



ANTIPHOSPHO...WHAT?

APS Foundation of America, Inc. Newsletter

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What Is "Micro-Clotting?"

Written by: Thomas L. Ortel, MD, PhD

Simply put, micro-clotting, better referred to as "microvascular thrombosis" describes blood clotting that is occurring in some of the smallest blood vessels in the body.

Our circulatory system includes a pump, the heart, which is responsible for circulating blood through our blood vessels. The arteries carry blood from the heart to our brain, organs, and limbs. As the arteries travel out, they split and become smaller and smaller. Tiny arteries are referred to as arterioles, which get even smaller and eventually become capillaries. The smallest capillaries may only be slightly larger than a red blood cell!

An important activity that occurs within the capillaries is that the red blood cells release oxygen to the tissues and pick up carbon dioxide to carry back to the lungs.

As the blood travels back to the heart, the blood vessels get larger and larger, first as venules, and then as veins. One of the biggest veins, coming up from the legs into the abdomen, is the inferior vena cava. We also have veins in our heads, referred to as venous sinuses. The vein draining blood from our intestines to our liver is referred to as the portal vein.

A blood clot in an artery may cause a stroke or a heart attack. A blood clot in a vein may cause deep vein thrombosis in an arm or a leg. If the deep vein thrombosis breaks loose and travels up and into the heart, it will travel to the lungs where it can cause a pulmonary embolism.

Blood clots that occur in the tiniest blood vessels are referred to as microvascular thromboses. In this setting, the clinical symptoms depend on the organs that are most strongly affected. For example, clots in the microvascular vessels in the head may manifest like a stroke, or even confusion. Clots in other organs, such as the liver or the kidneys, could cause those organs to fail.

Certain clinical disorders are associated with

microvascular thrombosis. One disorder is called catastrophic antiphospholipid syndrome, or CAPS. CAPS is associated with diffuse blood clotting in patients with antiphospholipid syndrome, including microvascular as well as macrovascular (in other words, clots in larger veins and arteries). CAPS can be rapidly fatal, if appropriate treatment isn't started in time.

"A blood clot in an artery may cause a stroke or a heart attack."

Primary treatments for CAPS include anticoagulant therapies ("blood thinners") and a process referred to as plasma exchange, or plasmapheresis. Plasma exchange is a process whereby the patient's plasma, or liquid part of the blood, is removed and replaced with plasma from normal donors. Other treatments for CAPS include steroids and other immunosuppressive agents, and support of blood pressure, kidney function, lung function, etc.

Other clinical disorders associated with microvascular thrombosis include thrombotic thrombocytopenic purpura ("TTP") and disseminated intravascular coagulation ("DIC"). TTP is also treated with plasma exchange, and DIC is sometimes treated with anticoagulant therapy. In general, it is not clear that anticoagulant therapy is particularly helpful in patients with microvascular thrombosis. The underlying disease also needs to be treated.

The diagnosis of microvascular thrombosis can sometimes be difficult, since there isn't an imaging test like an ultrasound or a CT scan that can reveal these tiny blood clots. In some cases, a biopsy may need to be performed in order to document the presence of microvascular thrombosis.

The Rare Thrombotic Diseases Consortium is an NIH-sponsored program that is developing several research studies involving patients with rare thrombotic syndromes, including CAPS. You can learn more about these rare syndromes, and about available studies, at the Rare Thrombotic Diseases website (www.rarediseasesnetwork.org/RTDC).



Friends of APSFA

Do you believe in our cause? If you do, you can now become a "Friend of APSFA". For a 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

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.

We Need Your Help!

We are in need of patient stories and Newsletter articles. If you would like to contribute something, please email us at 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.

Inside this issue:

What Is Micro-Clotting?	1
From the President	2
APSFA Board of Directors	2
Successful APS Pregnancies	3
Alternatives To Warfarin	3
Events To Remember	4
Life With an Autoimmune...	4
You Hear It All The Time!	5
5 Worst Memory Problems...	5
Phoneraiser	5
Husband Recalls	6
From the APSFA FAQ Page	6
Vitamin K & Warfarin	6
Advance Care Planning	7



Overheard in a hematologist office: A young lady was diagnosed with having the Lupus Anticoagulant. When she asked the doctor what that was, he replied, "bad luck".



