

Spikes & Spasms

The Tremoraction.org Newsletter

JUNE 2006

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HAPPY ANNIVERSARY!



WELCOME TO THE ANNIVERSARY ISSUE!

Spikes & Spasms:

One Year Later

Looking back, Spikes & Spasm's first article, Through the Looking Glass...What Andrea found, shares the author's revelation that as a teenager and young adult, she was aware of her great aunt's head and hand tremors, and then her uncle and aunt's tremors. When the author begins to feel shaky, her neurologist confirms ET is a family affair.

June is a month of family affair celebrations - graduations, Father's Day, and weddings. June is also part of National Family Month (May 14 - June 18). With families in mind, the 2006 June issue of Spikes & Spasms is dedicated to children and young adults with movement disorders.

Enjoy reading the June - Anniversary issue brought to you by Life In Motion coalition member Tremor Action Network. The LIM Campaign will continue through 2006.

Band-Aides & Blackboards

By Joan Fleitas, Ed.D., R.N.

Band-Aides and Blackboards is a website packed full of resources for children and adults. Its intent is to sensitize people to what it's like to grow up with medical problems. Too often, youngsters so affected must cope with the stigma of being 'different' as well as with the condition itself. Teasing often accompanies this stigma and adds a layer of pain to their experience of childhood. Unnecessary pain. Pain that isolates. Pain that affects not only the children who look or act or even just feel different, but all of the children they interact with at school and in their neighborhoods.

As I have developed the website, I have been the student, and children have been my teachers. They have taught me what it's like for them to live in bodies that don't always behave, and what it's like for them to be growing up in a world that is too frequently insensitive to their needs. They have spoken about a wide range

of dilemmas. For some children, the dilemma is the ambivalence of enjoying extra privileges, yet hating the reason that they're offered. For others it's the shame associated with medical diagnoses and a need that grows from that shame to keep hidden what is not directly observable. For many it's the ache to be popular and the belief that popularity is purchased with the coins of conformity. When that conformity forces children to ignore their need for medication and treatment, and when it demands of them a secrecy that consumes energy as it isolates, the price is very high.

The children who write to me, talk to me, and tell me their stories are children who are bothered to some degree by the social dimensions of their medical conditions. Many prefer not to think about their differences. And not to talk about them, either. Acknowledging them seems to tattoo the reality of the disease, condition, illness, medical

Their chronic illnesses or other medical conditions are part of them, but do not define them.

problem...you name it, on their identity. What they call it, then, becomes extremely important to them, with certain words having more power to isolate than others. As one child assured me, "I have this condition called diabetes. It's not a disease, because you can't catch it." And from a young man recalling his early school experiences with muscular dystrophy, "what I have is neither a chronic illness nor a disease. It's just a condition that seemed to affect others more than it did me, though I was teased unmercifully for my differences."

The most important thing I've learned from my conversations with children has been that they are first of all children, with the same needs, joys, hurts and misconceptions that all children share. Their chronic illnesses or other medical conditions are part of them, but do not define them. I hope that they will learn as they grow that they can be proud of who they are, and that what's going on with their health is a part of that pride, not something to be ashamed of.

I've tried to help children tell their stories on Band-Aides..., in the hopes that through the narratives, others will have an opportunity to "walk in their footsteps" for a short time, and will, in the process, begin to understand. As I have learned from the "BandAide experts", so too have I attempted to address the themes of their stories in educational and supportive ways. When they told me of teasing and exclusion, I developed a collection of pages on stigma. When they told me of their desire to be "just like everyone else...part of the gang", I ensured that the narratives they shared focused on their lives, not just the medical conditions that prompted their participation. When they told me that their friends focused on what they were unable to do, I created a hospital tour where the hospitalized children are the tour guides, the ones "in the know", and where healthy, typically developing children learn from them. When they revealed their confusion about medical words, diagnoses and treatments, I wrote

poetry about diseases; poetry that gets to the heart of self-blame, guilt, symptomatology and prognosis. A brief excerpt from a poem about leukemia will illustrate:

*You might think that leukemia,
A cancer I was told,
Is something you could catch from me
As if it were a cold.
But that's not true, it's not that smart,
It doesn't have a clue.
Traveling between us
Is a trick it cannot do.*

The website has grown a great deal since I first published it. Besides the stories, the site provides many resources for children, parents, health professionals and educators. Given that BandAides receives over 100,000 hits/week, my sense is that the site is responsive to the needs of all of those audiences.

