

## HEMO HINTS

Always remember...

“Boys will be boys”.

Try not to constantly

“hover” over your child.

Relax and let your

child be a kid...

You can always infuse.

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# INALEX EXCHANGE

A MONTHLY NEWSLETTER DEDICATED TO FAMILIES LIVING WITH A BLEEDING DISORDER

Volume 2, Issue 2

April 2008

## Caronna’s Corner

Joe Caronna—President, Inalex Communications



In 2003, Inalex launched its first full day workshop for men in the bleeding disorder community.

Today, five years later, Inalex presents workshops, retreats, and national teleconferences to not only the men within the bleeding disorder community, but also to thousands of woman, parents, adolescents and teens throughout the United States and Canada.

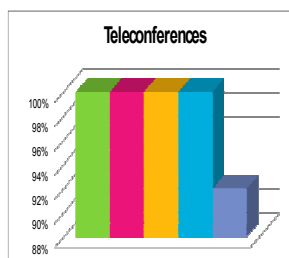
But how did we do? Did we meet the community’s expectations during the past five years? Did we meet our own expectations? Are the programs providing innovative, effective, and practical support and education tools to the community? To answer these questions, we decided to take this “five year milestone”, as an opportunity to do a self assessment of just how well we did during the past five years.

We compiled and reviewed over 1,200 workshop and teleconference evaluations forms that you,

the bleeding disorder community, completed after each and workshop and/or teleconference. The following are the key findings:

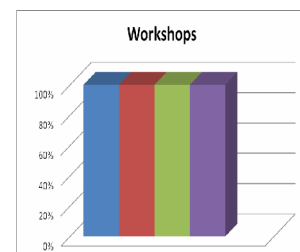
### Key Teleconference Finding

**1:** When the participants were asked how relevant the teleconference topic was, 100% said favorable. When asked if the topic was applicable to their life, 100% responded that is applicable to them. When asked if they will incorporate the lessons learned into their lives, 100% said that they would. When asked if the guest speaker was knowledgeable, 100% responded knowledgeable. When asked if the topics should be presented in a workshop setting, 92% were in favor.



### Key Workshop Finding

**2:** When the participants were asked if the workshop speaker was knowledgeable, 100% responded knowledgeable. When asked how relevant the workshop topic was, 100% said relevant. When asked if the workshop topic was applicable to their life, 100% responded that is applicable to them. When asked if they will incorporate the lessons learned into their lives, 100% said that they would



### Key Overall Program Finding

**3:** When asked all program participants if they would recommend both the teleconference and workshop programs to the bleeding disorder community, 100% responded yes, and 0% responded no.

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## Meet the Faculty: Fathers Finding Their Way: Dana Francis M.S.W

While attending a recent Inalex-sponsored weekend retreat for fathers and sons in Ohio, I thought a lot about the challenges we face as men and boys living in a culture that is in transition concerning issues of masculinity and femininity.

As men try to master the nuts and bolts where “matters of the heart”

are concerned, we sometimes find that the new roads we are traveling on are not well marked.

*And as we all know, it’s hard for men to ask for directions!*

I’ve had the privilege of growing up male in America, but it wasn’t always easy. I didn’t fit the very

traditional masculine mold when I was a child. Athletics weren’t my thing and bigger, tougher kids on the playground at recess were brutal sometimes. Perhaps this rough and tumble schoolyard training is what made the issue of gender roles become a life-long interest of mine.

(Continued Page 2)



***“I wanted to be a father and have children, but I knew that I didn’t want to repeat the things that my father did to me.”***

***Please Join us for the***

***Bayer Healthcare***

***Sponsored...***

***2008***

***National***

***Teleconference***

***Series for***

***Family Members***

***in the Bleeding Disorder***

***Community***

***Tuesday, May 20, 2008***

***Guest Speaker***

***Ron Potter-Efron Ph.D***

5:00 pm - 6:30 pm Pacific  
6:00 pm - 7:30 pm Mountain  
7:00 pm - 8:30 pm Central  
8:00 pm - 9:30 pm Eastern

***For call in number to attend this no-cost teleconference, please call 201 493 - 1399 or Email: Admin@inalex.com***

## Meet the Faculty: Fathers Finding Their Way-Dana Francis, M.S.W

(continued from page 1)

Why are there such rigid roles for male and female children? How did these roles evolve and why do we cling to them so vehemently? Are these roles changing with the times or are they intractable?

