



# ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter

Volume 2

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## Seronegative Antiphospholipid Antibody Syndrome (SNAPS)...and Snapping To It!

Written by: Gale A McCarty, MD, FACP, FACR

"You don't have the syndrome because your tests are low level or negative..." or "You have livedo, a heart valve problem, and thrombocytopenia, but these aren't listed as criteria for diagnosis" are comments made frequently by healthcare providers from many specialties to patients with clinical features suggesting the Antiphospholipid Antibody Syndrome (APS).

Resistance of healthcare providers to making a diagnosis of the APS when laboratory tests do not meet the initial 1999 Sapporo Criteria that required the presence of a "moderate or high titer" of antiphospholipid antibodies (aPLs) is very common. The Sapporo Criteria were derived from a consensus of experts from many medical specialties with both clinical and laboratory experience after careful consideration and much discussion (I had the privilege of being part of that group and privy to many animated discussions).<sup>1</sup> This multi-authored manuscript clearly states it was written "in the spirit of defining homogeneous populations of patients for studies, not to be applicable in the diagnosis of APS in an individual patient".<sup>1</sup> It is important to review how the term "seronegative APS" or SNAPS came into clinical usage, what it means, and why it is a legitimate concept for healthcare providers to consider, as it prompts thinking and rethinking about the right diagnosis and conditions that can mimic APS syndromes.

When I attended the first Kingston APS Study Group (KAPS) in the mid 1980s (and the subsequent International Symposia on aPLS which occurred every two years since), this terminology was not in general parlance. A recent detailed search for the use of this term from 1966 databases onward does not find it in the literature until the early 1990s, the year that three laboratories (primarily Krillis, Bevers, Koike and colleagues) contributed to the identification of  $\beta_2$  glycoprotein 1 ( $\beta_2$ gp1) as a major antigen to which APS patients' antibodies reacted.<sup>2</sup>

The term "SNAPS" has been used in various ways. When I first used it in 1996 in describing a cohort of 53/498 patients with Sapporo criteria-associated, and non-Sapporo criteria-associated features of APS<sup>1</sup>, they had had complete clinical evaluations and standardized tests every two to four months for IgG and IgM anticardiolipin antibodies (aCL) by a serum ELISA in my lab after my certification by Drs E N Harris and S Pierangeli in 1988, and also on a plasma sample drawn at the same time for the two most common coagulation-based tests at the time-an aPTT and dRVVT, all performed according to International Soci-

ety for Thrombosis and Haemostasis 1995 standards. These same samples were also studied for antibodies to phospholipids other than cardiolipins (CL) that were emerging in research studies (phosphatidylserine-PS, phosphatidylethanolamine-PE, phosphatidylinositol-PI, and phosphatidylcholine-PC) in collaboration with the laboratory of Dr. John McIntyre.<sup>3</sup> In order of decreasing frequency, these SNAPS patients had proven arterial thrombosis, livedo, migraines, recurrent fetal loss, mitral valve prolapse, thrombocytopenia, proven venous thrombosis, and autoimmune hemolytic anemia. Extensive investigation for infectious diseases and mimics of APS eliminated these other conditions-their diagnosis was APS.

In 1997, Miret et al<sup>4</sup> described two patients who had APS in evolution with transient "seronegative" features, and was the first article using this term as a descriptor. Laboratory evidence of antibodies being tied up in immune complexes changing over time was postulated as the likely reason for "SNAPS" here.

In 2000, a 3.5 year follow-up of my original "SNAPS" cohort by the aforementioned detailed clinical and laboratory studies showed that 12 patients converted from "SNAPS" to

seropositive APS. Ten patients developed aPE, one each developed dRVVT or aPC positivity. None of the patients developed aCL.<sup>3</sup>

Also in 2000, Harris and Pierangeli articulated an important concept that all patients and caregivers to APS patients should remember: "despite having achieved international consensus criteria for APS, although these will be of immeasurable help to investigators studying the disorder, they will be only of partial assistance to physicians managing patients who do not have "classical" clinical or laboratory features of APS, and "non-classical features" may well be part of APS, since the clinical and laboratory boundaries of the disorder are not known.<sup>5</sup>

In the first Sapporo Criteria validation paper in 2001 by Lockshin et al of 75 patients with primary/secondary APS, 131 SLE without APS, and 37 with lupus-like disease without APS, the Sapporo criteria for APS were felt to favorably compare with the ACR criteria for SLE and thus were validated in terms of acceptable sensitivity, specificity, positive/negative predictive values. This study attributed "false negatives findings" as being "due to patient classification on the basis of minor criteria that were not considered in the Sapporo criteria (livedo, thrombocytopenia, low-titer IgG/M aCL, IgA aCL, and anti- $\beta_2$ gp1)". However, there were two true "SNAPS"

Article continued on page 3...