I hope that you will invite your youngsters to participate in this project that allows them to share with others some slices of their lives, like Betsy

<http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/betsy.html>

already has:

Finally, a link to the front "door" of the site. May you enjoy your visit!

<http://www.lehman.cuny.edu/bandaides/>

About the Author

Joan is an Associate Professor of Nursing at Lehman College (City University of New York) in the Bronx. She has "worked with children and teens in hospitals for over 30 years." Her educational background is extensive, including Charity Hospital School of Nursing in New Orleans, Florida State University in Tallahassee, Emory University in Atlanta, Georgia, and Teacher's College at Columbia University. Band-Aides & Blackboards began as a project for Joan's dissertation.

The Pain, the Pride, and the Passion

*Band-Aides & Blackboards adaptation of
Why Am I Different?*

By Janice Bolick

Spikes & Spasms Note:

*Kathleen contacted Joan Fleitas of Band-Aides & Blackboards, responding to Joan's website invitation to "Your turn to write on the board," after noticing that Joan did not have a resource for ET. Kathleen suggested **Why Am I Different?** that had been well received by children, parents, and teachers. Joan and Janice connected, and their collaboration is the adaptation, **The Pain, the Pride, and the Passion.***

Hi there. My name is Janice, and though I am visibly different from other people, I am still happy. Figuring that you might want to know how I managed happiness in the face of my difference, I'd like to share my story with you.

I grew up with something odd called essential tremor (ET). ET is a disorder that involves shaking, usually of the hands, though it can involve the head and neck, the face, jaw, tongue- why even the voice. Some people have the tremor in their trunk, while fewer have it in their legs and feet. What all this shaking has in common is that it is NOT caused by any other problems like medications or any outside influence. It is strictly neurological. My dad has it, and so do I. Growing up with this brought me my fair share (and more) of pain and sadness, but, you know what, it brought me a lot of pride, too, and now a passion to make a positive difference to others who didn't ask for ET, can't get rid of it, and who are struggling to achieve happiness like I did.

I lived the life of an only child in a sheltered and loving home. Starting school when I was only four, I took off to kindergarten that first day with both joy and fear. My mother came with me, of course, and, with butterflies in my stomach, I started this new adventure.

Here's what went through my mind when I saw the room, and my classmates: "I am so excited. Boy, look at all these kids and all this stuff. They talk and play rather than sit and do nothing like my dolls. We are going to have a snack and drink. I already know I'm going to love school. I am one of the big kids now.

"Hey, cookies with sprinkles and orange drink-----WOW. We all get in line. It's my turn. This Lady gives me a little paper plate with two cookies and tells me to get a cup of drink from the next lady. I have my cookies in one hand and reach out to take my drink. Oops---my hand shakes some and the drink gets on my cookies. That's OK. They are just a little wet. OH NO! Now my other hand shakes a little and the paper plate lets a cookie fall off. I'm at the table and sit down beside new friends. I take a drink."

One of the girls asks me why I'm still a baby. "You hold your cup with both hands like my little brother Baby James." She laughs at me and tells me to get a baby bottle. Nobody else says anything mean but they stare at me.

"I can't help it. Makes my hands shake more when people watch me. I'll just tell them I'm full and then it will be OK. Good there's Mom. I can leave. I'm not sure about this. Maybe I can stay away from the mean girl and the other ones will forget.

