

Outreach

Fall 2006
Issue #19

A publication of the United Brachial Plexus Network, Inc.

- *An Interview with
Dr. Andrew Price*
- *Straight Talk from Fathers
with Injured Children*
- *The Use of Chinese Acupuncture in
Brachial Plexus Injuries*



.Game On!

Sports Participation in Patients with Brachial Plexus Birth Palsy

CONTENTS

- 3 ■ **President's Letter: Camp UBPN 2007**
- 4 ■ **UBPN News: Volunteers**
- 5 ■ **Free MedicAlert Now Available Through UBPN**
- 6 ■ **An Interview with Dr. Andrew Price**
- 8 ■ **Game On! Sports Participation in Patients with Brachial Plexus Birth Palsy**
- 9 ■ **3 Strikes: Mom's Perspective on Sports Participation**
- 10 ■ **The Use of Chinese Acupuncture in Brachial Plexus Injuries**
- 11 ■ **Join the UBPN Family Tree**
- 12 ■ **UCSF-Led Study Suggests Link Between Psychological Stress and Cell Aging**
- 14 ■ **Straight Talk From Those Who Live It Each Day: BPI Dads Share Their Experiences with Rich Looby, UBPN Vice President**
- 18 ■ **Living with TBPI and Chronic Pain**
- 22 ■ **A Few of Our Favorite Things**
- 26 ■ **Sample Letter to Schools**

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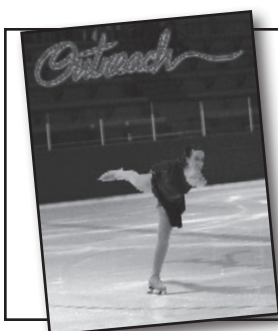
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On The Cover:

Marieke Dufresne of Canada skated since she was six and started figure skating lessons when she was 18. Born three months premature with LOBPI after a breech birth, she had to stop skating at age 28 (a few months following the taking of the photo on the cover) when she contracted Transverse Myelitis and was paralyzed from mid-chest down. She was immersed in rehab to learn to sit up and walk again. Today at age 31, she walks with the aid of a cane and a brace. She was a pre-k teacher, has her degree in Child Studies and has a PT tech degree. She is now a second year nursing student.

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President's Letter: Camp 2007

The crackle of pine needles underfoot.

The smell of fir and cedar.

The sight of the crisp evening sky spangled with stars.

AND the warmth of the smiles on the faces of friends & family.

Be prepared for all your senses to be awakened and soothed at UBPN's Camp 2007, which will be held at Camp Berachah in Auburn, Washington over Labor Day Weekend in 2007. Camp Berachah is approximately 30 miles from the Seattle airport.

The UBPN Board of Directors is working on programs and activities to make the camp a memorable experience for everyone in your family.

As with previous camps, this camp has hotel like rooms (with their own bathrooms) and lots of outdoor activities (including indoor heated swimming pool, therapeutic horseback riding, a climbing wall, and exclusively at this camp -- go karts and a zip line challenge).

We will be working on the perfect combination of activities and programs for all members of the family with lots of opportunities for both kids and adults to play together and learn more about brachial plexus injuries.

We will have more information available in the coming months and will have registration information available in the spring Outreach.

Cost figures have not yet been finalized but we anticipate that this camp will be comparable and maybe even cheaper in cost than the previous one.

We know that travel to Washington state will be quite a trek for some of you. We encourage you to think of combining camp with a vacation and extend your stay in the beautiful Pacific Northwest either before or after camp.

Mark your calendars now and we'll see you at Camp 2007.

Nancy Birk

Nancy Birk, UBPN President



Karen McClune, Camp UBPN 2007 Coordinator, at a recent visit to the UBPN Camp 2007 site.

Volunteers Are The Heart of Our Community and UBPN

The UBPN Board of Directors is made up entirely of volunteers who donate their time, talent and other resources to our organization. Those interested in serving in any capacity should contact any member of the UBPN Board of Directors or the UBPN office. There is certainly a place for you!

UBPN particularly needs volunteers with skills including website design, Microsoft Access, Microsoft Excel, grant-writing, and graphic design. In addition, we are currently seeking volunteers for our Open Arms, Awareness and Fundraising committees.

UBPN thanks those who have served on its past Board of Directors (terms run for 2 renewable years):

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New Director Amy Theis



Joining the UBPN 2006-07 Board of Directors for the first time is Amy Theis. Amy lives in Bemidji, MN three months out of the year and in Duluth, MN the remaining nine where she is a full time college student at the College of St. Scholastica. She is working on a Masters Degree in occupational therapy and a minor in psychology.