## Friends of APSFA

Do you believe in our cause? If you do, you can now become a "Friend of APSFA". For a membership fee of \$25.00 you will get our Friendship package which includes:

- Our quarterly newsletter in paper form
- 1 year 'sample' Anticoagulation log book
- Printed copy of all our Brochures
- APS Awareness pin
- Priority for answers with our "Ask A Doc" page

If you would like to become a "Friend of APSFA" please visit our website for how to do so. More information is located at [www.apsfa.org/friends.htm](http://www.apsfa.org/friends.htm).

## We Need Your Help!

We are in search of patient stories and newsletter articles. If you would like to contribute something, please email us at [articles@apsfa.org](mailto:articles@apsfa.org)

We are also searching for doctors who are currently treating APS patients for our Dr. List. Please see our website for more details.

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## Letter from the President



The APS Foundation of America turned 1 year old in June. I am sure there are many that thought we would not make it that long, but, yes we did and we have many more years ahead.

I must say thank you to Gundersen Lutheran Medical Foundation for granting us seed monies to make this foundation a reality. And a special thank you to my Board of Directors and Steering Committee for making a wonderful forum and website. Another thank you goes out to our Medical Advisors for making sure our information is medically accurate and answering the questions that we may have.

I would also like to take this opportunity to welcome Gale McCarty, MD, FACP, FACR, Al Lodwick, RPh, MA, Adedayo Onitilo, MD, FACR and R. LaDonna Hinch, RD to our growing Medical Advisory committee. We look forward to working with them in the future.

I am pleased to announce that we were granted our 501(c)3 status and are now an official non profit public charity organization.

The APS Foundation of America is actively working with our medical advisors and their respective facilities to get the education out about APS. We are attending various grand rounds and lectures talking to medical professionals about APS and the foundation. We have been well received and everyone is happy to hear there is finally representation in the US.

I am also pleased to report our segment on the Discovery Health Channel (DHC): Mystery Diagnosis has re-aired several times and can now also be found on The Learning Channel (TLC). Please check your local listings for the next air-date.

We have several new fundraisers starting. One big one is our affiliate programs. You can find the shops we are now working with on our foundation page. We are also now a listed charity on GoodSearch.com. We earn a penny a click if you search through that site. It is powered by Yahoo and also has a downloadable toolbar with pop-up blocker. Please support the APSFA by searching and clicking away.

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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## An APS Survivor ~ Larinda's Story!!

Written by: Larinda Brown

My name is Larinda Brown. I am an APS survivor. I call myself a survivor simply because one does not live with this disease. One survives it - DAILY.

I was diagnosed after surviving a pulmonary embolism, after both legs being completely occluded with DVTs in January of 1999. Since that time, I have had 18 more DVTs, another PE, and, yes, a Greenfield filter). I feel like a walking advertisement for Coumadin.

Through this, I have had to have a life saving hysterectomy because of hemorrhaging. I have had pneumonia several times, meningitis, etc. You name it; it has happened. I also suffer from Relapsing Polychondritis which is sooooo very painful, as well as Lupus, Sjogren's, Raynauds, and Fibromyalgia. Life is such a battle some days.

I was amazed to find that there are so many others that suffer from the same things that I do and are surviving right along with me! At 36, I feel like 100 sometimes. But it is so great to know that I am not alone. Others have been

robbed of life by these autoimmune diseases that seem to feed off of one another in some sort of frenzy.

I am thankful for one of the most skilled rheumatologists in the country, Dr. C. Saadeh, whose limitless research in the autoimmune diseases area has allowed me to live and watch my children continue to grow.

I also have a wonderful GP, Dr. John Howard, who monitors me very closely in the interim visits and takes care of the everyday aches and pains.

I am very fortunate, indeed, to have great friends, family, and physicians who help me survive this very rare, very cruel, very debilitating disease.

I just wish there were some way to get the message out to others who suffer and survive APS. There is hope. You ARE NOT ALONE. We are out here, and we are surviving too. We can, and we will, survive. And we will keep on surviving.