"I've been in school a couple of weeks now. I HATE SCHOOL!!!!!" That mean girl still makes fun of me. We are learning to write our ABC's. I know my ABC's and my numbers. I knew them before I came to school. I try my best but my A's and H's look awful. I try to hold my pencil tight so it can't shake but my A's look squiggly. My teacher tells me if I don't quit day dreaming and get my work done faster she is going to call my Mother. I do not daydream. I try to go as fast as I can but my letters all are squiggly."

I never want another child to have to overcome the barriers that I confronted.

The teacher called my mother, and of course she came right to school. My teacher told her that though I seem bright, all I do is day dream. "Rushes through her work to get it done." My mother explained that my Father has ET, and that I do, too. It was pretty good to hear Mom say that she'd like to tell the teacher a few things about ET. The teacher's face turned red. After the visit, she told me that from now on, she'd like me to do as much work as I can in school, and whatever I haven't finished, why I could take that home and finish it there. What a relief!

So that's a sample of my time in school. I did have some bad times. I cried a lot...but I learned to laugh a lot, too. I figured out that if I did my work at home where no one was

staring at me I did better. So I got the assignments from my teachers and did as much as I could the day before class. I took a tape recorder to school at a time before anyone ever started using them. I just couldn't take notes fast enough. My taking these notes turned out to my advantage because I was able to retain more than the other students. My father said the best way

to show someone I'm 'normal' is to make better grades than they do. As a rule, I did just that. I managed to stay on the A-B honor roll throughout school, and was I ever proud!

One very precious thing that essential tremor has given me is a love of people...for who they are, and not for what they have.

OK, I figure that when you have any kind of 'unpopular' difference, you can do two things. Feel sorry for yourself or fight harder and make a positive difference in your life and in the lives of others.

My father fought harder (remember, he had ET before I did) and became a plant manager of a very large textile mill. It is that very same mill where I found my life work...and passion. A career in Human Resources was perfect. I could

help others to be productive by looking at their work, not the clothes they wore, the way they looked, or the manner in which they spoke.

I had a hard time in the beginning because I was judged by my tremor...before I even opened my mouth. I thought about this, learned from it, and, essentially, beat everyone to the punch! For example, I went into an interview, shook hands and then informed the Human Resource Director that I had essential tremor. I made it known that ET did not affect my work. I was employed on the second interview, and my career took off!

To tell you the truth, ET turned out to be an asset, since I can form an impression of individuals based on their reactions to me. Now here's my passion:

I share my trials and tribulations with essential tremor for two reasons. 1st to let you know that a child remembers. I never want another child to have to overcome the barriers that I confronted. And 2nd, most importantly, to bring awareness to the teachers and administrators about this disorder. I want them to learn that children with ET are just as competent...or even more so, as other students, and that they have as much a need for acceptance and inclusion as anyone else.

ET is the most common movement disorder in the world, with millions of people affected. The toll that it takes on those who have it must be acknowledged and attended to...that is my goal. Since ET forces creativity, I bet I can figure out some novel ways to get the word out!

Thanks for visiting my page. Hope you'll drop me a line! [Jan](#)

Come visit the ET organizational [website](#) to learn more about this odd disorder!

About the Author

Janice Bolick, author of *Why Am I Different?* is a passionate Southern Advocate for children and adults with essential tremor. Her well known tag lines are: "My contribution to Next Generations is a good life's work...A single person is just one to fight the fight-----A group of friends is an army." She is co-owner/moderator of [Tremor](#), the first online ET support group for young adults and older. She resides in Tennessee with her husband Dennis, their children, grandchildren, and a menagerie of animals, including a stable of horses!

Achieving Better Mental Health by Slowing Down

By Mona Reeva, PhD, MPH, LCSW

Spikes & Spasms Note:

Feel calmed reading about "slowing down." Dr. Reeva's column focuses on mental health issues. Readers are invited to ask questions that will be answered and featured in the September issue. Contact [Tremor Action Network](#) or Dr. Reeva directly at mreeva@comcast.net.