As a father myself, I can see that there is truly a case to be made for both “nature” and “nurture”. Nature, of course, would support the old adage that “boys will be boys”. I can honestly say from observation as a parent that more boys tend to gravitate toward the physical and toward competitiveness.

Boys seem to be more interested in cars and trucks than in dolls and tea parties. I have come to believe that there IS some hard-wiring associated with the Y chromosome.

But I definitely see the issue of gender on a continuum. Maybe our ability and willingness to nurture allows our sons to lean toward the feminine and our daughters to lean toward the masculine (we used to call them “tomboys”).

In my perfect world, most people recognize the value of all the characteristics of both genders and we celebrate them. We value our daughters who want to become master electricians and enthusiastically support our sons who aspire to become nurses. Can we do so with pride? Are we secure enough in our own gender identity as men to be comfortable with offering this kind of genuine support to our children?

An exercise we were asked to try at the Father/Son Retreat

was to sit in a small group with our sons and tell them a short story about our relationship with our own father. I must admit, my first revelation was that I felt thrilled that I do have a “relationship” with my son.

Ours is an arrangement that requires communication, sharing, mutual respect, storytelling, and doing things together. Trying to actually talk to each other about things that matter to each of us! What a concept!

The story I told my son was about “interviewing” my own father about 15 years ago. Yes, you heard me correctly...interviewing. I called my dad and asked him if I could sit down and ask him some personal questions about his relationship with his own father when I came to visit him next.

I “interviewed” him because, in fact, I don’t have the kind of easygoing, comfortable relationship with my father that I wish I had. But what my father told me that day was very illuminating. He said that his own father had been a tough, cigar smoking, foundry foreman who was mean-spirited and nasty and had never said a kind word to him in his entire life. Grandpa had offered nothing to his son, (my dad), but criticism.

And then my dad said one of the most profound things he’d ever shared with me. He said, “I wanted to be a father and have children, but I knew I didn’t want to repeat the things my father did to me. Frankly, though, I really didn’t know what to offer in their place”.

And so my father mostly oper-

ated in a neutral vacuum. He went to work, he provided for the family financially, he disciplined when necessary, but the verbal communication, the sharing, the storytelling, the doing things together? It just didn’t happen. It was that vacuum, however, that prompted me to try to re-invent my own approach to fatherhood based on all that I had learned through my struggles from boyhood to manhood.

I have tried to take the gentleness and the kindness that I observed in my dad and apply it to my own way of fathering. I have sought out the wise counsel and experience of my male friends who are also developing true relationships with their children which involve depth, respect, a healthy use of their own authority (as the adult in the relationship), common sense, and a great sense of humor.

The wisdom, mentoring and role-modeling of my peers has been invaluable!

Our challenge, as fathers, is to listen to our children and listen to our hearts. Taking the time to develop a well-rounded relationship that respects “nature” and promotes “nurture” will not only expand the widest possibilities for our children, but will also help us, as fathers, to enlarge our own full humanity as well.

**Dana Francis, M.S.W. is a Social Worker for the Hemophilia Treatment Center at the University of California San Francisco Medical Center.**

## Spotlight on Men in our Community - Jeff Presti

*This month, the Spotlight is on Jeff Presti of Monroe Township, New Jersey. Jeff is the father of 9 years old Rhett, who has severe factor 8 hemophilia.*

I was born in 1964 in Passaic New Jersey. I was the youngest of three boys and lived a normal childhood until my mom passed away when I was a young boy. At that time, my brothers and I were sent to live with my grandmother, and she raised my brothers and I the best that she could.

It was very tough losing a parent so young, especially a mom. I didn't really get to know her or understand her, so I lost out on a lot of things, especially the guidance I knew that she would have provided to me. My brothers were there for me, and they were always good friends, but they too were dealing with their own issues.

Through the years, my grandmother did the best she could with what she had while raising us. It was very difficult for her, so a large portion of life's teachings happened on the streets of Passaic New Jersey.

As I grew and began High School, I became very interested in sports. Sports became my life. I loved to play any and every sport, football, golf, and especially baseball. During my High School years, I also met my wife Marie. It was love at first sight. After I graduated from High School, I went to College in Florida, and contin-

ued my passion for playing sports. In fact, my goal at that time was to become a professional baseball player. I had a pro-tryout, but because of the many injuries I had, I never quite made it.