Letter from the President



Winter is fully upon us already and before long we will be getting ready for APS Awareness Month in June. It is mind blowing to think that in June we will turn 2 years old.

I would like to thank everyone who donated to decorate our giving tree! Because of your generous donations, we were able to raise \$2310.00! The Giving Tree holds a special meaning for the members of the APS Foundation of America, Inc and the community it serves. And since the Giving Tree was such a big success, we will be making this a new annual tradition.

The APS Foundation of America has been actively with our medical advisors and their respective facilities to get the education out about APS. We have been contacting various newspapers and media sources to get the word out about APS and the foundation. We have been published in a few newspapers, newsletters and even "The Stroke Connection," a publication put out by the American Stroke Association.

We have been applying for some local grants. Our most recent grant came from Marshfield Clinic in Marshfield, WI. We thank them for their support. We were able to print a professional APS Information booklet with those funds. But these funds still are not enough for us to attend the conferences we have been invited to attend. Hopefully, that will be a different story next year.

We are working on getting APS mentioned on ER, Grey's Anatomy and House, MD. Personally, I think any of our stories would make a wonderful and dramatic storyline. 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.

Before I forget, our support forum is growing by leaps and bounds! We are almost 1000 members strong and have an average of 2,293 posts per month! Talk about a very active support forum. Check it out if you haven't already.

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

Sincerely,

Tina Pohlman

President & Founder

APSFA Board of Directors

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A Successful APS Pregnancy Story ~ My 4 Miracles

Written by: Michele Balara

In 1994, one week after sclerotherapy to both legs, I was diagnosed with multiple pulmonary emboli in both lungs. The scene was sudden and shocking starting with an ambulance ride to the ER in the middle of the night and ending with questions for my future. Many tests later, a diagnosis was still hard to come by— mostly it was a wait and see kind of thing. The more doctors I saw, the more questions were raised but the one thing they all said was the same – pregnancy was a big risk.

Six months later, after Coumadin therapy, I again had multiple pulmonary emboli in both lungs. My lupus anticoagulant was now positive along with the IGM antibody. APS was a diagnosis being lumped with the umbrella term “hypercoaguable state”. The bottom line was always, the diagnosis doesn’t change treatment – Coumadin for life. With my wedding now six months away, my husband and I took a “what will be, will be” attitude. I had already been told as a child that I may not be able to have children after being treated with radiation therapy for Hodgkin’s disease.

After one year of being married, the baby bug hit. My husband wasn’t about to take any chances. He would always say that he would rather have me than a baby. But after some research we decided to pursue having a baby. I was working as a RN in an ICU at two hospitals and going to part-time school at night for my graduate degree. So I felt confident in my choice of perinatologist and decided to go ahead and seek their opinions. The one that I trusted most and started the heparin pre-conception had some nursing issues so I made the decision to leave mid-treatment. Getting pregnant was taking longer than I had anticipated! While waiting for my appointment at the new perinatologist, I discovered that I was pregnant! When I called to see if I could see them earlier, they told me that they would follow my aPTT (Activated Partial Thromboplastin Time) until I reached 7 weeks and then be seen in the office. Well, the following week after that phone call, I met them in their ER with multiple pulmonary embolisms. I was so upset, angry, and sick. I had hormones kicking in and pretty much just cried once I got to my

room. The best feeling was being able to see my baby in the ultrasound with its little beating heart. The baby was surviving through the X-rays, nuclear medicine scan, and heparin. So I spent my 30th birthday and Thanksgiving in the hospital thinking, what have we done?

