It is greatly appreciated!!

This year we also announced the first World APS Day. Mark your calendars for June 9th from here till the end of time because it was a huge hit! Thanks to everyone who participated in World APS Day! We had 15 bloggers sign up for our Bloggers Unite event! We will be doing more on that date in the future. The APSFA is looking for pictures taken during World APS Day with their shirts on, burgundy on, APS gear on or other apparel (like stickers, buttons & the like). We would love to add them to the photo album. Please send them to tina@apsfa.org. Thanks!

The APSFA is in need for monies to update the APS Booklet & make a new print run, which will cost about \$3,000. The APSFA doesn't charge for these booklets when patients/clients, organizations, hospitals/clinics or conferences need them. Any business or family that donates the majority or the whole amount will be listed as a sponsor on our website for 2010 & on the booklet until this run is exhausted (about 2-3 yrs).

I also want to let you all know that Marv Nelson passed away. He was a moderator on APLSUK, always helpful & knowledgeable, and a prominent member of the APS community. He will surely be missed!

I hope this newsletter finds you in the best of health and with a perfect INR level.

Sincerely,

Tina Pohlman

President & Co-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 APS Foundation of America 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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My APS Journey ~ Susan's Story

Written by: Susan "Lexis" Portelance

I was diagnosed with APS over 15 years ago after having two unexplained DVT's in one leg and one in the other that broke off and went to my lungs causing a pulmonary embolism. I have been on anti-coagulant medications for over twenty years. My doctor at the time had read an article about APS and decided to run the blood tests to find out why I was getting unexplained clots and having what he was calling TIA's.

I tested positive for antiphospholipid antibody syndrome and lupus. I was at that time diagnosed with APS and Lupus and told I would have to be on anti-coagulation therapy for the rest of my life.

At that time APS was thought to be only a blood clotting disorder. My medical history however is far more complex than just APS. Since the age of nine I have had bouts of paralysis, as a child nobody ever tried to find out what caused them. I also fell down all of the time even before the bouts began again nobody ever looked into the reason. In the beginning these bouts lasted for a couple of weeks and occurred every few years, as I aged the bouts became more frequent at one time causing my entire body except for partial use of my right hand to be paralyzed, this lasted from start to finish five years. I was in my mid twenties for that bout, I never fully recovered from that, I did walk again but fell a lot and had to use crutches most of the time.

Currently I am wheelchair bound and paralyzed from mid way of my body down. The bouts are always accompanied with a horrendous pain in my spine with a banding tightness that is not so much painful but uncomfortable around the area where the spinal pain is, everything below where I get that pain goes paralyzed. To this day doctors have not been able or willing to figure out what is causing these bouts.

They now occur every several months I have accepted the fact that I may be wheelchair bound for the rest of my life and may never have an answer as to why. There is some thought that I have recurring transverse myelitis, but my MRI's are normal and doctors refuse to do a lumbar puncture to rule that out.

In addition to the above I have Meniere's disease and have lost 60-70% of the hearing in my right ear and am at the low end of normal in my left ear. I was recently diagnosed with this, the dizziness and vertigo and ringing in my ear is annoying but I can live with it,

I try to be as hopeful as I can despite the medical communities unwillingness or inability to treat me like a living, breathing human being. There are reasons that I am treated poorly by the medical community, as a child I was abused and taken away from my family, I was put on heavy duty anti-psychotic medications at a young age, and was kept on them until I went into kidney failure, which I almost died from because the doctors waited too long and said I was "faking it" at age 40.

They took me off all of the antipsychotics and anti-depressants and found out there was in fact a very normal happy loving human being with a great personality living underneath all those medications. The medications made me psychotic and depressed, I am no longer that way, I remain off of most psych meds and I am actually happier now than I have ever been in my life, despite the poor medical treatment I receive.

I no longer let the doctors' poor treatment get me depressed; it isn't worth it; they are not God although I feel at

times they think they are, they do not have all the answers, I realize some doctors don't like dealing with things they don't understand so they just write them off as psychological without ruling out medical causes.