Today I started thinking about the frenetic pace at which I have been operating since I returned from my vacation. I have this long litany of things waiting for me to do: calendar spaces to fill in, people to make appointments with, places to go, shopping, cleaning out my closets, appointments with health professionals to keep, pilates, exercise, and other tasks that I can't even think of and aren't yet on my to do list. What am I doing, I ask myself, continuing to ponder. After all, I am now "retired" whatever that means, although I have filled my time with a myriad of volunteer jobs, including writing this article. I am out of breath even considering my state of being.

On vacation everything or almost everything is held in abeyance. Except for the most essential tasks such as making sure that my bills are paid, my focus is on what I am seeing, doing, and taking in, either through my senses or my camera. I feel a lightness that seems to elude me at home. The same is true for my husband. Our relationship changes,

gets lighter also, more enjoyable, more in mutual connection.

I believe our individual struggle is to create a living space that incorporates this lightness of being so that life itself does not become weighted down with the tasks of daily living - those required and those we heap on ourselves. Sometimes I think that we are a society addicted to being busy for the sake of filling time and space, as if we don't have a right to relax and possibly be stress free. Keeping busy seems to be a requirement put upon us by our culture that demands busyness.

My vacation was in Greece. Their schedule is early to work from about 8:00 AM - noon or one, then siesta time until 4:00 PM or 5:00 PM before going back to work until 9:00 PM. Then dinner time. At 10:00 PM to 11:00 PM. A very interesting schedule unless one is in the service industry that caters to tourists who are moving about all day and night. Otherwise, and especially outside the cities, people can be seen sitting at cafes, strolling or in their homes. Well, perhaps in their siesta time they are running around like crazy taking care of their required tasks. I don't know as I didn't ask. But let's say that there is more "down time" there for sake of comparison and perhaps even mimicking.

I reflect on the difficulty and wonder if filling time is a leftover of puritan attitudes that the devil gets to those who are not occupied, or parents yelling at their kids to stay busy or that if they aren't, kids are called lazy. How many adults recall a parent saying such words to them if they were just sitting around dreaming, looking and watching.

Have you noticed that at the moments taken to stop, look and see, so much comes into view - things we never saw before, even if we have been in that same spot many times over. I never stop being amazed at this realization when I

have gotten enough control of myself to stop - slow down - see my world that surrounds me. Wow, when did that store open, wow, where did that bird come from, wow, look at all the details in that flower growing in the corner that I don't pay much attention to.

I am impacted by this slowdown in ways I can't always understand, and in ways that say to me - what is important in our time on this planet is being and being in relationship. Relational awareness and interaction creates mutuality of spirit, and allows us to feel, yes, feel our feelings and recognize the empathy and love we can have for each other and the beauty of this world. Slowing down allows us to counteract that feeling of isolation that comes when I fill every moment with busyness.

Slowing down allows us to counteract that feeling of isolation that comes when every moment is filled with busyness.

Try it, you might be surprised by what takes place. And as for me, yes, I realize that by sitting and writing this article, I focus on my feelings and awareness and feel calmed.

About the Author

Dr. Mona Reeva has worked in the field of mental health and human services for over 40 years. She has taught in China and Japan. Dr. Reeva offers mental health consultation, and personal and professional coaching. She can be contacted at mreeva@comcast.net.

The Journey Continues, Myobloc, Type B

By Nancy A. Muller

Spikes & Spasms Note:

Dystonia Awareness Week is June 4 - 11.

Solstice Neurosciences, Inc. released new data confirming the effectiveness of Myobloc as a first-line therapy, and also results on the first prospective botulinum toxin study of long-term effectiveness and safety in patients treated for up to 4 years. For further information on Solstice Neurosciences, please visit:

<http://www.solsticeneuro.com>.

What do you do when you find out you have become immune to Botox A? You change over to Type B, or it's more common brand name being Myobloc, of course. I myself spent approximately 12 years on Botox A, and the past 6 years I have been on Myobloc, which I have injected by my neurologist every three months.