Over the next nine months, I was followed very closely. I saw a pulmonologist, cardiologist, and hematologist. My husband went with me to every appointment. He was such a great support and was able to ask questions about my care. At about six months, my aPTT was bouncing all over so I was admitted for IV heparin and sent home with an SQ pump. This was a wonderful piece of equipment that looked lovely with all my maternity attire. I



The Balara Family

had weekly visits from the nurse to check my aPTT and MRI to check the baby’s growth. There was so much concern about the placenta clotting off and any clotting harm to me. I was convinced that I was going to die in childbirth or soon thereafter.

Then that magical day came and I had my beautiful baby boy. I declined the epidural because I didn’t want to come off the heparin for any reason. The only post-partum complication that I had was some bleeding due to the heparin and Coumadin therapy. They weren’t taking any chances. That first pregnancy experience was so hard but I learned so much. In 1999, I had more sudden and severe pulmonary embolisms. My family had now relocated and I found myself with new doctors. I met a wonderful hematologist that finally gave me the diagnosis; APS. He said he had lots of patients with the same clotting problems that I had. After he sent me to a rheumatologist to rule out lupus, he sent me to see a perinatologist. He followed me on my Coumadin until I got pregnant with my second child and switched me to Lovenox. Then we moved again, this time to Illinois. The doctors in the Midwest were very different from the east coast but still followed me on Lovenox. The APS “specialist” there said that I did not have APS because I did not have a history of miscarriages. After that comment, my husband and I were ready to jump ship but felt trapped. Here we are, in the middle of no where, at the best hospital in Chicago with doctors telling me after five pulmonary embolisms that I did not have APS. We chose to ignore him and pray that

we would see the other doctors in the group every week and at my delivery.

Lovenox seems to have been the key for us. My husband and I call it the miracle drug. It has less bleeding risks and was much easier to regulate leaving time to concentrate on my cardiopulmonary status. Because of my history of radiation therapy and PE’s, my lungs are not the strongest. I saw them again every other week and I rested more and enjoyed my son a little more everyday. At 38 weeks, I had another beautiful son and we went about our life. No complications this time. Post-partum, I was sent home therapeutic on Coumadin.

After so much success, we decided to go again. Following the same path as baby number two, I stayed on my Coumadin and switched to Lovenox when I got pregnant. This time we again moved back to the east coast and I was happily reunited with my old doctors and had another baby boy. Post-partum again stuck to the Coumadin with weekly INR checks.

My husband and always wanted a big family and knowing we could move back to Illinois, we decided to go for number 4 while we were with our favorite doctor. I had such successful pregnancies—and what did we have to lose? I became pregnant with baby number four while my last son was four months old. I started taking my Lovenox but not with the same care as I had in the past. I started skipping doses; after all didn’t I have two babies without complications? Look how far I had come. Christmas Eve 2003 sent me right back to the ER with multiple PE’s for the 6th time. I was so sad. Again, what had I done? I have three kids at home. This time the doctors were telling me that I may have damaged my heart. I admitted to not taking my Lovenox on a few occasions and was able to go home without much testing. So after getting the wake up call that I do in fact have a very serious chronic illness, I took my medicine without a whimper or complaint for the next nine months.

My daughter was born without complications and I now take Coumadin for life. I thank GOD that I have them and myself happy and healthy. The baby thing is over for us now. I cannot believe that I have four children after all that I have been through. I am committed to get my INR check regularly and learning more about APS.



Events to Remember

Written by: Heidi Ponagai

Support the fight against heart disease:

Everyone (men too!) can support the fight against heart disease in women by wearing red on February 2, 2007— Go Red For Women DaySM. It's a simple, powerful way to raise awareness of heart disease and stroke. By joining together with thousands of women, companies and organizations, and cities across America, you'll help the American Heart association support ongoing research and education about women and heart disease.

For more information visit: www.goredforwomen.org



March is DVT Awareness month:

March, 2007 marks the fourth annual Deep-Vein Thrombosis Awareness Month sponsored by the Coalition to Prevent Deep-Vein Thrombosis. March is officially recognized as Deep-Vein Thrombosis Awareness Month by United States Senate Resolution 56.