I also realize I cannot erase the 300+ psych hospital admissions and all of the psychotic things I used to do from my record even though none of that is with me now, and doctors seem to be incapable of looking past those records as well.



Susan & her canine companion, Max

I have had a PET scan and SPECT scan both were very abnormal, this was prior to what some doctors called an apparent untreated CVA in April of 2009, depending on the doctor I had one or I didn't. I began to heal from that episode which caused my entire left side to go into flaccid paralysis, caused me to develop swallowing issues called dysphasia and caused

me to become incontinent of both bowel and bladder, I am there again except this time it is an episode of the pain in my spine that has caused it again. Just a few weeks ago I was starting to get some movement back in my legs, now I am completely paralyzed again.

I also found out about in spring, 2010 that I have thyroid cancer. The diagnosis of my thyroid cancer is just another example of how the medical community does not treat me well medically. I had an ultrasound over a year and a half ago, it apparently showed nodules large enough that they should have been a biopsy done right away but my doctor at the time had told me the ultrasound test was normal. I recently got a new endocrinologist who said I had to have a biopsy done, she had to fight with the local hospital to get them to do the biopsy for several weeks, turns out I have cancer and

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About the 13th International Congress on Antiphospholipid Antibodies (APLA 2010). “Antiphospholipid by the beach”

Written by: Silvia S. Pierangeli, Ph.D.- Chair, APLA 2010

The 13th International Congress on Antiphospholipid Antibodies (APLA 2010) was hosted and conducted in Galveston, TX this past April 13-16th 2010. These triennial international congresses are the primary forum for worldwide interaction between leading researchers, physicians and other health professionals with interest in APS. Our goal this time was to make this event a truly international and multispecialty one. We are proud to report that we were able to bring to Galveston more than 40 invited speakers from all APS-related specialties and more than 250 attendees from 28 different countries. The congress was accredited and supported by the University of Texas Medical Branch (UTMB) as a CME event.

The three and half day event included state-of-the-art lectures, selected abstract oral presentations, poster sessions, a pre-conference consensus workshop to re-evaluate and validate the Sapporo revised classification criteria and discuss un-solved issues such as treatment and diagnostics in APS. Seven task forces assembled to address those questions and were further discussed at the preconference workshops. Recommendations from those task forces/workshops will soon be published and will be available to the public.

In addition, APLA 2010 included a very well-attended pre-conference laboratory wet workshop where participants were able to evaluate “hands-on” new tests proposed to help in the confirmation of diagnosis of APS and discuss with experts issues on standardization of currently used assays.

One of our main objectives was to attract the attention of young scientists that have the potential to move the

field of APS forward in the future. One way to do that is to offer awards for excellence in research work. We received an unusually high number of papers applying for the Young Investigator Awards and thanks to our supporters we were able to award three prizes to the highest scored papers.

Importantly, the APLA 2010 scientific program featured for the first time “Meet the Professor” sessions on topics such as: “Treatment”, “Diagnosis” and “Equivocal Cases of APS.” The programs of the sessions were superb and the seats filled up rapidly, indicating the interest of junior scientists and physicians on learning and getting updates on the quickly growing field of APS.

New this year too, were the patient/doctor forums that focused on the latest developments on all aspects of APS including new treatments and clinical trials. Those sessions encouraged a direct interaction of APS patients with two internationally-recognized leaders in the field: Drs. Munther A. Khamashta and Michael D. Locksin. We are pleased to report that those sessions were very well attended as well, underscoring the interest of the patients as well as the commitment of our physicians to patient care and communication of what is new in APS. They also fostered productive collaborative interactions among patients, patients’ advocates and physicians and further discussions in the hallways and congress social events.