Just to freshen your memory from my previous article, I have had Cervical Dystonia, which I might add is a lot easier to pronounce than Spasmodic Torticollis, but is the same condition, more up to date name, for 18 years. The cause of cervical dystonia is not completely clear, but normally the brain sends chemical signals to the muscles to keep their movements smooth and controlled. One of the chemical messengers is acetylcholine. In patients with cervical dystonia, these signals fail to work properly and more than normal amounts of acetylcholine are released, causing the muscles to become tense and overactive. There are various degrees of the condition. Sometimes there is pain, sometimes twisting and pulling and abnormal positions of the head and neck, and sometimes all of the symptoms are present. In some cases there is head tremor of various degrees. It's a very unpredictable condition and you just

**The main goal of
botulinum toxin therapy
is to relax muscles.**

never know what you might experience from one day to the next.

Treatment with Myobloc, also called Botulinum Toxin Type B in a purified formulation, are injected directly into the affected, overactive muscles to block the release of acetylcholine, and disrupt the spasm and tension that accompany cervical dystonia. In other words, the main goal of botulinum toxin therapy is to relax muscles.

It takes about 2 weeks after being injected to notice improvements to head and neck positions and pain levels. But you must remember everybody's response to treatment is different, and so response time is hard to predict.

You must also realize it will take more than one treatment to reach optimal results. Don't expect a miracle with one treatment, and most importantly, don't be discouraged if you don't get results right away. Be sure you give the treatments a fair chance.

When I began being injected with Myobloc, I did find it somewhat more painful, because of the PH of the solution; I found it burned when injected. Working with my physician, we figured out if he always injected slowly, it no longer hurt. If you are going to begin treatment with Myobloc, ask your doctor to be sure and inject slowly, it will make a big difference.

Side effects are also a big issue in treatment. When I started treating with Myobloc 6 years ago, I think I had all the side effects listed. The most common one is dry mouth, which can be eased by chewing Biotene gum. They also have a spray and mouth wash if this is what you prefer, and it works very well. I also found from the dry mouth I'd get hoarse and food would stick especially dry things like bread and crackers. Usually this kicked in about 1 week after the injection. Make sure your throat is moist before eating these things and you'll be fine. I also had heartburn and

indigestion, which I take Protonix to control. I sometimes have flu-like symptoms, but over the years of treatment the side effects have pretty much diminished.

Sometimes it is necessary to treat with a combination of Myobloc and oral medications, but that is determined by your symptoms and which would be the best choice according to your physician.

In closing, I would like to say how thankful I am that considering I've had cervical dystonia for 18 years now, My quality of life would have never been as good as it has if Botulinum Toxin serotypes were not available for my treatment.

I'd like to thank David Duff, Myobloc® Product Director, for the informative resources he provided so I could give the proper information to my readers regarding Myobloc. If you would like more information regarding Myobloc, you can go to their website at www.myobloc.com. They also have a patient services program you can call at 1-888-461-2255, for eligible patients who are subject to financial hardship if they are denied coverage or who are not covered by third party insurance.

I'd like to thank my friend Kathleen Welker, president and founder of TAN for giving me this forum to educate and support patients with various forms of dystonia. Kathleen is one of the most dedicated individuals I have been associated with that provides so much support and education for patients with Essential Tremor. Kathleen is honest, knowledgeable, caring, and so very compassionate. I am very proud to be serving on her board of directors and truly believe in her mission.

I would love to hear from any of our readers if you have any specific questions for me about my experience with Myobloc and any other subjects you might like me to cover in future issues of Spikes and Spasms. I can be reached at my e-mail address of nmuller406@aol.com. Please feel free to contact me at anytime.

About the Author

Nancy Muller's column focuses on dystonia and various health issues, including but not limited to patient advocacy. She is also a contributing author for the NSTA Magazine, writing columns devoted to up front and personal questions from members.