According to the American Heart Association, up to two million Americans are affected annually by DVT. Of those who develop pulmonary embolism, up to 200,000 will die each year. That is, more Americans die annually from DVT/PE than from breast cancer and AIDS combined. Yet, according to a national survey sponsored by the American Public Health Association, 74% of Americans have little or no awareness of DVT.

For more information, visit: www.clotcare.com

12th International Symposium on APS:

The 12th International Symposium on Antiphospholipid Antibodies (12th ISAPA) will be held from April 18 - 20, 2007 in Florence, Italy. The program will address all clinical/basic research and treatment aspects of APS, and includes a session for patients. Sessions for patients will include lectures and discussion with experts. No registration is required.

For more information, visit: www.antiphospholipid.net



- Submitted by Dr. McCarty, Member, Int. Adv. Board for ISAPA for the meeting Co-Chairs Dr. PL Meroni and Dr A Tincani.

Life With Autoimmune Disease

Poem Written by: Marie Tophoney

*They say looks are deceiving and I know I don't look ill,
But a life with auto-immunity, feels like all you do is ail..*

*I live with intermittent pain, sometimes in my hips or my knees,
Sometimes it just too painful to get from point A to point B.
You never can tell where it's gonna be.*

*My headaches are debilitating and sometimes they last for days,
I'd rather not even stand up, cause my head keeps thumping away.*

*My body doesn't do well with mental or physical stress,
I really can't take on your world , because it just may do me in,
This doesn't mean that I don't care, so don't take it personally,
I'll be there when I can for you, Please don't fault me, if this cannot be.*

*I'm always saying that I am tired, and trust me I am not lazy,
But when I try to sleep at night, it feels like something
wants to bust out of me.*

*My arms, my legs, my fingers and my toes,
If I can walk today, I get out of bed and go.*

*I know you may not realize this,
But I suffer from forgetfulness,
Although you told me seconds ago, I may not remember it.
Can you imagine putting something down and when you turn around,
You forget where you just put that thing and you begin to turn things
upside down.*

*Or picking up the phone to call someone in your family,
And going in a panic cause I can't remember which keys,
I dial this number everyday but I guess for now I'll just wait.
This is not selective memory, This is, a very scary thing.*

*The embarrassment of the rashes, itching and no less,
My hair is falling out again, not to mention the medicines,
And all the side effects.*

*It hurts me when you think that I am just a hypochondriac,
These ailments I suffer from truly do kick my A_ _.*

*Remember all the things we did, go shopping and walking around,
I'm sorry, I can't always do these things, as it is hard to get around.
It's not that I don't love you or want you to be around,
I'm sorry to disappoint you, my illness, once again is bringing me down.*

*This disease causes me misery, and I ask that you understand,
I did not ask to be brought into this world, let alone,
ask to be dealt this hand.*

*At night I lay upon my bed reciting the very same prayer, Dear Father,
Please don't let tomorrow be the start of another flare.*

*If tomorrow I should awake and my disease has brought me down,
I ask that you just let me heal, I promise I will come back around,
And when this comes to an end again,
I'll be me with a great big smile, my friend.*

*Yes, I have an invisible disease,
Wreaking havoc inside of me,
I hope this helps you understand,
Life with auto-immunity.*





You Hear It All the Time!

Written by: Kathi Harpst

You hear it all the time...don't stress! But, what does that mean? Does it mean that I am over reacting in negative situations? Does it mean I'm just completely hyperactive? What does it mean? And more importantly, what do I do about it? I've got drugs, but they don't help. I've got friends, but they don't help. I can clean the house. I feel better about my cleanliness, but that doesn't help either.



Sometimes, when we're really busy with good and bad situations and activities, we forget to look inside. There has to be a balance. What do we need to reduce stress?

- Have good friends.
- Have a good support group.
- Exercise.
- Eat right.