We are extremely appreciative to all our supporters (diagnostic and pharmaceu-

tical companies, other patient advocate groups as well as private donors), to UTMB and the city of Galveston that helped make this congress a truly successful scientific event. In particular

the APS Foundation of America gave the congress generous sponsorship. From the early stages in the organization of

the meeting, the APSFA showed their interest in APLA 2010. The APSFA provided funds to cover the first prize of the Young Investigator Award, helped with the advertising of the congress through their website, was represented with a booth at the exhibit hall and sent APSFA volunteers to be present at every social and scientific event. Thanks Tina, Heidi, Cindi, Dana, and all of you at APSFA!!!

A special thanks to Lorraine Terrel from the CME office and to Alvaro Schleh and other members of the Antiphospholipid Standardization Laboratory for the long hours and the dedicated support and hard work to make this event possible. The proceedings of this meeting are published in a special issue of *Lupus*. Thanks a million to Drs. Bertolaccini and Khamashta for co-editing this issue with me.

Finally, the next international congress on APL antibodies will be in Rio de Janeiro, Brazil in 2013 (date to be confirmed). We are counting on our APS patients’ participation on that event as well!

APLA 2010 website:
www.utmb.edu/APLA2010

“One of our main objectives was to attract the attention of young scientists that have the potential to move the field of APS forward in the future.”



54 Ways You Say You Respond to “You look so good!”

Submitted by: Heidi Ponagai

“You look so good!” Over 1200 of you took our survey last year ([you can still take it here if you want](#)) and you shared how you respond to this compliment that pulls at the heartstrings.

Sometimes you just have to respond... a smile doesn't say all that you want to say, but one of the temptations is to use sarcasm in our response.



Most of us can say that it depends on who says it. We may be more likely to smile and say, “If only it were true!” to a friend who doesn't really get it. To the person behind at us the grocery store who commented about our groceries, we are more likely to say something sarcastic since we don't have to deal with repercussions of a stressed relationship.

Just remember that our seemingly justified bitter comments back at them can only alienate people more and it does nothing to create an awareness of invisible illness. But who of us doesn't relate with wanting to say a few of these things on the list below?

The most telling comment I read was from a woman who simply said, “I wonder why they can't see my pain in my eyes?” It's a good reminder that though we sometimes think the world should accommodate our emotional needs, who around us is hurting for other reasons (divorce, loss of job, loss of loved one, etc.) and they are wondering about us, “Why can't she see the pain in my eyes?”

Be sure to add your own at the bottom in the comments section!

1. I am hangin' in there...
2. I am so blessed. God is so good.
3. Drugs are a wonderful thing
4. I have my good days and I have my bad days.
5. I clean up well.
6. I have my 'good' days....but this isn't one of them!
7. Thanks, I wish I felt better.
8. That's a perfect example of how you can never judge a book by it's cover.
9. Thanks, but there are many aspects of MS which you don't see ... would you like to know more about it?
10. That's what most people think since pain can't be seen most of the time. Have you heard about Invisible Illness Week? It's really helpful to let people now that most illness is invisible.
11. I'm trying to appreciate that fact. I know the day may come when I have to use a wheelchair or a cane, and my illness will be more visible.
12. You should be on the inside.
13. Thanks. I have more to be grateful for than I have to complain about - which means I have a LOT to be grateful for!
14. Well I guess I did good job on my makeup, because I am having a hard time to tell the truth.
15. ...And that's all that really matters, isn't it?
16. Powder and paint, make you what you ain't!
17. It took a lot of work to look like this.
18. It's God shining through me
19. It's nice of you to think so, but you're missing the pain and agony that I really am in.
20. And you look so wise. Looks can be deceiving though, huh?
21. I'm having a “good face” day.
22. Yeah. My kid thinks it's cool I'm an ill person working undercover!
23. I do a great job hiding how I really feel. My life is still very challenging and probably will always be, but I am hanging in there, keeping a positive faith, and gratitude as THE attitude. Thanks for their concern.
24. I'm trying my best to do well OVER my circumstances instead of being under them!
25. It's up and down.
26. I'm still struggling, but it IS nice to have a day when I am able to pull myself together and make it out of the house!
27. I'm not complaining about my looks.
28. I'm very good at pretending.
29. Good, because if I looked like I feel it would scare you to death.
30. Actually, I still am really hurting...
31. I am 36 years old outside but 85 inside
32. Thank you. I'm on my way to the Oscars.
33. Thanks, I'm grateful for this good day.
34. Things aren't always what they seem.
35. Praise God, I'm glad that he enables me to look so much better than I feel.
36. Thanks, that's God's joy shining through!
37. Have you ever heard of the



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and depression as their first symptom—not neurological issues. Ms. Baron-Faust pointed out specifically that people with Lupus should ask about APS. I purchased her book, which was available at the conference, and I am looking forward to learning about her theories in more detail.

