

## HEMO HINTS

Talk with your child's care team, including your child's health care provider, school nurse, principle, teacher, and school staff.

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# INALEX EXCHANGE

A MONTHLY NEWSLETTER DEDICATED TO FAMILIES LIVING WITH A BLEEDING DISORDER

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## Caronna's Corner - Back to School

Joe Caronna—President, Inalex Communications



**Ah September! The month of change. You can just smell it in the air.**

The days are beginning to get shorter and the evenings are starting to cool down.

While I will surely miss the long, warm lazy days of summer, I defiantly look forward to the Fall season. September means vacations are over, the pool is closed, and most importantly, my kids are back in school.

It's also time for me to get back on the road to present my workshops across the country. So far this year, Inalex has presented full day workshops in the state of California, Ohio, Florida, North Carolina, Nebraska, and Toronto, Canada. The remainder of the year will take us to Washington State, Virginia, Washington D.C., Pennsylvania, Illinois, Arizona, Alabama, New Mexico, New Jersey, and Colorado. Quite a number of workshops, and opportunities for us to provide education and support to our bleeding disorder community!

Inalex is not the only organization spreading innovative education and support throughout our community. We have numerous outstanding programs such as HFA's *Dads in Action*, the *NHF's First Steps* program, and HHS's *Kid's Karing* to name a few. There is certainly no shortage of hemophilia education if needed.

We've made great strides in edu-

cating our community. It's been a long but fruitful journey, but still, I'm shocked at the lack of knowledge in our society overall.

Just recently, I was presenting a workshop in a rather large city, when a hotel worker inched over to me and asked me what the topic of our meeting was. Not wanting to be untruthful, I told him that it was a workshop for people in the hemophilia community. "Oh, my friend's son has that. You could just put him in the middle of the room and he'll bleed", he said almost with a chuckle. I was shocked. Maybe because, for the past thirteen years, I've been living and breathing hemophilia everyday, and I forgot that not everyone knows what we know. But when I hear comments such as this, I'm quickly shocked into remembering that little is known about hemophilia in the general population.

This is unfortunate because we, as people living within the bleeding disorder community, still must live and be productive within the "real world", and yes, must interact with people who do not understand what hemophilia is. And some of these people are scared to death because we could just "bleed in the middle of the room".

Now it's September, and as parents of children with hemophilia, we face these fears and obstacles every year in school. I've noticed that the parents of children with hemophilia are especially stressed

out when their kids go back to school. Questions abound such as what would happen if my child gets hurt or has a spontaneous bleed in school. Will the teachers and school personnel know what to do? How can I educate them? Will my HTC or chapter want to send a nurse to the school to educate the school staff? If so, will that in itself frighten them? We all have heard or experienced the horror stories concerning children getting hurt while in school.

Recently, a parent in Alabama was tell me of an experience they had when their child with hemophilia got hurt playing soccer. The coach, unaware of the child's condition or unaware of the serious nature, demanded that the child continue, telling him to "walk it off" thus causing more damage to the injured joint.

In this day and age, and even with the advances in factor, as well as the use of prophylaxis, most school nurses, teachers and coaches just don't understand hemophilia.

So what do we do as parents? How do we educate the educators? Well to start, we can ask the Hemophilia Treatment Center nurse to make a visit to the school. This is a very effective way to educate the school personnel rather quickly and effectively. But what if you live outside of the HTC district in a rural area, and a HTC visit isn't

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Ron & Pat Potter-Efron  
are clinical psychotherapists  
on the Inalex faculty

***“One of the most important things you can do as a parent, teacher, or other adult in a child’s life, is to help them respect themselves and others, so they can be happy in the world.”***



***To receive a complimentary copy of “Angry Children”, please send email to [admin@inalex.com](mailto:admin@inalex.com) or call the Inalex office at 201 493-1399***

## Parenting Skills: The Angry Child - Ron and Pat Potter-Efron

**As we all know, children become angry in a variety of situations.** Little Mary may be angry with Mom because she won't let her go to a friend's house to play. Little Johnnie gets angry with his Dad because he won't let him buy gum at the store. In our role as caregivers, we want to give parents some skills for dealing with these situations, but first, here are some signs of anger in children:

- Behavioral outbursts, many times without an obvious cause.
- Sleep problems.
- Fights at school or home.
- Physical attacks on others or animals, even among pre-schoolers.
- Disobedience from otherwise well behaved children.
- Child state he/she is really sad and does not know why.
- Complaints of stomachaches and headaches; or vague aches and pains.
- Other reactions similar to those of adults.