- Take a warm bath.
 - Drink a cup of tea (not green!).
- But, what haven't they told us?
- Sever poisonous relationships if you can. (That'll save you about 20 years of aggravation and reduce your doctor visits by about 20%.)
 - Take a drive in the country. Let someone else drive. You just listen to music. Look out the window.
 - Talk to your kids/mom/dad/friend/cat/dog while looking him/her in the eyes. Remember, they own their lives, experiences and feelings; you own yours.
 - Fall in love with yourself. You have so much energy, love and compassion to offer. Don't you love others who have these characteristics?
 - Take a nap all curled up under the covers. Gently allow your muscles to relax and bask in the warmth. (Those of us with Raynaud's know what this is

all about!)

- Sit and don't think! Listen to yourself. You've listened to others. Just take a moment to listen to yourself. Feel your body, in your mind, from head to toe. Check it all out. Give yourself a 120-point, full-body inspection.

Do you hear it? You can hear your loved one and all that he/she says. You can see the sun shining, the snow falling, the rain blurring. Watch the leaves. See them dance in the sky. Watch the fireflies as they light up your night. Take your time and enjoy that ice cream cone. Can you taste the vanilla beans? Smell them? See them? (Okay, then you're not eating Breyers!)

Notice, you can hear yourself. You learn to feel the flare when it's beginning. You can hear what your body is telling you to do to take care of yourself. Listen to yourself. Give yourself the same respect you give to those you love.

Regroup, rethink, rebuild and DON'T stress!

Your 5 Worst Memory Problems...SOLVED!

Submitted by: Tina Pohlman

Different types of memory issues call for different techniques, says Scott Hagwood, a four-time winner of the USA National Memory Championship and author of *Memory Power* (Free Press). These are his tips for downloading the most reluctant information from your mental files.



1. **Names:** The mind remembers visuals best, so put new names to paper. Read what you've written again before bed and it will stick in your mind better. Also, say the name aloud, which gives the brain another route to recall.

2. **Directions:** If you're like most people, you're able to recall only the first two steps in a set of directions. To remember more, try the Roman room method: Picture your bedroom, and link movements through the room to those that will take

you to your destination. "Turn left and go two lights," for example, might translate to pivoting left at your sock drawer and then pulling out two socks.

3. **Where you put your keys:** Train yourself to put glasses and keys in the same spot every time. It's only the only way to consistently remember because you always have more important things on your mind when you set them down.

4. **Where you parked:** As you walk away, turn around and look at the location of the car to lock a visual image of the environment into your mind.

5. **Why you're here:** You just came upstairs - but why? Think back to where you started and try to recall what was on your mind at that time. Better yet, carry something in your hand that reminds you of your mission, such as a pencil or hanger.

Source: Family Circle - September 2006

PhoneRaiser

Written by: Heidi Ponagai

We have started a new fundraiser for 2007. We are collecting used cell phones and ink cartridges. This is another easy way to donate to and support the APSFA without making a monetary donation.

The average American family has 3 old cell phones in their home.

Phoneraiser was founded in 2003 to provide an environmentally responsible way to raise funds for a wide variety of organizations.

Phoneraiser campaigns are good for our environment because all collected cell phones and electronic devices are either refurbished or disposed of using only the most ecologically sound methods.

Contact us for more information about collecting phones for the APSFA in your area.





A Husband Recalls His Wife's Year Living With APS

Written by: Mike Stuart

When I think of APS, I recall our family dealing with a mysterious illness which caused my wife to experience aches, pains, and temperature fluctuations day and night. It was a heart-rending experience to watch her trying to figure out and manage the various symptoms. We all knew it was undoubtedly difficult to be in her skin. Much like the seven-headed *Hydra* in Greek Mythology, the symptoms of her illness manifested themselves nearly daily, and with intensity that was hard for all of us in her family to live with. It is often noted that patience is a virtue. Such a virtue is much needed when dealing with an unrelenting illness. A typical day with my wife included us wondering if she would pass out, have a migraine, miscarriage, or some other medical emergency. Those fears exacted a toll on the family, as we were all uncertain as to what was going on. We all wondered what, if anything, we could or should do, and whether she would lose her ability to function

as a mother, wife, worker, and the overall active person she desired to be. So this was a sketch of what our family faced on a daily basis prior to medical diagnosis and treatment of this illness known as APS.