Essential Tremor in Youth

By Allison Ashley-Koch, PhD

Spikes & Spasms Note:

Dr. Ashley-Koch, along with Principal Investigator John Gilbert, PhD, Jeffrey Stajich, Senior PA-C, Stefanie Knauer, Clinical Data Technician/Participant Coordinator, and other members of the CHG essential tremor research team, are searching for genetic factors in families with several ET individuals. The identification of genes is extremely significant in understanding the cause of ET. For additional study information please visit: <http://www.chg.duke.edu/diseases/et.html#anchor4>.

*Don't miss Romert, Tremor Action Network's essential otter **It's a Family Affair** request, asking "for the help of many families to discover the genetic factors that cause ET!"*

While it is well established that risk for essential tremor (ET) increases with age, as many as 5% of all individuals with ET are children (Rajput et al., 1984). There is very little information about ET in children and how the clinical course may differ from ET in adults. But a few observations have been made which we hope will tell us more about the underlying biology of ET.

The most consistent observation is that there are more male children with ET than female children. There have been two hypotheses put forth to explain this. First, it is possible that male children with ET seek medical assistance before female children with ET simply because the male children are engaging in more sports and thus

their ET symptoms impact their daily living more than in female children. Alternatively, gender may simply influence the expression of ET through an unknown biological mechanism. There seems to be more support for this latter hypothesis as the preponderance of males with ET continues until about age 70 when the male to female ratio appears to even out to 1 to 1 (Larsson and Sjogren, 1960). If this latter hypothesis is true, it would suggest that hormones may play an important role in the expression of ET. Possibly male hormones cause an earlier onset of ET or female hormones delay the onset.

Another observation in children with ET is that the frequency of head tremor is reduced. While head tremor is present in about 34% to 53% of adult patients with ET, in children, it is only observed 3% to 18% of the time (Louis et al., 2001; Louis et al., 2005; Jankovic et al., 2004). This observation may reflect the natural history of ET, whereby tremor tends to start in the hands and only in the more progressive state move to other regions of the body, such as the head and voice.

Because ET is believed to be a late-life disease, children with ET may be misdiagnosed and not receive the medical care that they need. For example, Jankovic and colleagues (2004) found that nearly half of their pediatric cases had another neurological diagnosis other than ET. The most common were dystonia and Tourette syndrome. The diagnosis of Tourette syndrome in this group of children often preceded the diagnosis of ET, suggesting that it may simply be misdiagnosis.

In our genetic sample of families with ET, we observed 7 out of 35 participating children (18 years and under) who met the criteria for ET. All seven children were Caucasian and the age of onset of ET symptoms ranged from seven to seventeen years. The frequency of male children was approximately 43% (3 of 7), contrasting sharply to what

has been previously reported in the clinic cases above. Of the 7 children with ET, none of them had a history of head tremor. In our overall study population, head tremor was present in 22% of 169 affected individuals. Thus, our data support previous results that head tremor is less frequent in children with ET compared with adults. However, in both our overall study population and the childhood subset, the frequency of head tremor was somewhat lower than what was observed in the clinical cases. Interestingly, none of our children demonstrated a vocal tremor, either. Only one of our children with ET had another diagnosis, which was asthma. None of the seven children had ever received a diagnosis of dystonia or Tourette syndrome.

There is no doubt that there is still much to be learned about ET in childhood.

In summary, in our genetic sample, we did not observe the male bias in childhood onset ET as was reported previously. Further, our pediatric cases appear to be less severe than was previously reported. This is most likely because the previously published cases were ascertained through neurology clinics, which implies that these children were experiencing difficulties. In contrast, our pediatric cases were ascertained for participation in a genetic study through other affected family members. These data suggest that some children with ET may experience considerable difficulties, including difficulty obtaining the proper diagnosis and treatment. However many children with ET are likely to have a milder clinical course. There is no doubt that there is still much to be learned about ET in childhood and future research studies specific to children with ET are needed.