Amy found UBPN in the fall of 2001 while working on a research paper for her ninth grade health class. She has always been interested in her injury and loves to learn more about it while helping other people to learn about their injuries as well. She has always enjoyed volunteering and especially likes working with young children. Amy has a ROBPI and is very excited to serve her term on the UBPN Board of Directors!

Welcome to Amy and thanks for volunteering!



Ryan McClune sits on the floor beside the UBPN server. He tells us that he spent a lot of time sitting on the floor working on it, as it could not be moved while working. This photo was taken after the server came back online, hence the smile!

Thank You Ryan!

The UBPN website (www.ubpn.org) experienced a downtime of a little more than five weeks, during the past June and July.

To tell you what happened in as short an explanation as possible, we had both the primary and backup hard drives fail at the same time – an unlucky occurrence. Both of the drives had to be replaced in order to bring the server back online and recovering data from the failed drives was painstakingly slow. The new drives were then tested and the site brought back up.

We apologize to those who relied upon our message boards on a daily basis. We are glad to be back.

A hearty thank you is extended to Ryan McClune, who has spent countless hours doing the tedious work of getting us functioning again.

Change of Address

Please let the office know of any change in address. The post office charges UBPN a considerable sum of money for forwarded mails and especially for "unable to forwards." It would save valuable funds if UBPN has your mailing address changes in advance.

You can phone in your address changes by using UBPN's toll free number at 1-866-877-7004 and leave a message, stating clearly and slowly your new address, or you can e-mail the change to info@ubpn.org.

Brachial Plexus Injury Research Survey Study

The Brachial Plexus Injury Program at Children's Mercy Hospitals and Clinics in Kansas City, Missouri, is conducting a research study to examine social concerns in youth with Obstetrical Brachial Plexus injuries.

The group wants to include youth, ages 11-17 years, with all severities of this injury, including mild, moderate, and severe.

The study will examine factors such as social functioning, self esteem, perceived social support, coping skills, and degree of limb impairment.

Participation in this research study will require parents to complete three forms and youth to fill out five brief questionnaires. This should take about 20-30 minutes for parents and 45-60 minutes for youth.

Participation is voluntary. Only study numbers, and not names, will be recorded on all study questionnaires to keep information confidential.

For more information, please contact the Study Coordinator:

Andrea Melanson, OTR
(816) 234-3380

amelanson@cmh.edu



Outreach

Additional copies of *Outreach* are available in bulk for support groups for the cost of postage.

Past issues of *Outreach* are also available by request.

Call the UBPN office at
1-866-877-7004
to request copies.



MedicAlert®

Free MedicAlert Now Available

UBPN is pleased to announce that through a special grant from The MedicAlert Foundation that they are able to provide sponsored (free) memberships to all children under the age of 18 referred by UBPN.

MedicAlert is able to provide this through the generosity of their membership and the wife of their founder, Mrs. Chrissie Collins, who in a special memorial established a fund in support of children with medical conditions, called The Chrissie Collins Children's Fund..

For more information on MedicAlert, you can visit their website at: www.medicalert.org.

What is provided?

- One MedicAlert stainless steel bracelet or pendant.
- Medical information on file with MedicAlert that can be updated as often as needed.
- Engraving of membership number and the 24 hour hotline number for responders to call for full medical information.
- Engraving of the primary medical condition (Brachial Plexus Injury).
- Or engraving of the words "Call Immediately" which alerts responders that there are multiple conditions on record.

Who is Eligible:

- All children with brachial plexus injuries under the age of 18.
 - Adults will be considered if they have financial difficulty.
- No documentation of need is necessary.

How to Apply:

- Email Judy Thornberry, who is on UBPN's Board of Directors, for an application (judy@ubpn.org).
- Fill out the application.
- Include a cover letter that Judy will mail with the application.
- Send the application and the cover letter to the address given by Judy.



An Interview with Dr. Andrew Price

■ *with Nancy Birk, UBPN President*

UBPN President Nancy Birk recently interviewed Dr. Andrew Price, who is the Director of the Center for Brachial Plexus & Peripheral Nerve Injuries at the New York University Hospital for Joint Diseases.

Could you tell our readers about your medical practice?

I am an orthopedic surgeon who spent a year doing a pediatric orthopedic fellowship. Most of my practice is doing pediatric orthopedic surgery. I am an associate professor of orthopedics at NYU Hospital for Joint Diseases and am also affiliated with St. Luke's Roosevelt Hospital Center in New York and Miami Children's Hospital in Florida, where I travel once a month to care for brachial plexus patients.

Why did you choose medicine as a career path? And particularly, why did you choose to focus on brachial plexus injuries?