The third discourse revolved around ways to cope and “take control of your illness.” It was presented by Virginia Ladd, the President and Executive Director of AARDA. I was amazed by how many people in the room raised their hands when asked if they were ever told “it’s in your head” or “you don’t look sick” by doctors, family, and friends. I didn’t wholly agree with the advice given for this very frustrating problem. The first suggestion was made to try to put on a brave face so that your friends won’t get sick of hearing about how sick you are (in my opinion, if a friend can’t empathize with you he/she is not a real friend).

The second suggestion was to change the way **we** communicate with our doctors so we aren’t labeled as “doctor seeking.” Given that the majority of attendees had been told by doctors that they were making up symptoms, this area of discussion caused some grumbling and tension in the crowd. As one attendee said to the group, there is such a thing as idiopathic illness (illness with no cause) – in her opinion, that means that the doctor is an idiot because he/she can’t figure out what’s wrong with her! I personally believe that doctors are the ones that need to change **their** approach. Doctors need to learn to **listen** better to their patients and to sort through the information that they are given to make a proper diagnosis and develop a sound treatment plan. It is their professional obligation, in my opinion, to put themselves into the shoes of their often worried, scared, and hurting patients. After all, we pay for them to help us, not the other way around!

On a positive note, I liked the idea of keeping track of and being specific about changes in your condition (new symptoms), how you physically feel, and how your disease is affecting your daily life. A number of other good suggestions were given:

- ◆ Do know your family’s history of autoimmune disease (your “A.Q.”);
- ◆ Do follow your recommended treatment plan and take all medications as prescribed;
- ◆ Do not let autoimmune disease define you as a person;
- ◆ Do surround yourself with positive people;
- ◆ Do give our significant others specific ways to help us rather than complain (it can be frustrating if they see you hurting all the time and can’t do something to help);
- ◆ Do not use our disease as an excuse to get out of things that you really don’t want to do to begin with;
- ◆ Do use “I” instead of “you” when speaking with others;
- ◆ Do find a forum that isn’t a “pity party” (thank goodness, the APS Friends & Support Forum doesn’t fall under that category);
- ◆ Do realize that the disease is not your fault.

Ultimately, Ms. Ladd said to use your disease as an excuse to take better care of yourself. Eat better. Make healthy choices when it comes to smoking and alcohol. Take a day when you are feeling well to do something nice for yourself rather than rush to do all of the things that “need to be done.” Avoid the cycle of burnout. View the illness and the issues it presents challenges to overcome rather than something that you have fallen victim to.

The final discourse was about future treatment options for autoimmune disease. Dr. Rose likened autoimmune

disease to a train. There are many compartments in the train (various diseases), but all of them are linked and are traveling along the same track. It is urgent for doctors to jump aboard the train early on in the disease process and not wait until it is at the last stop when damage has been done and the illness has profoundly affected the patient’s quality of life. To that end, he is hopeful that the human genome project will eventually provide doctors with biomarkers that can be used to identify susceptibility to autoimmune disease and allow for “predictive and personalized” treatment to patients. This combined with more research into environmental triggers could have a very positive impact on heading off autoimmune disease in the future.