About the Author

Dr. Ashley-Koch is the co-Principal Investigator for the Duke University Center for Human Genetics (CHG) ET Study. She is also an Assistant Professor. To view her extensive background in genetics, please visit: <http://www.chg.duke.edu/faculty/aashley-koch.html>.



The Power of A Fact Understood

By Darby Ludwigs

Spikes & Spasms Note:

*The day after Darby's article appeared at www.americanchronicle.com, Kathleen extended an invitation to Darby to contribute an article for the June newsletter. Darby generously granted permission to use the American Chronicle article. On behalf of Tremor Action Network, thank you Darby for allowing us to reprint your article. **The Power of A Fact Understood** is a poignant reminder that we need to focus more on children and young adults diagnosed with essential tremor and related movement disorders.*

Woodrow Wilson once said, "Comprehension must be the soil in which grow all the fruits of friendship." Knowledge, we get at schools from books, lectures, notes and tests but comprehension and understanding we only get when we experience life. Understanding becomes the tangible object that holds the world's population together. There is no way to teach apathy, we only begin to understand things in everyday life through friends, strangers and through trial and error.

However, in order to comprehend or understand something first you must know something about it. So today, I am going to tell you about something you have probably never heard of, Essential Tremors.

Knowledge is power, but understanding is powerful.

Essential Tremors is a disease that progresses over time, and has various symptoms for its sufferers but typically it is diagnosed when there is uncontrollable shaking in the hands or legs when in use. Those who do not know of the existence of such a disease often recognize ET (as doctors and victims shorten it to) as being Parkinson's disease. Due to it being a neurological disease, no one knows how it works, not even the doctors who diagnose it. However, they do have research that has shown what the symptoms are as they progress. The tremors gradually move from the hands to the arms and from there they move to the shoulders, neck, and voice. People who have the disease become people on the outside of society. Someone who shakes his or her head uncontrollably all the time cannot ever feel normal in public.

I met a girl with Essential Tremors in Dallas. I was at an Essential Tremor convention, trying to learn more, so that I myself could understand. The girl was 18, and rather shy. When the presentation the doctors were giving began, I was in shock. The doctors had such knowledge over essential tremors.

They recited the prognosis "incurable" with the bluntness only an MD can give. They told the audience of the three treatment options. 1) Brain surgery- where they implant a form of a pacemaker that controls the electrical impulses in the brain. 2) medicine- much like those used for patients with Parkinson's disease. Which side effects include but are not limited to birth defects, stillborn children, and infertility. The medications given are only to hide the tremors like a mask. There is no known cure for Essential Tremors to date. While patients are on the medicine, tremors decrease but when the masking medication is discontinued tremors come back with a vengeance, this is explained by the fact that the medications only hide the progression of the tremors from our eyes. Furthermore, Meds only work for 7-9 years before you become immune to them.

Lastly, there is the option of doing nothing. The two white coated doctors presented this all matter-of-factly at the convention. But as I sat there I realized something, yes, these doctors know a lot but they don't comprehend the impact their knowledge has, or the levity that comes with such knowledge.

As I looked around in the small room, I felt burdened. The people in the room were all in the mid-sixties and seventies exhibiting signs that the disease had already progressed greatly. A few women's heads were uncontrollably shaking and as an elderly man spoke, he spoke with a trembling voice. He said to the doctors and us, "I am eighty-two years old, I won't be here much longer, I have lived since I was twenty with this disease, I've been through two wars, and I've never had a child, I will die alone because of the medicines." No one spoke, but I looked over at the young 18-year-old girl I had met earlier and noticed her looking at her hands in her lap with fear in her pale blue eyes. I realized that this room was her future and my heart broke. She would become like one of these women, unable to hold their head high and still, always looking down out of fear of being noticed for their differences by those who do not understand.

The doctor smiled simply at the man and said, "I'm sorry about your case, next question." How is it a man so smart and knowledgeable did not see the downcast faces and the men and women looking beaten by this disease? How can someone so all-knowing, not understand these people? I imagined these people's everyday lives and how people who didn't know about the disease would treat them. Badly, I knew.

