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The Advocate

RECOGNIZING INDIVIDUAL NEEDS ... Exceeding Expectations

Specialty Therapeutic Care is an organization dedicated to meeting the specialized needs of individuals with chronic or life threatening disorders. Through high quality care management, we continually devote ourselves to provide efficient and compassionate treatment that extends beyond traditional service parameters by actively working with patients, physicians, health plans, patient advocacy organizations and pharmaceutical companies we serve.

What Next...Stress

By Dr. Mike McNamara

Stress is something we all hear about, something we all experience. Hemophilia and other bleeding disorders bring stress with them. Financial, emotional and physical are the big three. There is also stress in personal, family and professional relationships.

Typically we see stress as "bad" and no stress as "good." There are actually two types of stress identified by the experts. We all know about distress, the kind that leads to worry, eating problems and short tempers. The other kind of stress is called eustress.

Eustress is the kind of stress that occurs when something positive is happening. A promotion at work brings eustress, where a demotion causes distress. A vacation brings eustress, working overtime brings distress. Winning the lottery brings eustress (not that I would know about that though!) while getting one of "those" notices from the bank brings distress. What all this means is that, stress happens!

It is sometimes hard to accept that stress is present in all aspects of life. Stress is what makes trees strong. If a tree is staked out and not allowed to move in the wind, it is actually more vulnerable to breaking as it grows. In



the same way, building muscles requires stressing the tissue so it will rebuild stronger.

In the middle of the stress, it is often hard to realize that the stress we are experiencing is actually going to make us stronger. We actually prefer to escape the stress and the causes of the stress. It is only later that we can look at the stressful situation and say, "I actually grew from that situation."

The challenge comes in trying to keep an attitude that says, "I can grow from this situation." The art of stress strengthening is to apply stress in the best manner for the

appropriate length of time. With real life, we don't always get to control all of the aspects of stress. This is where our attitude toward stress is what makes the difference in our experience.

I recommend that people acknowledge the stress they are experiencing. Identify the real source of the stress. Look for positive solutions to the stress. Write these things down, they can be the road map for you to follow as you work through the situation.

Once the stressful situation is passed, take some time to look back and see what you learned from it. How did you grow? What would you do differently next time? Can you pass this knowledge on to others? Is there a way to anticipate this kind of stress in the future?

I encourage people to take time to celebrate some after a stressful situation is resolved. This doesn't have to involve spending a lot of money. It is an acknowledgement that something that was difficult has been completed. Celebration is an attitude. Celebrate that you are now stronger for finding a way through the eustress or the distress.



How do you move from raising and supporting your adult child to releasing them into the world, letting them go whether they fail or succeed? How do you move them from being on your insurance to assisting them with their own? How do you preparing them for the life of Hemophilia without you? Not that you won't be there for your son or daughter in the future, but you need to prepare them for what may happen when you are no longer around or are unable to help with their needs? You have to let them go at some point, but at the same time you want them to succeed. What is the best

way for you to do this? Here is the question of the year!

First of all, encourage your child to go to college. Life with hemophilia is hard enough, but finding insurance as an adult without a college degree is even harder. Some parents keep their child on their insurance until they either have completed college or until they are at the age limit for their state, to allow their child the time to find a career. The last thing we all want is for an insurance company to tell our child that they have a pre-existing condition that cannot be covered because insurance has lapsed. We must teach and support their success with insurance and life.

Also, help your child become more involved in the community, whether it is with

hemophilia camps, support groups, or speaking at your local chapter meetings. Your adult child has the opportunity to share their experiences of living life with hemophilia with younger generations, and just as they would have appreciated it, so will the younger kids. Help them strive to become the best they can be. Get them involved in the National Youth Leadership Council when they are teenagers so that when they are ready to leave home, they will be better prepared. You have the opportunity to bond by participating together in the hemophilia community. Parent support groups may be an avenue for you to share and perhaps in your own way to find the answer to the question of the year!