I think I went into medicine because, in my youth, I worked as a lifeguard, and I really enjoyed putting a band-aid on a kid's knee. With respect to brachial plexus injuries, it all began I suppose when I was a child and my younger sister had Erb's Palsy. I remember the old statue of liberty splint she had to wear as an infant and the exercises my mother would do with her. Then, in 1990, John Grossman approached me about starting a brachial plexus clinic when we were both at the New York University Medical Center. Even though Dr. Grossman moved to Miami, our program continued to grow. Our program stresses a team approach to brachial plexus injuries and it includes Lorna Ramos and Dottie Bergeron,

occupational therapists. We see patients in Miami and New York.

My experience with my sister gave me a special interest and a unique perspective. From there, we developed a team approach to brachial plexus injuries and the clinic grew.

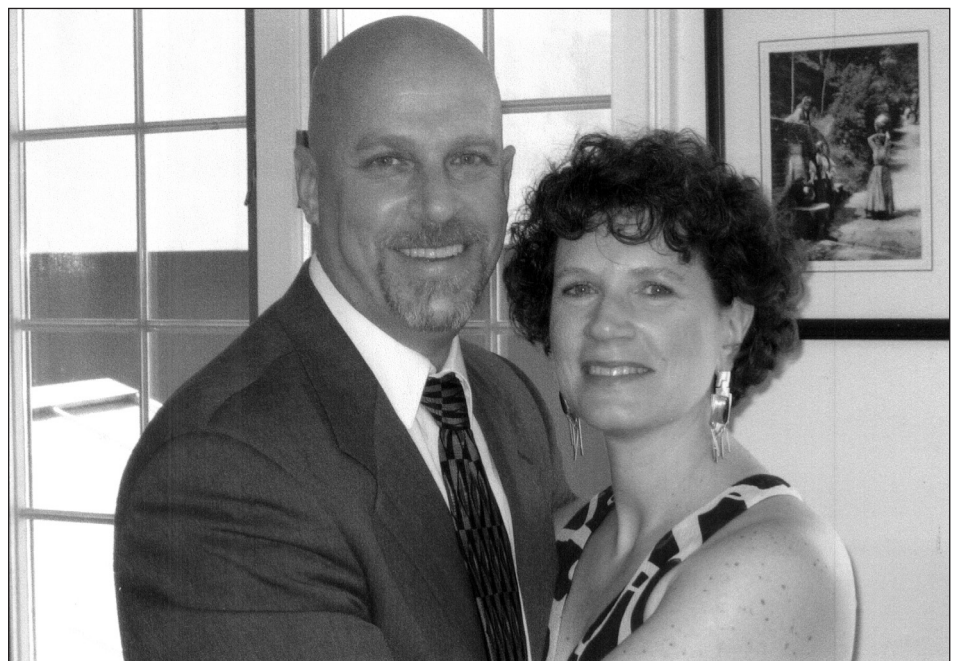
That is truly inspiring and rather a unique situation among brachial plexus surgeons, to have such a personal connection and understanding. Can you tell us more about growing up with your sister? What were your feelings about her injury? What does she think about your choice of profession?

When my sister had Erb's Palsy, the treatment at the time was largely one of benign neglect. She initially was put into a statue of liberty splint made of metal and leather straps and I remember being a little bit repulsed by it as a 5 year old. My mother was given some simple exercises to do, but I don't remember her

doing it that often. My sister certainly did not get OT or PT, but fortunately, she recovered most of her neurologic function. Because my parents' time was not spent on therapies and managing the problem, I didn't experience a lot of what siblings do today. However, my sister had deficits that included posturing of her arm, loss of supination, shoulder elevation and external rotation. She was able to function quite well and it didn't prevent her from doing anything, but it probably had some impact on her confidence, body image and self-esteem. Today, my sister is an attorney, married with two daughters. She is delighted that I have become a specialist in Erb's Palsy and brachial plexus injuries, and likes to know what is new in the field.

How does this injury impact upon the entire family? Do you feel that family therapy should be a part of the whole approach to the injury?

Dr. Price and his sister, Robin Powell



As I mentioned previously, the prevailing attitude in medicine and society when my sister was young with this injury was one of benign neglect. This was probably the result of the article by Sever in 1925, when he reported on 1100 cases of brachial plexus birth injuries, where the half that he operated on did no better than those treated conservatively. Today with advances in microsurgery, intraoperative electrophysiologic monitoring, and understanding of the pathology, the treatment is much more sophisticated.

I think that siblings are probably an untapped resource of therapy. I'm sure they can be taught to engage in play activities that can strengthen, improve motion, or just helping the therapists. I also believe that they can be cheerleaders for our patients and help motivate.

What do you see is on the horizon in the treatment of bpi?