...SNAPS article continued...

patients who had false negative results and became positive, although the term "SNAPS" is not traditionally used by this group.<sup>6</sup>

By 2003, Khamashta and Hughes addressed "SNAPS" in a short communication espousing that "the use of the term SNAPS could be viewed as an inducement to clinical sloppiness as a catch-all to embrace all those diagnostically suggestive cases failing to meet Sapporo criteria".<sup>7</sup> They listed concerns: a) APS was the wrong diagnosis and there was a different coagulopathy present; b) a laboratory problem, in that conventional laboratory testing (meaning here the IgG/M aCL and one LAC test) did not pick up cases with antibodies directed against different PLs or protein cofactors; or c) a prior positive test became negative, such as in Sneddon's syndrome, where patients have livedo and a stroke with a persistently negative aCL test. They specifically state that "it is universally recognized that routine aCL and LAC tests may miss some cases".<sup>7</sup>

The revised Sapporo criteria by Miyakis et al<sup>8</sup> has readdressed the clinical and laboratory advances since 1999, and lists the level of evidence used to qualify whether non-criteria associated features have now become criteria-associated features. To address the patients described in my opening sentence, who likely have APS in that they have livedo, heart valve problems, thrombocytopenia, neurologic problems, IgA aCL, IgA anti-β<sub>2</sub>gp1, anti-PE, anti-PS, or anti-PS/prothrombin, the revised criteria detail much food for thought in Tables 3-6, to which patients and care providers are directed for a detailed review and to update their knowledge and thinking. Anti-β<sub>2</sub>GP1 is now a serologic criterion, so the "standards" are changing.

In the next newsletter, I will review recent longitudinal studies about how APS-related antibody test change with time, and new data about levels of tests.

Lastly, in any human disease, the individual patient (not the group for a controlled drug study) is the most important unit of analysis, and patients exhibit many different combinations of clinical features as well as laboratory tests. Caregivers should remember guidelines are guidelines, and not diagnostic criteria applicable to an individual patient, so minds should be kept open to patients who present with APS features suggesting careful clinical, laboratory, and imaging studies be considered. Proximity of a patient's test to active livedo, itself a thrombosis in small vessels, and a proven recent arterial or venous thrombosis theoretically could affect the antibody test levels, so thinking and re-thinking about APS in all its forms is important. An educated patient partnered with a caregiver who reads and critiques the literature is a "win-win" situation for all.

1. Wilson W et al: International consensus statement on preliminary classification for definite APS. *Arth Rheum* 42:1309-11.
2. McCarty GA. The Lupus Anticoagulant and APS. In Hahn BH, Wallace D: Dubois' *Lupus Erythematosus*, Ch 27, Lippincott Williams Wilkins 2006 in press; Ch 25, 2004 Edition
3. McCarty GA et al: Seronegative APS (SNAPS) in 53 patients: seroconversion rate at 3.5 yrs. *J Autoimmunity* 15: OC35, A13, 2000.
4. Miret J et al: APS without antiphospholipid antibodies at the time of the thrombotic event: transient "seronegative" APS? *Clin Exp Rheum* 15:541-4 1997
5. Harris EN, Pierangeli S. "Equivocal APS?" *J Autoimmunity* 15:81-5 2000
6. Lockshin MD et al: Validation of the Sapporo criteria for APS. *Arthritis Rheum* 43:440-3 2000.
7. Khamashta MA, Hughes GRVH: Seronegative APS. *Ann Rheum Dis* 62:1127, 2003
8. Miyakis S et al: Update on the international consensus criteria for APS. *J Thrombosis Haemostasis* 3: 1-12, 2005.

## Grand Rounds at Marshfield Clinic

Written by: Tina Pohlman



The APS Foundation of America, Inc (APSFA), was invited to attend and speak at Grand Rounds in Marshfield, WI, at Marshfield Clinic. The speaker was Adedayo

Onitilo, MD, one of our new medical advisors.

Michelle and Angie drove up from Iowa to attend, and Tina came from La Crosse. Check out our new photo album on the foundation page for pictures ([www.apsfa.org](http://www.apsfa.org)).

The presentation was CEU, CME, and APCE-certified and was very well put together. Many of the speaking points were items that the APSFA has been stressing for quite some time. It was also pointed out, to the approximately 150 medical professionals in attendance, that the Sapporo Criteria was for clinical trials and is a guideline but not a rulebook in practice and that there is such a thing as seronegative APS (SNAPS). (Please see "Seronegative Antiphospholipid Antibody Syndrome (SNAPS)...and Snapping to It!!" on the cover.) Listening to

the patient and individualizing treatment were stressed also.