A man told us of how he had given up eating soup in public because of his hands shaking, and I could not imagine how painful that must feel. Throughout the whole presentation, the doctors remained cheerful and laughed even at some of the symptoms of medicines. I asked the 18-year-old girl about her choices of treatment, and she said to me that she is taking no meds. She continued to say how all her life, all she has ever wanted to be is a mother, and how she will

not risk having her future children hurt by the medicines. I think it was right about then that I realized that without the doctors understanding the things they knew about, these people were alone in the world. The doctors' knowledge was useless without their understanding of the impact it had.

And I lied, I did not just meet this 18-year-old girl at the convention, she is my sister. In addition, I began writing this, wanting to inform of Essential Tremors. Then I realized that informing someone is not helping him or her without trying to help him or her understand as well. Therefore, in essence, this article did cover Essential Tremors but moreover it was about comprehending what we are informed about and what we have learned in the past. So, I have informed you of the disease my sister and 10 million other Americans suffer with nationwide, since first you must know about something before you can comprehend it or understand it. After all, yes, knowledge is power, but understanding is powerful.

About the Author

Darby is an avid reader and has a passion for telling the stories of those often ignored. She is a student and plans on furthering her career in journalism and writing fiction pieces. Growing up mostly in the liberal area of the Bay Area she carries those views with her in most of her life and attempts everyday to be open to new lessons.

Favorite Quote:

"Always forgive your enemies; nothing annoys them so much." - Oscar Wilde

Darby's online article may be viewed at:
<http://www.americanchronicle.com/articles/viewArticle.asp?articleID=8580>

Poems for Sadie

By Trish Cross

December 20, 2003

Sadie do not despair
Your help is on the air
We know just how you feel
For us these shakes are real

Whenever you feel low
You know just where to go
We understand your needs
And don't judge you as others
Who do not know

Keep your head up high
If they laugh, just laugh on back
You are a special child
Essentially don't you know

This poem I write to you
Has come from one who knows
The hurt we sometimes feel
How life seems unfair, not real

So smile a lot
We're by your side
True friends
Look at you inside

December 21, 2003

On the day that you were born
The Angels thought you special
So they touched their wings
Upon your face and showed you how to tremble

They knew that you would find it hard
When other kids laughed at you
But gave you courage to cope with it
That was far beyond your years

They wanted you to show the world
That you were real unique
They wanted you to tell the world
That you were not a freak

They took you by your little hand
And showered you with love
They promised you were not alone
That others understood

They taught you it's okay to cry
And taught you how to laugh
They whispered secrets in your ear
That you will learn to cope
They told you stand up tall our friend
You're a very special child
They smothered you with kisses
Upon your little cheek
They then all said adieu

So now when children look and tease
Although at times it hurts
Remember all those Angels
And say I have ET

Those children they may run away
And giggle as they go
But you our friend

Although you're young
Don't turn your back on them

Don't be shy to tell them why
You shake the way you do
True friends will understand
The others you don't need to know

About the Author

Trish Cross wrote Poems for Sadie at the request of a grandmother in despair, in need of help for her grandchild, who was being teased by other children. Trish has been writing poetry for 25 years. Her poems come from the heart, helping others to know they are not alone, and that someone does care. She has led a varied life; as an officer of the Queensland Police Force after graduation from high school, Postmaster of a local office in the small village of Mondure (Queensland, Australia), owner of a beef cattle ranch and sawmill, the latter in operation for 20 years. Trish is visiting the USA, and is in the process of obtaining permanent residence.

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ALFAH MAHAN



WE NEED TO IDENTIFY THE CAUSE OF ET. WE NEED THE HELP OF MANY FAMILIES TO DISCOVER THE GENETIC FACTORS THAT CAUSE ET. CONTACT STEFANIE AT (877) 244-9272 OR EMAIL SKNAUER@CHG.DUHS.DUKE.EDU.

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