

HEMO HINTS

Be a role model.

Children will do what you do. If you wear your helmet during physical activities such as bicycle riding, they will also!

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INALEX EXCHANGE

A MONTHLY NEWSLETTER DEDICATED TO FAMILIES LIVING WITH A BLEEDING DISORDER

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Caronna's Corner

Joe Caronna—President, Inalex Communications



After getting the kids settled back into their school routines

and extra curricular activities, the harsh reality that the cold north-eastern winter is on it's way, hit me hard. The days are getting shorter, it gets darker and darker earlier and earlier, and the nights are starting to get colder and colder.

While the trees change colors, and they are certainly beautiful and make for nice weekend viewing, the reality is that it won't be long before they are bare and we see the first signs of winter peeking through. It can be easy to get a little blue this time of year, and decide to just sit in front of the TV and wait for spring to arrive once again.

On the other hand, this may be the perfect time to get involved in projects with the family. Whether it is outdoor leaf raking, planting bulbs for spring, or fixing up things around the home that were neglected during the summer, this is a great time for the whole family to spend time together and bond.

Sometimes, in families with children with chronic diseases such as hemophilia, we tend to concentrate on the special needs and neglect to focus on the needs of each other. Benjamin Franklin said the only things a person can be sure of in this world are death and taxes. It should be noted that a third sure thing exists. This third

reality is family stress and it involves change. Children change, parents change, often for the better. But we are also expected to endure those not-so-pleasant life events such as managing the issues surrounding hemophilia in the family. Certainly, these events may bring about feelings of hurt, frustration, anger, and depression. We may also experience marital conflict, sibling conflict, or parent-child conflict, all in response to family stress.

As father, husband, son and sibling, we need to be aware of this. I've seen many cases of families breaking up because of the stress of the chronic disease on the family dynamics. For example, in some families, dad and mom may be playing the "blame game". In all probability most people have heard that phrase more than once in their lifetime – "It's your fault!" No matter who says it, the recipient is usually annoyed by the innuendo that they have done something wrong.

It seems that no one likes to be tagged by a fickle finger pointing at them and blaming them for something. Do you play the Blame Game in your relationships? Well, I can tell you that nothing good comes out of playing this "game", so don't fall into this trap.

We all know that raising a child is a joint effort, and this is a time to work together, not tear apart. I see too many relationships in the bleeding disorder community end in separation because the dad is

playing the blame game, or "too busy" to help care for the child. Open dialogue is difficult but essential in these times.

Inalex Communications has developed numerous workshop, led by subject matter experts, to help address some of these issues. The one day workshops, sponsored by Baxter BioScience, assist in opening up the lines of communication, as well as help to guide us to learn how to better deal with the stress of caring for a child with a chronic illness. Some of these workshops include "Building Strong Relations for Couples", "Discovering Positive Lessons in your Life", "Stop the Worry-Stop the Stress", "Parenting on the Same Page". In addition, we offer numerous workshops for men only, teens only, father and sons, as well as a new 2009 workshop for siblings.

Developing skills to respond to family stress occurs over time. How successful the families are, is based upon what they do, and how they use the resources both from inside the family and throughout the community. It is the action the family takes to remove the stressors, and live with the hardships, and Inalex is dedicated to continue to develop new resources in response to a the issues we face within the bleeding disorder community. So do things as a family. Reach out to the community. Take advantage of the resources. **Then sit back and enjoy the change...together!**



“Despite continued caution from the massage community, healthcare professionals are now indicating that massage does in fact, have a place in the comprehensive care of hemophilia patients.”



Meet the Inalex Faculty: Massage Therapist - Avi Penhallow



The professional massage therapy schools currently indicate that massage therapists should avoid working on persons with hemophilia. The bleeding disorder is considered a general contraindication due to potential risks of injury or exacerbation of an existing condition for clients.

However, there is also an emergent interest in the possibility that those who are affected by hemophilia can benefit from massage therapy.

As further research is being conducted commensurate with specialized training in accommodation techniques, more knowledge will be gained about the efficacy of massage therapy for people with hemophilia and other bleeding disorders.

The standard medical treatment for patients with hemophilia is prophylactics and blood clotting agents. However, healthcare providers are increasingly recognizing the need for complimentary therapeutic methods to ensure the most comprehensive treatment for their patients. Clients with hemophilia may be referred to physical therapists by their primary physicians to strengthen muscles and maintain joint flexibility. Mental health professionals such as psychotherapists are often called upon by patients to assist with the management of emotional, social and psychological issues related to their medical conditions.