Points of discussion included the following:

- that most doctors will typically keep their patients at an INR of 2-3 unless continued or new problems arise or the initial event was arterial based,
- more and more central nervous systems (CNS) manifestations are being connected to APS,
- Angie was used as an example of Chorea during the CNS portion of the lecture,
- it was pointed out that she has low titers,
- that obstetric patients should be treated with Lovenox and aspirin for the term of the pregnancy and some sort of anticoagulation six weeks postpartum, and
- the use of Plaquenil and bone marrow transplant were discussed.

All in all, we could put member names, from the forum and based on their patient story, to about 75% of the slides. Our statistics match quite closely to what was presented in the round.



## To Be a Friend...

Written by: Audrey Kron, MS, CGP



How many times have we heard, "To have a friend, be a friend"? The late Audrey Kron, medical psychotherapist and licensed marriage counselor, offered a popular "Ask Audrey" service to help chronic illness patients. In a letter to Audrey, one patient voiced a concern shared by many individuals who find themselves having to learn new "rules" for maintaining friendships: "One of the concerns that I have is how to make and keep friends when I have an illness. Sometimes I find it easier just not to see people."

**"Remember that you are not just an illness; you are a person, with all kinds of ideals, values, and opinions."**

Audrey, whose own life had been altered greatly by chronic illness, shared some ideas for building and supporting friendships. Here was her answer.

Dear R.K., friends are very important, especially if you have a chronic illness. There are many ways to make and maintain friendships, despite the limitations of chronic illness. Let's look at some of them.

- Let your friends help you. They may feel helpless, too. They may want to do something, but not know what to do. Asking them to do a small task can relieve their sense of helplessness. You may need a ride to the doctor, a dinner brought in, or just a phone call or visit. It makes people feel better to be told specifically how they may help you.
- Limit talking about your illness. It's tempting, when something is hurting, to tell everybody all the details. You can get a repu-

tation as a hypochondriac. Others may be interested for a while, but they will become uncomfortable when you elaborate too often. If every time they ask how you feel, you say, "My stomach hurts. I feel terrible, etc." eventually they'll stop asking. Share your feelings about your illness with some people, but be selective. Make sure they really want to hear.

• Be an interesting person. You cannot blame people for not wanting to be around if your illness is the only topic of conversation. Read the newspaper. Listen to talk shows. Become aware of the world around you. Remember that you are not just an illness; you are a person, with all kinds of ideals, values, and opinions.

- Be a friend. If you want friends, you have to care about others and be considerate of their needs. During times when you are feeling better, it's important to help your friends and be supportive.
- Accept your friends and their flaws. Nobody's perfect. If you look for acceptance, learn to be more accepting. Talk about problem areas in your friendship. Try to identify how the problems make you feel and what can be done to solve them.
- Get involved in organizations. Help others that are less fortunate. You will not only have more interesting causes to talk about, but you might even meet some new people along the way. Your local support organization is a great place to start.
- Make an effort to keep social appoint-

ments and be prompt. Of course, this can be very difficult with a chronic illness. Allow yourself extra time and plan to rest if necessary.

- Try to adapt to situations. Instead of saying, "I can't go," make the situation one you can handle. Again, use your creativity. Sometimes advanced planning may be required, like checking out whether the bathroom or the physical area is convenient for you. You may have to make special arrangements for food or for being dropped off at the door, etc. Do what it takes to make yourself as comfortable as possible.
- Don't be afraid to share your feelings. Making yourself vulnerable allows your friends to do the same and creates closeness.
- Take the initiative with social activities. Don't stand on ceremony waiting for someone to call you. There is someone that would be happy to hear from you right now!

Your medical treatment is very important, R.K.; but don't underestimate the power and support of your friends. Good friends are treasures that will help you through some of the more difficult times. Work on finding and keeping a circle of friends.

Source: [Meeting the Challenge: Living with Chronic Illness](#), Audrey Kron, M.S., CGP; for information, Dr. Lawrence Kron, phone 248-330-2368, e-mail LawrenceKron@aol.com.