Due to the highly painful and frustrating experiences associated with her illness, she and I went to several doctors to try and figure out what was going on. Well, I can't say the answer came quickly, because it didn't. Not too many physicians are aware of the pattern of symptoms that make up APS, so naturally many overlooked the diagnosis, or simply weren't aware with what they were dealing. These frustrations and fears of losing control of one's body, and to some extent one's mind, led my wife to devote herself to work with a team of persons who have experienced the illness first hand. She, as well as the others, have recounted their experiences,

educated themselves as to the nature and extent of APS. They do this so they can educate the public regarding the symptoms, experiences, and resources needed to manage the symptoms of APS in a healthy manner.

Each evening and sometimes on weekends, and yes— even holidays, I over-hear my wife and the team of APS devotees working on ways to build awareness of this illness. I am in awe of the time that she and others devote to those in need of answers regarding this illness. I applaud her and those with whom she works for the education, support, and resource linking they give to those long-suffering like my wife. It is fitting that I am writing this article on New Year's Day, for as with the new year comes the hope that many more who suffer from this illness may find relief from the anxiety and despair of this illness through the unrelenting efforts of my wife, and all those who contribute to the APS Foundation of America.

"A typical day with my wife included us wondering if she would pass out..."

From the APSFA FAQ Webpage:

I've been diagnosed with APS. What are your thoughts on nutrition and exercise to help with this condition?

There are no specific diet or exercise guidelines for the APS patient. If you have APS, you're at heightened risk for problems involving the heart, lungs, and circulatory system. That means you should follow lifestyle guidelines calculated to minimize risk to those parts of your body, and they are essentially the very same guidelines that have been



widely publicized for people who are known to suffer from high blood pressure, high cholesterol, and familial tendencies to overweight and/or diabetes.

To wit: Don't smoke. Avoid heavily sugared and heavily salted foods, and foods containing (or prepared with) saturated fats and trans fats. Eat a generally well-balanced diet, being sure it includes fruits, vegetables, and fish (if you're a vegetarian,

talk to your doctor about supplementary omega-3—and while you're at it, ask your doctor's advice about a multivitamin supplement). Keep your weight within the range your doctor says is right for you. Engage in moderate but regular exercise (needn't be a formal program; do whatever you enjoy, but DO it), which is good for weight control, keeping bones strong, and circulation generally.

Vitamin K and Warfarin

Written by: Al Lodwick, RPh, MA

Sconce et al (Blood. 2006 Nov 16; [Epub ahead of print]) studied 70 people randomly assigned to receive vitamin K 150 micrograms (mcg) daily or a placebo in an attempt to learn if this would stabilize International Normalized Ratio (INR) numbers. The theory behind this is like entering a dark room. If you turn on a 30 watt lamp in a 3-way bulb, you notice a large increase in the amount of light in the room. If you then switch to the 60 watt lamp you notice a lesser increase in the amount of change. Switching to a 90 watt lamp causes even less of a noticeable increase.

At the end of the six month study, they compared the INR levels during the study period with those from the six months before the start of the study. Of the 35 people who got the vitamin K, 19 were found to have stable INRs. Of the 33 people in the placebo group, only 7 had stable INRs. The authors conclude that supplementation with vitamin K may help stabilize the INRs of people

who have unexplained fluctuations.

Going back to the light bulb analogy; if you took in no vitamin K for a period of time and then suddenly took in a moderate amount, the change would be dramatic. However, if you were always taking in some vitamin K then the same shift up or down would be a lesser percentage of change.

Of course your warfarin dose will have to be increased, so do not try this without routine monitoring.

This information is from a pharmacist and is not intended to replace consultation with your physician. In accepting this information you agree that its misuse by you does not create liability on the part of the sender.