The overall message that I received from this program was that we are not alone; APS is just one thread in the large tapestry that is autoimmune disease. There are at least 80 known autoimmune diseases. About as many people are affected by autoimmune disease as those who are affected by heart disease, and there are significantly more people with autoimmune disease than those with cancer. Yet, doctors have traditionally dealt with autoimmune diseases have traditionally as individual, compartmentalized diseases. While there is the National Heart, Lung and Blood Institute and the National Cancer Institute, there is no National Autoimmune Disease Institute. There are no autoimmunologists that we can go to for specialized help.

Yet, there is hope. According to this program, there is a shift developing in how doctors think about and approach autoimmune disease. More doctors are starting to look at autoimmune disease as a whole rather than focusing on the symptoms of the individual diseases. AARDA is keenly interested in the outcome of newly-formed autoimmune disease clinic in Israel and hope to eventually have such clinics here in the United States. They are also trying to

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earn the \$100,000 needed to develop a curriculum at Johns Hopkins to provide doctors with much needed education about autoimmune disease.

As mentioned, hope is also being placed on the genome project and potentially finding biological markers that indicate susceptibility to autoimmune disease. To that end, AARDA asked all of us to contact our legislators about H.R. 2084, also called the "Prevention, Awareness, and Research of Autoimmune Diseases Act

of 2009," that has been introduced by Senator Patrick Kennedy. This legislation could provide funding to research the biomarkers and environmental triggers of autoimmune disease. If you would like to learn more about this legislation, please go to AARDA's website at

www.aarda.org/advocacy_issues.php

Overall, these changes in how our doctors view and approach autoimmune disease will hopefully give us a more powerful collective voice. Right now, as was stated during the program, we are all "whispering" as individual diseases. If we raise our voices together, we will have a

greater chance of being heard by those who have the means, power, and influence to help us. Realizing that we are not alone, that we are a part of the larger struggle of autoimmune disease, can help us to cope and find additional strength in each other.

This program will be repeated throughout the year. An additional free informational sessions will be held in Cleveland, OH on September 18, 2010. Please go to www.aarda.org for further information.

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now have to have my thyroid removed and will be on thyroid medication for the rest of my life.

I live with horrendous pain every day. Luckily, pain meds take the edge off. I was also recently given a tens unit which helps a lot. What I think helps the most is I refuse to give up on myself even when others have given up. I see my friends on my support forum going through so much and being so strong, we all support each other and I truly believe that we keep each other going.

I have many other medical issues that may or may not have to do with APS including a seizure disorder which is under control with medications. I take a lot of medications every day, mostly to keep me alive. I am living with a terminal life threatening illness that doctors seem to write off because in my opinion they don't want to or don't care enough to take the time to learn about APS and the symptoms that alone causes.

The most important message I hope that comes out of my story is that there is hope. I may not know what is wrong with me but I am able to care for myself with help very well. I am happy to have a won-

derful new dog that I love dearly. I live in an accessible apartment in a very nice small town. I attend a wonderful spiritual center and I believe spirituality is key in healing and having hope. I have hope that someday there will be a cure for APS and Lupus and all of the other diseases and syndromes I have. Maybe not for me but if my story or my body once I leave it can help the medical community find a cure or help just one person my life will have been worth all of the ups and downs and pain I have dealt with. They're going to have to wait a while for my body; however, I don't plan on leaving it for a long time. Peace to all. Thanks for reading my story.

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spoon theory?

- 38. I am upright which is better the alternative
- 39. Thanks, want to swap bodies for a few days?
- 40. Thanks, I guess I am fortunate that I have an illness that can't be seen.
- 41. Thanks. I like good days.
- 42. Want to step inside my skin?
- 43. It's amazing what a shower can do. I guess I am all cried out for now
- 44. Thanks...I wish I felt it!
- 45. I'm not complaining about my

looks.

- 46. I'm very good at pretending.
- 47. Looks can be deceiving (and smile)
- 48. Thank God for makeup!
- 49. Thank you for caring. I try to act like I feel better than I really do.
- 50. Thanks, I am trying to even though it will never go away. i just try to remember things could be worse.
- 51. I'd be great if it wasn't for the pain.
- 52. I'd complain but who wants to listen.
- 53. If I can't feel good, at least I am

determined to look good!