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## From the APSFA FAQ Webpage:

### What lifestyle changes must be made to accommodate Antiphospholipid Antibody Syndrome?



For asymptomatic individuals who have antiphospholipid antibodies, some doctors recommend aspirin therapy, but, generally, no major lifestyle changes are necessary. For patients who have the antiphospholipid syndrome and have had a blood clot, treatment consists of anticoagulant therapy ("blood thinners"). Anticoagulant therapy with Warfarin (most commonly, Coumadin®) does require attention to one's diet (for a stable intake of vitamin K) and regular blood checks to

monitor the medicine. Other recommendations for patients on Warfarin therapy would be the same as for any individual who needs to take Warfarin. Patients with problems with recurrent miscarriages may need to take a different type of blood thinner (a low molecular weight heparin, such as enoxaparin or dalteparin) during subsequent pregnancies. Lastly, patients with antiphospholipid antibodies should try to minimize any other blood clot risk factors (for example, not smoking, or not taking oral contraceptives or hormone replacement therapy).

## If I Were Healthy

By: Kathi Harpst

*If I were healthy, I'd climb a tree.  
I'd run down the street.  
I'd swim in the sea.*



*If I were healthy, I'd eat like a pig.  
I'd fill all my dreams.  
I'd do a little jig.*

*I work toward healthy every day.  
I take meds and rest.  
And, always, I pray.*



*I'll be healthy once more.  
A cure will be found.  
And I'll be . . . myself.*



# The Antiphospholipid Syndrome Collaborative Registry: A Unique and Invaluable Resource

Written by: Robert Roubey, MD

The Antiphospholipid Syndrome Collaborative Registry: A Unique and Invaluable Resource  
Although the Antiphospholipid Syndrome (APS) is much more common than is generally recognized, research is hampered by limited numbers of patients at individual medical centers. To address this issue, a group of leading APS researchers have joined together and formed the Antiphospholipid Syndrome Collaborative Registry (APSCORE).

APSCORE is a national, multi-center, disease registry sponsored by the National Institutes of Health. The goal of APSCORE is to collect and update clinical and demographic information, laboratory data, and blood samples from patients with APS, as well as individuals with antiphospholipid antibodies who do not have symptoms of APS. Then these resources are made available to the research community. APSCORE is designed to support a broad range of research on the causes, mechanisms, diagnosis, and treatment of APS.

APSCORE is led by Dr. Robert Roubey, a rheumatologist in the Thurston Arthritis Research Center at the University of North Carolina at Chapel Hill. Dr. Roubey has been actively involved in APS research and caring for APS patients for nearly 15 years.

Other APSCORE sites are Duke University Medical Center in Durham, NC; the Hospital for Special Surgery in New York City; Johns Hopkins University Medical Center in Baltimore; the Morehouse School of Medicine in Atlanta; the University of Texas Health Science Center in San Antonio; and the University of Utah Health Science Center in Salt Lake City.

Patients have been recruited from different medical specialties – rheumatology, hematology, obstetrics, and neurology – representing the broad range of medical problems associated with APS.

Enrollment in APSCORE began in 2002, and ap-

proximately 900 patients have been entered into the registry. Two-year follow-up visits have been conducted with 350 patients. Twelve research projects are either being supported by the registry or under review. Examples of these

projects are studies of new diagnostic tests, or biomarkers that may help predict which individuals with antiphospholipid antibodies are at the greatest risk of thrombosis, and studies on the genetic suscepti-



bility to APS.

Due to funding limitations, no new patients are being enrolled currently in APSCORE. Follow-up visits and support for research projects are continuing.

For further information about APSCORE visit the registry's website at [www.apscore.org](http://www.apscore.org) or contact APSCORE at 919-966-0572 or email to [apscore@med.unc.edu](mailto:apscore@med.unc.edu).

## A Story of Strength

Written by: Elaine McGonagle



This is a short version of my Mother's life and the obstacles and struggles she overcame.

Mom always had a rough life. Born 85 years ago weighing

only two pounds, but due to her strength and her Mom's great care (being kept warm by the stove), she survived.

Fast forward to her engagement and marriage to my Dad. It was awesome! He proposed while overseas in India during World War II. They married on November 30<sup>th</sup>, 1946, and began a wonderful life together.

The first tragedy my Mom and Dad suffered was the loss of my brother, Thomas, Jr. aka Bo, at the age of 13, on December 26<sup>th</sup>, 1951, of lymphoma. They had a total of five children. Mom experienced 2 miscarriages.

Things went well until, on their 25<sup>th</sup> wedding anniversary, Mom landed in the hospital for an emergency gall bladder surgery. She underwent many operations after that to open blocked bile ducts.