Many adults have learned to ignore their feelings of anger, or to express these feelings by hitting or yelling at someone. Therefore, adults often deal with a child's anger by demanding that he or she stop being angry. They might send a child to his or her room until the child can behave better, and sometimes, an adult may hit a child. However, these actions do not help children learn to handle strong emotions such as anger.

Although feeling angry is a part of life that no one can avoid, we can teach children positive

ways to cope with anger. Adults can teach children the difference between feeling angry and acting on anger. Children need to be told that feeling mad is neither good nor bad, but hitting someone out of anger is not OK.

In the short run, life at home will be easier when children learn how to work through anger. In the long run, children will continue developing ways to cope with anger as they become teenagers and adults, and will pass these skills along to their own children.

**Specific ways children can cope with anger:** Children can learn to handle their anger in several ways. Give children several choices so they can pick those that work best for them. Remember that some angry episodes take longer than others to solve.

**Do something physical:** Do something with your body such as stomp your feet (the "Mad Dance"), run around the house, or punch a pillow. Or, play with play dough, clay, or bread dough, which can be rolled out, pounded, twisted, and pulled apart. Any of these physical activities can help children focus their anger on something else and help them to calm down.

**Talk about your feelings:** Some young children can talk to a parent, brother or sister, grandparent, a child care provider or a friend about what is making them angry. Talking helps some people work through their anger so they can accept what is making them angry, or solve the problem in a positive way. If children can't or won't talk to a person, they can be encouraged to talk to a family pet, a puppet, or an imaginary friend.

**Sing an "un-mad" song:** Help

children make up words to a song or poem that expresses what they're feeling. Words from a favorite song can be substituted with this "un-mad" song. For example, the words "I'm so mad 'cause I can't play. Go away, go away, day!" can be sung to a familiar or made-up tune.

**Ask other people how they cope with their feelings of anger:** Help children collect ideas from other people on how to cope with anger. Help the child decide which ones are OK based on the information in this publication. For example, some people take a fast walk to drain off anger, while others take deep breaths when they get angry.

**Drain the anger from your body:** Let children relax with some water play activities or finger-painting. Or let the child scribble as hard as she can on a scrap of paper and throw the paper away as if throwing the anger away. Or encourage the child to dictate a story about what has made her angry to an adult and have the adult read it back. The child can then crumple up the paper and throw it away.

One of the most important things you do as a parent, teacher, or other adult in a child's life is help them respect themselves and others so they can be happy in the world. While it takes years of practice, it is a vital process that pays off.

Teaching your young child to manage anger and talk about feelings can prevent many angry outbursts in teenage years ahead, in their adult relationships, and in their own relationships with their children.

## Spotlight on Men in our Community - Doug Stempek

*This month, the Spotlight is on Doug Stempek of Polk City, Florida*

I was born on January 12, 1954 in Washington DC., and grew up in Maryland. I have Hemophilia A Moderate. I wasn't diagnosed until I was 9 years old, when my appendix was removed. I remember before the diagnosis, I used to spend hours on the living room couch because my knees used to swell. I was told that I had "water" on the knees as a child, until they did some tests and realized that the "water" was actually blood. Still the doctors failed to properly diagnose my condition.

When I was finally diagnosed, I was treated with cryoprecipitate. I remember having to travel to the hospital in Washington DC and laying there for hours in pain as I received my treatment.

My father was a wonderful guy, but he couldn't cope with my disorder, and eventually became an alcoholic. My mom. I believe, suffered from guilt of passing the mutated hemophilia gene to me.

When I was 14 years old, I took my first job, and naively told them I had hemophilia and got the job. After that, I didn't think telling people that I had hemophilia would be a big deal. At 16, I went on another job interview, and again, was open with my hemophilia. This time I didn't get the job. In fact they seem to be afraid of me, as well as my hemophilia.. My friends also did not like the idea of hemophilia. In fact they used to beat me to see how much I would bleed. I decided that

hemophilia was something I didn't want to share with anyone.