- 54. I'm in good shape for the shape I am in!

What do you say? Or what *would* you say if you could say anything (keep it clean!)

This list is compliments of National Invisible Chronic Illness Awareness Week at www.invisbleillness.com, based on a survey of over 1200 respondents. Get involved in Invisible Illness Week each year during September, including our 5-day virtual conference online.



Will You Receive Disability Benefits If You have an “Open and Shut” Case?

Written by: Tim Moore

Most people who file for Social Security disability benefits are in for a fight, even if it seems to them that they have an “open and shut” case. It’s important for those filing for SSD/SSI to realize that there is no medical condition in and of itself that qualifies one for disability (though there are certain conditions that may qualify for expedited processing).

Disability decisions are based on two things:

- 1) The existence of a severe, ongoing mental or physical impairment, and
- 2) an inability to earn living as a result of this impairment (which, for the social security administration, equates to the inability to work and earn at least the monthly SGA, or substantial gainful activity, amount that is in effect for the current year).

Proving the existence of a severe medical impairment can be difficult, particularly if the claimant hasn’t recently sought medical treatment for the condition, a situation that can easily come to pass, of course, if the individual no longer has health insurance.

The general rule of thumb is that if the claimant hasn’t seen a physician in the 90 days prior to the evaluation of the disability claim, a disability examiner will schedule the individual for a consultative medical exam (CE).

CEs are performed by doctors who are in private practice (not Social Security employees) and who are paid by Social Security to perform medical examinations and mental examinations and mental testing. CEs can be very brief (physical CEs probably last an average of only 20 minutes), and are intended to provide only a snapshot of the claimant’s current state of health.

There are really no substitutes for solid medical records from a treating physi-

cian documenting the date of onset (when symptoms began), how the impairment has developed over time, a prognosis, and, especially, some indications of how the claimant’s condition has reduced their functional ability to engage in normal activities of daily living. However, when this information does not exist for whatever reason, a claimant will likely be required to go to a consultative exam.

Are the results of a CE a good substitute for records from a treating physician, particularly a medical source statement from a treating physician that succinctly explains that the claimant’s remaining functional capacity does not allow a return to work activity? Of course not. And as a disability examiner, I found few examples of cases that were approved solely on the strength of a consultative examination report.

Medical record documentation from a physician who has an established history with a claimant and who continues to provide medical or mental treatment will always be the bedrock on which [social security disability](#) and SSI disability cases are decided.

Yet, just the same, even those who have copious medical records in support of their disability claim, and even physician statements, sometimes get turned down for disability. About 70 percent of all disability applications filed each year are denied, and first appeals are even less likely to succeed. Does this mean that the majority of people who file for benefits are not really impaired in some way? Hardly.

Statistics also show that most people

who request a second appeal, a hearing before an administrative law judge (ALJ), go on to win benefits. This fact alone strongly throws doubt on the ability of the federal disability system to make accurate decisions at the initial claim and reconsideration appeal levels that occur right before the disability hearing level.

Of course, it can take years to work through the entire disability process from initial application, to reconsideration appeal, to the disability hearing.

Some would argue that’s the idea: wear people down over time so that they just give up and go away. However, those who stay the course and go through with the disability hearing win their cases more often than not, and these individuals are usually rewarded with considerable back pay in addition to monthly benefits. However, by that time

the financial and emotional toll is considerable.

The lesson in all this? If you are disabled and unable to work, do not assume that your case will be “open and shut.” When it comes to winning SSD/SSI, there’s no such thing. Instead, begin documenting your medical treatment as soon as you begin to experience difficulty working.

And, if your application for disability is denied (and most are) do not give up. The chances of being approved for disability go up at each level of appeal, particularly at the administrative law judge hearing level.

Tim Moore is a former disability examiner and the creator of [Social Security Disability Secrets](#). He currently writes at [My Disability Blog](#)





The Other Guy

Written by: Gary Robertson

I have been very physical most of my life. You know the type, the jock, always looking in a mirror at his muscles thinking he looks better than he does. Telling old football tales over and over until the family begs him to stop. That was me. I am 62. APS may have slowed me some but I now have a very different outlook on life.