Additionally, people with bleeding disorders may seek alternative therapies, such as

therapeutic massage and yoga therapy, for relaxation and pain management.

Increased interest in complementary and integrative medicine within the American culture has opened new doors for the hemophilia community to obtain more holistic treatment and pain management options. A clear shift can be detected within the medical community, as evidenced by increasing numbers of health insurance policies which recognize the health benefits of massage therapy.

Currently, there are a handful of massage therapists that work exclusively with persons with hemophilia. However, the massage community at-large, continues to cautiously advise against massage therapy for clients with hemophilia, as concerns about legal liability for the massage therapist are considered.

Despite continued caution from the massage community, healthcare professionals are now indicating that massage does in fact, have a place in the comprehensive care of hemophilia patients. This is evident in literature from the National Hemophilia Foundation (NHF). In its, *Orientation Manual for Health Care Professionals*, the NHF describes the role of massage therapists and mental health professionals as instrumental in providing comprehensive care.

In the NHF Manual, 1995, it is stated, “Mental health professionals can help patients identify resources for other methods of pain relief, such as hypnosis and massage therapy”.

The future of comprehensive care in the hemophilia community could very well include the regular ser-

vices of massage therapists. One massage therapist, Renee Weaver, has in fact, dedicated much of her efforts to research touch therapy for clients with hemophilia.

Weaver is the founder of Touch Factor Foundation, a non-profit organization which provides programs in education, outreach services, and research in the use of massage therapy techniques for people with hemophilia and other bleeding disorders. Since 1996, the Touch Factor Foundation has pioneered a protocol to safely and effectively bring the benefits of therapeutic massage to an untouched community in order to improve their quality of life.”

Certainly, massage and bodywork for clients with hemophilia would require specialized modifications and accommodations. These modalities would ideally be developed and taught at certified training centers, such as massage therapy schools in the future. In doing so, such institutions could literally touch a community that is often advised against participating in many activities considered “dangerous”.

As massage therapy for hemophilia evolves from a “contraindicated status” to a “specialized comprehensive care status”, it will become a springboard of sorts, for other communities that would benefit from the healing touch of massage therapy.

Avi Penhallow is co-founder of Pangea Integrative Therapies, LLC, located in Denver, Colorado. He is a massage therapist, trained at the Colorado School of Healing Arts.

Spotlight on Men in our Community - Dave Burgeson

This month, the Spotlight is on Dave Burgeson of Naples, Florida

I was born in Albany, NY a very long time ago ;0) I attended the State University of New York in Buffalo and took a job in banking that I enjoyed. I was well settled into my Western New York life, meaning I loved the summers, endured the winters and was a proud Buffalo Bills fan. I thought I was set...until I attended my ten year high school reunion in Suffern, NY.

During that weekend event I spent time with an old friend from my high schools days and we hit it off as we never had before. One year later that high school friend and I were married and Barbara moved to Buffalo with me. It wasn't long before we discovered my new bride was not as tolerant of WNY winters as I was and we were on our way to Naples, FL where we have lived for the last twenty years.

In 1992 our son Eric was born. Eric's was a difficult birth and the staff at Naples Hospital were completely baffled when our son kept bleeding as a result of some rough treatment with the forceps. They ran tests, including a spinal tap, and called in for second, third and fourth opinions.

Eventually, he was transported to All Children's Hospital in St. Petersburg, FL. In St. Pete, and hemophilia was immediately suspected and tested. I told the doctor that it wasn't hemophilia because there was no hemophilia in either of our families. That was the limit of

my knowledge and turned out to be wrong. There was no history of hemophilia in our families but Eric's diagnosis was severe Factor VIII deficiency, and our lives changed.

Barbara and I spent the next seven days and nights in "All Kids" and Ronald McDonald House as Eric recovered from the nearly fatal blood loss. We sat in the cafeteria or ICU and we talked. We knew that our lives would never be the way we had envisioned. We knew we were being challenged in a way we had never anticipated.

We eventually got over the shock and I accepted that football wasn't likely to be in our son's future. We also realized that we had a lot to learn. We shared the news with our disappointed and concerned family and we called our insurance company.