Hemophilia Walk

Specialty Therapeutic Care had a team that participated in the Hemophilia Walk in Houston, Texas on September 19, 2009. Our team had over 150 walkers and raised \$4,529.00. Specialty Therapeutic Care was also a sponsor of the event. We want to thank everyone who participated in this successful event that raised over \$170,000.00. This is another example of what Specialty Therapeutic care and the community can do for the future of hemophilia.



Picture: (left to right) Matt Angell, Mercedes Calderon, Jose Calderon, Charlene Signorino

Texas Conference - "Cowabunga Awesome!"

By Lisa Ryan

The year was 1993. Teenage Mutant Ninja Turtles III was still the excitement at my house. The ad read, "without a map, without a clue, without a pizza." We didn't have a map. We didn't have a clue. We did have lots of pizza!

My son Patrick had been diagnosed with severe hemophilia A. My husband and I were scared and lost. We found out about an upcoming hemophilia meeting. One of the best decisions we made was to attend the meeting. We drove through the night with our three boys in tow. The National Hemophilia Foundation (NHF) accepted us with open arms. Childcare was provided so that my husband and I could attend educational seminars and group sessions with other parents. Through the years, the programs offered by NHF are the ones that made the difference. They empowered and educated us. We made lifelong friendships. We came out of our "shells."

Sixteen years later and only 20 miles away, the Lone Star Chapter of NHF held the 1st

annual South Texas Bleeding Disorder Conference. The weekend retreat was another opportunity to get better informed and to meet new families. Just like my experience in 1993, families were embraced and given opportunities to get answers and find support. I met new families. I reunited with families of the past who are now like my own family.

The sessions included but were not limited to Genetics, Insurance, Meet the Manufacturers and breakouts. No matter how many hemophilia meetings I attend, I always come away with new helpful information. My favorite sessions are given by the people living with hemophilia and their families. The mom that shared her story about using video game incentives to infuse her son brought back memories. I learned that the Houston area has developed a group of doctors (Hematologists & Gynecologists) that worked together to coordinate the care of a woman with a bleeding disorder. I was thrilled to learn about Hemophilia Walk

2009 and the opportunity to raise money for a good cause-OUR CAUSE!

These meetings are not possible without sponsorship. Specialty Therapeutic Care was a major sponsor of this event. This is another example on how STC continues to give back to the community. Debbie Delariva, Melissa & Brian Compton and their immeasurable staff and speakers made it look easy. I can't imagine the countless hours that went into preparing for the weekend.

The final night event included a free trip to SeaWorld! We were given a family picture as a souvenir. Maybe I'm a little biased because the meeting was in my hometown of San Antonio, but I thought the meeting was "Cowabunga awesome!" For more information on future meetings and/or events contact the Lone Star Chapter at (713) 686-6100 or www.lonestarhemophilia.org.

Matt's Pharmacy Corner

Speak Up...Help avoid mistakes with your medicines!

The following is information Matt thought you might find interesting and useful.

Medicine mistakes happen every day at the doctor's office or hospital, even at home. You can get the wrong medicine. Or, you can be given the wrong amount of medicine. This brochure has questions and answers to help prevent mistakes with your medicines.

Who is responsible for your medicines?

A lot of people—including you!

- Doctors check all of your medicines to make sure they are OK to take together. They will also check your vitamins, herbs, diet supplements or natural remedies.
- Pharmacists will check your new medicines to see if there are other medicines, foods or drinks you should not take with your new medicines. This helps to avoid a bad reaction.
- Nurses and other caregivers may prepare medicines or give them to you. You need to give your doctors, pharmacists and other caregivers a list of your medicines. This list should have your:
 - prescription medicines
 - over-the-counter medicines (for example, aspirin)
 - vitamins
 - herbs
 - diet supplements
 - natural remedies
 - amount of alcohol you drink each day or week
 - recreational drugs

What should you know about your medicines?