As I remember I first noticed having a problem with my breathing when doing little things like walking up a hill or stairs. This was about six years ago now. My chest would feel tight, mildly uncomfortable. I have had similar feelings after exerting myself during a workout so at the time I didn't think much about it. When I look back it is just as everyone says, my mind found a reason to let it pass. Nothing was wrong, not me! Just need to work a little harder, must be getting a little out of shape. I need to push myself and get rid of this tightness. Some men are nuts! I would not admit that anything was wrong. No matter how hard I worked out the tightness came back and at times hurt a bit.

The first real scare came when I had just finished a meditative retreat. I practice Soto Zen and at these retreats I sit with legs crossed for long periods of time. When this particular retreat ended I left and was walking to my truck. I had to walk up a fairly steep hill. Upon reaching the top it happened, I could not catch my breath. It was like having the wind knocked out of me. What's going on here? How did I get this out of shape? I kneeled down and slowly recovered. Boy, I thought, this age thing is coming on harder than I had anticipated. I need to regroup and work harder. Enough of this crap.

The following day I started a much needed vacation. I was flying to Sara-

sota, Florida from Minnesota to visit my younger brother. It was winter here and I was looking forward to the gentle breezes and warm weather of Florida. Not to mention the wonderful sights on the beach. The flight went well and I was met at the airport by my brother. Everything was just as I had imagined lots of sunshine, no snow, and no agenda. Yes, this was going to be great. The first thing I did when we arrived at his house was to get into the pool, and the first thing I noticed was I was out of breath. I sat on the edge of the pool until my gasping stopped. My brother asked me if I was alright. Was I sick from the flight? I told him no; I was just out of shape and needed to relax some. He was planting tomatoes at this time and I decided to help him. Same problem again, short of



breath and with pain so I stopped digging and sat. I told him I was on vacation so no digging. He laughed and silently I was scared. What should I do?

My plan was to take it real easy and not do anything to aggravate my breathing. I would see my doctor when I returned home. After seven days of sun and good food I said good bye and I boarded my return flight. The tightness in my chest was with me most of the time now. I did everything with measured caution. I was scared. It was about a three to four hour flight and I was happy to be home. I remember after departing the plane that I had to walk up a short flight of stairs, no escalator was needed here. When I got to the top of the landing I went down. I could not breathe. Several people helped me to a chair and got medical help. This must be a heart attack! I was in some real pain here and did not know what to do.

I was taken by ambulance to an emergency ward. One of the responders strapped oxygen support on my face and several others were hovering over me. All I could think about was this might be the end of my life. I'm not sure what all they did to me when we arrived. There were lots of quick checks on the condition of my heart. All that was found was that my blood pressure was high. My heart seemed to be OK. Now what? After several hours of lying in a room by myself someone came in and said they were going to x-ray my lungs to see why I had such labored breathing. This took another hour, as they had to find someone that could take the type of x-ray needed. They had to get someone to come in to do this. Finally the doctor on call came in and said, "Your lungs are full of small blood clots. You have pulmonary embolisms." They started me on Lovenox and Coumadin. I was sent to see a hematologist who after several days of testing my blood informed me I had Lupus Anticoagulant which meant I had Primary APS. I have been taking Coumadin since and will be taking it the rest of my life.

I often wonder how close I was to death because I didn't pay attention to what my body was telling me. How lucky I am to be alive. There is a lot to do and know to live with APS. I needed support and understanding. Let me tell you something, there is very little around. The problem is I look and act healthy so everyone, and at times myself, forgets the danger of having this autoimmune disease that has no cure. Well needless to say my life style has changed.

My hope is that anyone who reads this and thinks like I did will wise up and pay attention. Listen to yourself and get help. Don't keep putting it off because you don't want to believe something is happening to you. I always thought these kinds of problems happen to the other guy, well, I am that other guy!

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