Slowly, I began to recognize that following close on the heels of accepting the diagnosis, I was feeling an unexpected satisfaction. I was satisfied to think that our little family shared the responsibility of dealing with a rare disorder. I felt all the expected fear and anxiety but without a doubt, I felt a certain hard to describe satisfaction that we had a special son and we would find a way to handle it.

Within weeks of returning home with our new child, we were visited by a young man from our neighborhood. Glen had hemophilia, he was fun, intelligent, a happy guy who told us that Eric's future was bright. We spoke for hours about how his folks had divorced in order for him to qualify for government

health care. He shared with us the difficulty of succeeding at school when he missed so much time due to his bleeds. He told us a lot about the challenges he faced but he left us feeling optimistic about the future.

Glen also told us that our son would almost certainly not have to deal with the viral issues that right then were devastating the hemophilia community in a way that has accurately been described as a holocaust. He described how the factor concentrate products had improved and we may be able to keep Eric from ever having joint damage. He told us that the future was bright.

We remained friendly with Glen for the next few years. His outlook remained positive until the end came, just a few short years later as a result of AIDS.

Three months after Eric was born, our thirst for information sent us to our first NHF annual meeting. At this meeting we began to embrace the opportunities that Eric's diagnosis offered to us. We became involved with NHF and with our local chapter. Barbara eventually served as volunteer president of the Hemophilia Foundation of Greater Florida for five years and I became chauffeur and chief box and bag carrier for her to the events and meetings which were mandatory part of her position.

Through that involvement, we came to know a great deal more about hemophilia and about the community of individuals who make it up.

We lived through some terrible
(Continued on Page 4)



“We eventually got over the shock and I accepted that football wasn't likely to be in our son's future. We also realized that we had a lot to learn.”

This newsletter has been made possible by a generous grant from

Baxter

2008 Workshops

01/19 - Laguna Beach, CA
02/02 - Dayton, Ohio
02/23 - Orlando, FL
03/01 - Charlotte, NC
05/31 - Rochester, NY
06/14 - Toronto, Canada
07/24 - Lincoln, NE
08/16 - Tampa, FL
09/13 - Keniwick, WA
09/19 - Scotrun, PA
09/21 - Richmond, VA
09/27 - Chicago, IL
10/11 - Scottsdale, AZ
10/18 - Montgomery, AL
10/26 - Santa Fe, NM
11/08 - Newark, NJ
11/13 - Denver, CO

For information or to inquire about having a "no-cost" workshop for families living with bleeding disorders, please go to www.inalex.com, call 201 493 1399 or Email: Joe_caronna@inalex.com

Spotlight on Men in our Community - Dave Burgeson

times with the rest of our bleeding disorder community as each meeting became a time to discover who would not be making the meetings anymore. It remains a sad fact of life that many within our community live a precious life monitoring their health with a very cautious eye.

Eric was born into the time of safe factor and has been an example of what is available to today's generation of children and young adults with hemophilia. A life full of promise and potential. Not that we haven't spent time fruitlessly arguing with Emergency Room staff that factor, before x-ray, is more than just a saying, as well as dealing with the occasional teacher who needs to be brought up to speed about our child's condition (*thanks for the handy DVD Inalex!*).

I must say that we are coping

and much more than coping. Eric takes on more responsibility for his condition all the time. He's a terrific student and spends free time with a wide variety of friends.

As a junior, Eric is captain of the varsity Scholar Bowl team, a member of both the National Honor Society and the Spanish National Honor Society and a competing member of the national math club. Most weekends find him with his girlfriend volunteering with a group of underprivileged children from the area.

Life is good and full of promise for the future. Barbara and I watch Eric mature and take his place among his peers. We think that his experience with hemophilia has helped him to grow into a sensitive and giving young man and we are so proud of him. We know he will work

hard to achieve his goals. He currently is interested in psychiatry and counseling.

It's been a long road, and we've met many good friend along our journey. I've learned that no two families are alike. Hemophilia is an equal opportunity disorder. Anyone from any financial situation, social condition, any color, or religion can be forced to deal with a bleeding disorder in their family. I have come to appreciate the scores of people I have met in the last sixteen years, and I appreciate the lessons that I have learned from them.

As Barbara and I now face the future, it certainly looks bright, for us as well as for Eric. And we, as a family, **together, we look forward to enjoying Eric's bright future !**

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