- Make sure you can read the handwriting on the prescription. If you can't read it, the pharmacist may not be able to read it either. You can ask to have the prescription printed.

- Read the label. Make sure it has your name on it and the right medicine name.

- Make sure that you understand all of the instructions for your medicines.

- If you have doubts about a medicine, ask your doctor, pharmacist or caregiver about it.

What if you forget the instructions for taking a medicine or are not sure about taking it?

Call your doctor or pharmacist. Don't be afraid to ask questions about any of your medicines.

What can you do at the hospital or clinic to help avoid mistakes with your medicines?

- Make sure your doctors, nurses and other caregivers check your wristband and ask your name before giving you medicine. Some patients get a medicine that was supposed to go to another patient.
- Don't be afraid to tell a caregiver if you think you are about to get the wrong medicine.
- Know what time you should get a medicine. If you don't get it then, speak up.
- Tell your caregiver if you don't feel well after taking a medicine. Ask for help immediately if you think you are having a side effect or reaction.
- You may be given IV (intravenous) fluids. Read the bag to find out what is in it. Ask the caregiver how long it should take for the liquid to run out. Tell the caregiver if it's dripping too fast or too slow.
- Get a list of your medicines—including your new ones.

Read the list carefully. Make sure it lists everything you are taking. If you're not well enough to do this, ask a friend or relative to help.

Questions to ask your doctor or pharmacist:

- How will this new medicine help you?
- Are there other names for this medicine? For example, does it have a brand or generic name?
- Is there any written information about the medicine?
- Can you take this medicine with your allergy? Remind your doctor about your allergies and reactions you have had to medicines.
- Is it safe to take this medicine with your other medicines? Is it safe to take it with your vitamins, herbs and supplements?
- Are there any side effects of the medicine? For example, upset stomach. Who can you call if you have side effects or a bad reaction? Can they be reached 24 hours a day, seven days a week?
- Are there specific instructions for your medicines? For example, are there any foods or drinks you should avoid while taking it?
- Can you stop taking the medicine as soon as you feel better? Or do you need to take it until it's gone?
- Do you need to swallow or chew the medicine? Can you cut or crush it if you need to?
- Is it safe to drink alcohol with the medicine?

The above information has been provided by the Joint Commission.

www.jointcommission.org



Fact-or Fiction: Hemophilia Trivia

What does MASAC stand for and what do they do?

MASAC is the Medical and Scientific Advisory Council and they help to establish

quality of care guidelines for the treatment of hemophilia and other bleeding disorders. Find out more at www.hemophilia.org

What is HANDI and how can I get information from them?

Since 1991, HANDI has grown to become a full-fledged resource center for coagulation disorders. Its primary objective has always been centered on service – answering con-

sumer's questions, providing quality educational publications, making referrals to additional sources of assistance and responding to the needs of the entire community.

They can be reached at: 1-800-42HANDI or email at handi@hemophilia.org. Requests can also be faxed to (212) 328-3799.

What is hemophililia.org?

It is the web site to find out anything you want to know about the National Hemophilia Foundation, try it out sometime. If you don't have internet access, call HANDI and they can send you information in the mail.

What is hemophiliafed.org?

It is the web site for the Hemophilia Federation of America whose mission is to assist and advocate for the bleeding disorders community and the do this by making sure that the bleeding disorders community has removed all barriers to both choice of treatment and quality of life. It is a great web site too, you should check it out!

What is SweetAffliction.com?

It is an awesome website with great articles about living with hemophilia. Check it out at

www.sweetaffliction.com

“Hemophiliac”

By Mindy Ritchie

I am the mom of an “almost ten year old” as he tells me, with severe hemophilia A. I do not and will not call him a “hemophiliac” as so many of the “older” generation with hemophilia call themselves. I just can’t get past the label, nor do I want others to get stuck on the label, before they get to know him.