It was not until a few years later that she was found to have pancreatic cancer. She underwent surgery called the Whipple Procedure, and we were told she would not make it past six months. That was about 26 years ago. She told

us she was not ready to go as she had too many things to do here on earth. My parents lived a long and happy life until Dad died five years ago.

I was the first in my family to be diagnosed with Factor V Leiden and APS. My Mom got tested, and she was positive also. She did okay until a slight trans ischemic attack (TIA) that caused her to fall down a few stairs. The doctors never ordered a cat scan of her head even though she landed headfirst. She suffered many bruises, and the next day had a small TIA or seizure. The doctors thought nothing about this and discharged her.

A couple of weeks later, she was suffering extreme pain in her head, and the doctor sent her for a cat scan. Results showed a large hematoma in her brain. She was admitted to the hospital. She spoke with a neurosurgeon who told her it had to be removed, or she would die. Mom, at her old age, chose the surgery, a craniotomy, by herself. She successfully underwent the operation, and recovery told us to go home, she was fine.

In the middle of the night, she began to have seizures, and the neurosurgeon decided to operate again. During this operation, she suffered a major hemorrhagic stroke. It was a very trying time as Mom did not want to wake up – took weeks. Well, she began to respond and, once again, said it was not her time to go yet.

After months of intensive rehabilitation, Mom was left-side paralyzed but seemed to accept it. Unfortunately, she had to be put in a nursing home, as she required 24-hour care. She never lost her

sense of humor. We called her the Mayor of the nursing home as she was always watching out for the health and well-being of the other patients!

Well, fast forward again. The second week of January 2006, she started to suffer extreme back pain that radiated to her stomach. The doctors thought it was due to a disc problem in her back and just prescribed pain medications. Her abdomen continued to become extended, but no doctors showed up to examine her.

After a week of hearing her cry, over the phone, in pain, I insisted on an ER visit, which turned into two. A cat scan showed a massive bleed due to Coumadin. As a side note, my mom was assigned to a new doctor, prior to the ER visits, who switched her from Warfarin to Coumadin and at the same time decided that she only needed to be tested once a month as opposed to the weekly INR she had been receiving. They gave her a vitamin K shot and sent her back to nursing home at 4:30 a.m. At about 6 a.m., she was taken to the bathroom where she either suffered another stroke or a heart attack. But it was all related to Coumadin bleed.

She died in the emergency room after suffering low blood pressure, which lead to atrial fibrillation.

I am writing this to make all of you recognize how important it is to keep track of your INR no matter what clotting disorder you have whether it be Factor V Leiden, APS or one of the many other hypercoagulable states and to honor the strong, courageous life of a much-loved, much-missed mother.

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### APS Foundation of America, Inc.

#### Our Mission Statement

Founded in June 2005, the APS Foundation of America, Inc. is dedicated to fostering and facilitating joint efforts in the areas of education, support, research, patient services and public awareness of Antiphospholipid Antibody Syndrome in an effective and ethical manner.



## Join the RTDC Patient Contact Registry!

[www.RareDiseasesNetwork.org/rtdc/takeaction](http://www.RareDiseasesNetwork.org/rtdc/takeaction)

### Who can join?

We encourage patients in the US and around the globe to join the RTDC Contact Registry. Patients with the following types of thrombotic diseases are particularly encouraged to register:

- Antiphospholipid Antibody Syndrome (APS)
- Catastrophic APS (CAPS) or Thrombotic Storm
- Heparin-Induced Thrombocytopenia (HIT)
- Thrombotic Thrombocytopenic Purpura (TTP)
- Paroxysmal Nocturnal Hemoglobinuria (PNH)

*Everyday, research studies are in action, directed at improving our knowledge and treatment of thrombotic diseases. These continued efforts of researchers seek to improve the quality of life for all who are suffering from these rare diseases, but this research cannot happen without our vital partnership with patients.*

### How the Patient Contact Registry works:

The Patient Contact Registry is a method for patients with thrombotic diseases to register themselves with the RTDC.

Patients, or parents on behalf of their children, can register their contact information the secure Patient Contact Registry. People in the Patient Contact Registry will be contacted and informed of clinical research studies that are run in our new multi-center Rare Thrombotic Disease Consortium. Private information will not be given to researchers. Instead, with this information, patients decide which research studies they want to learn more about, and contact the researchers directly if they wish to participate.

You can learn more about the Patient Contact Registry at our Web site:

[www.rarediseasesnetwork.org/rtdc/takeaction](http://www.rarediseasesnetwork.org/rtdc/takeaction)