To see our line of "Had you had your rat poison today" merchandise please click on www.cafepress.com/warfarinfo





Striving for Quality Advance Care Planning

Written by: Linda Briggs, RN, MS, MA

Associate Director Respecting Choices® and Ethics Consultant



What does it mean to do advance care planning well? One would hope that the question yields a uniform response based on best practice and consensus. Recommendations are emerging on

the elements necessary for successful advance care planning programs.¹ Embracing these will not be easy and will require a cultural shift and commitment to change and leadership. There are many individuals and teams across this country and beyond who share this vision of advance care planning, are leading the cultural shift, and are making a difference.

The first important issue we need to acknowledge is that advance care planning is a process of communication and not an event of signing a written advance directive. Too often, consumers complete advance directive documents, such as a "living will" or "power of attorney for healthcare" without understanding what a quality document should consist of. They often have a false sense of security that their true preferences will be honored. To be most effective, advance care planning communication needs to include the purpose of advance care planning; information about the many choices to consider to create plans that reflect someone's goals, values, and beliefs; and encouragement to reflect on their choices prior to making decisions. In addition, effective advance care planning communication involves the chosen health care surrogate and other loved ones in ongoing discussions. This focus on communication means engaging people in the advance care planning process well before a medical crisis, well before admission to the hospital or scheduled surgery. We would develop a community engagement campaign to normalize advance care planning as a component of good, preventative health care. Individuals would be exposed to health care planning in the communities in which they live: schools, churches and synagogues, cultural and ethnic groups and in the organizations in which they receive health care: clinics, assisted living, and long-term care

facilities.

Second, we need to educate professionals how to facilitate individualized and appropriately timed advance care planning discussions.² We would challenge the current trend to view advance care planning as merely distributing written materials or asking the mandated question on admission, "Do you have an advance directive?" We would realize that advance care planning is not a "one size fits all" conversation, and we would shift to teaching the advance care planning facilitation skills necessary for different groups of individuals. Included in this group are the healthy adult; the adult with chronic, progressive illness; and the adult who we would not be surprised to die in the next 12 months. We would also see the need to create a team of advance care planning facilitators who work together to identify the needs of the individual, make referrals to one another, and re-engage with individuals as their illnesses progress or their goals and values for living well change. Advance care planning facilitators would become an integral component to health care delivery and would be available when needed.

Third, we would develop systems in our organizations and communities that are capable of insuring that peoples' preferences for future health care are honored. We would reject the current reality of documents that are inaccessible, ambiguous, or unclear, or do not accompany the patient upon transfer. We would shift our efforts to creating policies, practices, and tools that help busy professionals do the right thing. We would promise that written plans are accessible wherever needed, that preferences get transferred to physician orders that are universally recognized in the community, that written plans are transferred with the patient throughout the health care continuum, and that advance care planning discussions are documented and used to continue the process of health care decision-making. We would develop quality improvement programs to monitor ongoing activities and make improvements when necessary. And last, we would have systems that recognize when a patient's preferences are not honored and create

solutions to prevent future medical errors.

Fourth, we would realize that this vision is not only advantageous for the community we serve, but also for the professionals who work diligently to help patients make informed health care decisions every day. This vision of advance care planning can bring health professionals back to the essence of caring, of why they entered health care. In my experience facilitating advance care planning discussions with patients with chronic, progressive illness, I have been rewarded in many ways. They have been eager to share their fears, hopes and concerns, and have taught me how important it is to provide the opportunity for such important conversations.³

Respecting Choices® advocates such a vision for creating an advance care planning program, one that is based on experience and research. Since 1993, the La Crosse, Wisconsin-based advance care planning program has demonstrated success.⁴ Data about advance directives and end-of-life decisions were collected by evaluating 540 adult deaths from April 1995 until March 1996 from a population of approximately 95,000 people. These deaths occurred in the community's two hospitals, six nursing homes, and three home health/hospice organizations. Of these adults who died, 85% had written advance directives and 96% of these documents were in the medical record. Of those who had advance directives, 98% of the decisions made at the end of life were consistent with written directives. Respecting Choices has developed a national curriculum to assist other communities to replicate the principles inherent in achieving quality advance care planning outcomes.

For more information about Respecting Choices® please contact Matthew Isbell at (800)362-9567 x54887 or email him at: mrisbell@gundluth.org

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