During the late 60's, there was a wave of race-riots in Junior High School. Due to the violence in school, my principle decided to have me schooled at home, and sent a teacher to my house five days a week. It was a difficult time for me because I no longer could see my schoolmates. I became very lonely.

I later moved into High School, and in the 10<sup>th</sup> grade dropped out. I did this not because I wanted to, but because the bleeds in my knees became much more frequent and I began missing school regularly. I was told that if I continued to miss school, I would be expelled.—which I was, many times. I decided that the educators were not interested in my problems, so decided not to attend any longer. Even though I had ambitions, I felt that the educators gave up on me, so I got depressed, and gave up on myself.

In 1975, I went back to school and got my High School diploma, I then became pretty much became a hippy, and worked on and off in construction. I liked this work because they never asked questions, and I got paid by the day. So if I got a bleed and needed a week to recover, I wouldn't get hassled - I just didn't show up, and when I wanted to work, I did. I also had to do other things to make money, that today, I'm not particularly proud of.

In the early 80's, I got the job of a lifetime. I became a carpenter apprentice. I realized that I loved this work, and I was good at it. Soon though, the knees

buckled, and I couldn't stand, so I had to leave that job as well.

During this time, I met my wife and had our first child Christopher. Two years later, we had our daughter, Ellen.

In 1982, my brother Duncan died in a automobile accident. Duncan and I were very close. He was younger by 5 years, and we counted on each other. We were there for one another, and then one day, he was gone; ripped from my life. He was an incredible person. I miss him very much, and think of him all the time.

In 1989, I decided to leave Maryland. The construction jobs were far and few between, and I moved to Polk City, Florida. I decided to move there because Polk City was a good community, and was very affordable.

Until that time, I never met another person with hemophilia and now met many. I toyed with the idea of getting a knee replacement. I decided not to do it because I don't have too much confidence in doctors. The doctors I spoke to regarding the procedure, sounded much too eager.

Today, I'm still living in Polk City, and still suffering with knee bleeds. In April, I became a grandfather of a wonderful boy named Cordell.

I look back on my life with hemophilia, and I have nothing positive to say about it. I believe that if I didn't have this disorder, my life would have been very different. I would have gone to college. But unfortunately some things we can not change, we can just continue living our life.



***"I look back at my life with hemophilia, and I have nothing positive to say about it. I believe that if I didn't have the disorder, my life would have been very different"***

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*For information or to inquire about having a "no-cost" workshop for families living with bleeding disorders, please go to [www.inalex.com](http://www.inalex.com), call 201 493 1399 or Email: [Joe\\_caronna@inalex.com](mailto:Joe_caronna@inalex.com)*

## Caronna's Corner - Back to School (con't)

possible, or you just decide that a HTC visit isn't something you'd like to do?

Well, I'm extremely excited to announce that Inalex Productions has developed an educational DVD in the "A Bright Future" series for school educators. This DVD is sponsored by Baxter BioScience, and is now available to the hemophilia community at no charge.

This is the third DVD in the series. It provides the busy educator with a powerful learning tool to effectively support and manage the student with hemophilia in their classroom.

Segments of this innovative DVD include fear and misconceptions of hemophilia, managing the disorder at home, strategies for a team effort, the HTC support, physical activi-

ties, identifying signs and symptoms of an injury, and tips and recommendations.

This DVD has been very well received by educators. Colorado teacher and psychologist, Anita Penhallow, M.S., Ed., MA, said "this DVD is an invaluable tool to help teachers meet the needs of a child with hemophilia". Registered Nurse, Mary Gill-Shutt, from Florida said "it's imperative to have relevant and current information. This inspiring DVD provides both!", and Jeff and Marie Presti, of New Jersey, and parents of a child with hemophilia commented that "this DVD shows what is possible when parents, educators, and HTC's work together!"

We at Inalex are committed to creating many more DVD's that will effectively help in educating not only the school personnel, but also the entire bleeding and "non-bleeding disorder" community.

So while we approach the fall season; the season of change, let's all reflect and get our there and see how we can make a difference in our community, and in our children's lives. Education is enlightenment and we owe it to our children to make life for them as easy and normal as possible.

As Malcolm Forbes once said, "Education's purpose is to replace an empty mind with an open one", let's all commit to opening minds.

To order a free copy of the "A Bright Future" DVD series, please contact the Inalex office at 201 493-1399, or send email to [admin@inalex.com](mailto:admin@inalex.com).



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