After college, I got a job in the automotive business, married Marie and began a family. Ryan was soon born, and did not have hemophilia. Eight years later we decided to have another child, and Rhett was born with severe hemophilia.

I never heard of hemophilia until I met Marie and she told me that her father had the disorder. I knew that there was a 50% chance that my son's could have it, but never thought too much about it.

When Rhett was born with hemophilia, I wasn't shocked, but concerned, until I met a wonderful hematologist who spent time explaining the disorder and how well it's managed today. But even after that discussion, I was still fearful of the impact hemophilia would have on my family. I later found out by experience that hemophilia wasn't as catastrophic as I imagined.

Knowing that there have been great strides in the purity of the product from the time my father-in-law lived with hemophilia and today is a great relief for us. The risks today are at a bare minimum for any contamination, and it gives both Marie and I comfort knowing this.

I truly believe that Rhett can do anything he wants in life. Yes, he won't be a football player, but it doesn't really matter...it's not what life is about.

I'm also really proud of my two sons. They really love each other, and are good friends, I must also say that hemophilia has not really been too much of an issue in our life. We try to treat each boy the same. Marie and I don't really focus on the differences between the boys as much as the similarities.

The bottom line is that they are both growing boys and more importantly, there is no difference between the ways we love them. We just deal with each situation as it comes along, we know as a family what we must do, and we do it.

I always say that hemophilia is not a disability, but a "slight disadvantage" in today's world, so we have to manage it and move on. I always tell Rhett that hemophilia is not everything about you, just a part of you.

I recognize there are no contracts or guarantees in life, we all have to make the best of what we have, and for Rhett, I hope that he lives a full life, one that may include a cure in this lifetime, but even if that doesn't happen, I want him to know that he can accomplish anything he chooses to, and to ensure that hemophilia doesn't lead him, it's just something he carries in life.. If he lives his life that way, then I did my job as a dad.



***“Hemophilia  
doesn't lead  
him...  
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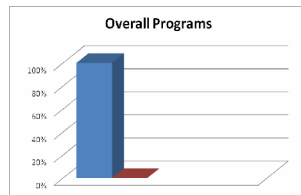
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generous grant  
from***

***Baxter***

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  
08/23 - Newark NJ  
09/13 - Kennewick WA  
09/27 - Chicago, IL  
10/11 - Scottsdale AZ  
10/18 - San Francisco CA  
11/15 - Denver CO  
TDB - Pittsburgh PA  
TDB - Ontario Canada  
TBD - Washington DC  
TDB - Tennessee  
TDB - Alabama

*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)*

## Inalex Celebrates 5 Years of Program Excellence



### Written Comments

Many participants provided written responses to specific questions on the survey and added their own comments. Below are just a sample of the comments received:

- ◆ "Inalex is teaching us real skills to improve real relationships."
- ◆ "These are *must do workshops*, full of positive fun energy."
- ◆ "As an old timer, I would say that this is the best bleeding disorder workshop I've ever been to!"
- ◆ "It will benefit me and my family tremendously...the open discussion is given in an original, well thought-out manner, and it all remains in the room!"
- ◆ "The speakers are warm and caring...It's about time a program like this is finally available!"
- ◆ "This was truly an outstanding workshop...we shared feelings that we haven't shared in a very long time"
- ◆ "Unlike other academic exercises, the emotional responses of each individual exercise was very special...it focused on how we really feel...and everything was about the specific problems of the specific individuals...using specific tools...it was truly memorable!"

Several major themes emerged from the comments. One that was particularly important was for the continued need for these programs within the bleeding disorder community.

During the first five years, Inalex has reached many unbelievable goals, made wonderful friends, and by all indications, has a great future ahead, as we continue to provide programs that are effective and straightforward, and inspiring. So please feel free to go to [www.inalex.com](http://www.inalex.com) to read more about us and the work we do for the bleeding disorder community, ask about a workshop in your area, and join one of our monthly national teleconferences. I hope to see you soon, as we look forward to another five years of *Hope, Information and Inspiration!*

**Inalex Communications**

**38 East Ridgewood Avenue, #244**

**Ridgewood, NJ 07450**