You see, when I was student teaching in South-east San Diego, back in 1989, I took a class about “person first labeling.” I was taught that if you put the label, any label, **before** the person, then you are making it harder for that person to live their life. People hear that label, and then that is the first thing they will always think about when they refer to that person. Would you rather be known as, “Joe – who just happens to have hemophilia” or as a “hemophiliac” named Joe?

I suppose this has become sort of soapbox for me, in the hemophilia world. I don’t want my son, or any boy with hemophilia to be called a hemophiliac, simply because when people hear this they begin to see this as who the boy is, instead of all of the other wonderful qualities that make up the “whole” person.

I have long held this belief, and each time I have attended any sort of national event like the NHF Annual Meeting and heard the men with hemophilia referring to themselves as “hemophiliacs” it always made me cringe. How could they use this label on themselves, I would wonder? I have talked to many men about this and have come to understand that it is a sort of generational difference. Our society, and doctors for that matter, used to label everyone. He is a hemophiliac, an asthmatic, a down’s baby, and so many other labels. It was easy for doctors to label people that way, and we, as a society, used to just accept it. Some men with hemophilia have let the label become a crutch, a sort of excuse for them; some have chosen to rise above it and not let it hold them back.

I have been lucky enough to meet so many men with hemophilia, who call themselves “hemophiliacs” but have not let it get them down, and have instead gone on to become successful students, husbands, fathers and contributors to society. They have chosen to rise above the label that society and doctors have put

on them and to just be whoever they are. I understand the generational differences. They were “given” this label and have had to live with it, rise above it, and become successful despite it. But I say, “Why should we strap the younger generations with hemophilia with this label?” Yes, they are boys (and even some girls) with hemophilia, but they also happen to be athletes, students, artists, scientists, comedians, writers, musicians, etc. Let us let them be a person first, a person who just happens to have hemophilia!

Mark Your Calendars:

Lone Star Chapter of NHF

Family Camp

Camp for All

October 2-4, 2009

Tex Cen Chapter of NHF

Hearts for Hemophilia Gala

Dallas, TX-Omni Dallas Park West

October 3, 2009

Tex Cen Chapter of NHF

HTC Education Day

Dallas, TX

October 17, 2009

NHF

61st Annual Meeting

San Francisco, CA

October 29-31, 2009

Bleeding Disorder

Foundation of WA

Annual Meeting

Edmonds, WA

November 7, 2009

Texas Central East

Holiday Party

Tyler, TX

November 14, 2009



Manufacturer’s Symposium & Ballgame

September 27, 2009 Dallas, TX

Left to right: Patricia Espinosa-Thompson (Baxter)

Steve Henson (Bayer)

Randy Smith (Baxter)

Shane Melton (CSL Behring)

Shelly Embry (TX Central Hemophilia Assoc., Dallas)

Charlene Signorino (VP of Specialty Therapeutic Care)

Debbie Nelson (Wyeth)

Oregon Annual Meeting at the Zoo

By Charlye Perry



Every year in September, the Hemophilia Foundation of Oregon has a meeting at the Zoo in Portland. What a fabulous way to spend the day! Everyone has the opportunity to gather informational material, visit with their favorite home health care company, such as Specialty Therapeutic Care, and view pictures from kids camp through the eyes of their children via a DVD. This year was a huge success, I can’t wait until next year!

Developing a Stronger Sisterhood

By Charlye Perry

The hemophilia “brotherhood” has come a long way and is a fabulous means for the guys with hemophilia to share and support each other. Now, we women with bleeding disorders have the opportunity to develop a large “sisterhood” allowing us to form new friendships and support each other in a group environment. Women have unique circumstances to deal with and we share different needs and experiences. Check with your local chapter for a Women with Bleeding Disorders group in your area. Contact Specialty Therapeutic Care and NHF for more information.



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WE ARE MOVING!

Effective November 16, 2009

Our new address:

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