We are working on fine tuning and standardizing the approach to the treatments. Some of the questions that we are working on include what is the best way to release an internal rotation contracture of the shoulder? How much

Dr. Andrew Price, M.D., is a Clinical Associate Professor at New York University Hospital of Joint Diseases and its Department of Orthopedic Surgery . He graduated from the NYU School of Medicine and served in an internship capacity at St. Luke's-Roosevelt Hospital (General Surgery). His residency training was at NYU Medical Center (Orthopaedic Surgery). He served in a clinical fellowship at Newington Children's Hospital (Pediatric Orthopaedics). He is board certified in Orthopaedic Surgery and his medical specialties include Pediatric Orthopaedic Surgery, Fractures, General Orthopaedics, and Compression Syndrome. His medical interests include brachial plexus injuries, Erb's Palsy and neuromuscular disease.

potential for recovery does the shoulder joint have when it has been subluxed or dislocated? In this circumstance, when should we reduce the dislocation and do a muscle transfer and when should we do a rotational osteotomy?

The future will see the addition of nerve growth factors to the fibrin glue substrates that are used during plexus or nerve repair. We also hope to be able to someday "plug" an avulsed nerve back into the spinal cord.

The obstetricians are working on ways to prevent the injury from occurring. They are developing models for training obstetricians how to handle a shoulder dystocia. They are actively engaged in better controlling gestational diabetes and trying to find a way to more accurately predict a baby's birth weight right before delivery. They are trying to learn more about the nuances of shoulder

dystocia and what other factors might contribute besides large babies.

So, the future will hopefully bring advances in both prevention and treatment.

That's a very bright future and we all hope these advances happen sooner rather than later. Thank you for sharing your perspective with us and for all you are doing to advance the treatment of brachial plexus injuries.

Is there anything else that you would like to say in conclusion?

I think is important to mention about the correct approach to this injury is that every child is different and needs to be carefully and individually evaluated by a team and a specific treatment regimen developed. Cookbook approaches to all children with brachial plexus injuries will not optimize the result.

Consider a Donation to UBPN, Inc.

You can make a real difference in the lives of those dealing with brachial plexus injuries by making a tax-deductible donation. Your donations support communication, education and support services that directly help the brachial plexus community. With your help we can continue to reach infants and adults with this injury and to give support to their families. In addition, you may specify that your donation go toward Camp UBPN 2007 or another specific UBPN Program.

Please complete and return the form below, along with a check made payable to UBPN, Inc. to start making a difference right away. As UBPN is a non-profit 501c3 charitable organization, your contribution is fully deductible under IRS guidelines. You may also make a secure, online donation via PayPal.com. The account is donation@ubpn.org. ***No amount is too small – all contributions make a difference.***

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Game On! Sports Participation in Patients with Brachial Plexus Birth Palsy

■ **Robert J. Yu, MA, Peter M. Waters, MD**

Child and adolescent participation in sports has increased dramatically in the US over the last century. This trend is mirrored in the physically challenged pediatric population, which comprises approximately 12% of school-aged children. With this upward trend in participation has come an increase in sports-related injuries. As the director of the Brachial Plexus and Hand/Upper Extremity programs at Children's Hospital, Boston, Dr. Peter Waters and his colleague Dr. Donald Bae see children who during birth have suffered various degrees of damage to the brachial plexus. As an international referral center for brachial plexus birth palsy (BPBP) patients, they see children with this condition on a regular basis. Drs. Waters and Bae recognized that parents of patients frequently ask them whether it is safe for their child to participate in sports, sparking the doctors' interest to try to answer this question. At the time, there had been a lack of research investigating the incidence of injuries sustained by athletes with disabilities and none specifically focusing on children with brachial plexus birth palsy. So, Drs. Waters and Bae conducted a research study at Children's Hospital, Boston with Dr. Nicholas Avallone, an orthopaedic surgery resident-in-training, and other members of the research team to investigate the relative frequency and types of injuries sustained by patients with BPBP during their participation in a variety of sports.

Parents and patients were asked to fill-out a questionnaire regarding the patient's participation in sports. The questions

asked what sports patients played, types of injury that occurred while participating in the sport, when it happened, and how it affected the patient. The goal was to determine if patients with BPBP are at a greater risk than the general population of sustaining an injury during athletic activities, including what types of injuries this group is prone to endure in specific sports. In addition, information was obtained on skill level of participation (e.g., recreational, town league, school league, high school, regional league, or national/professional level). The information on injuries, specific sports, and skill level of participation was

compared to national statistics by age for children.

After almost two years, data was collected on 85 patients ranging from 6 to 19 years of age. Of these 85 patients, 75 played sports. The results are summarized in Tables 1 and 2. Fifty-three patients played 2 sports and forty-two played 3 sports. In the patient's primary sport, 42% felt that they had a disability playing that sport, 14% of children feared being injured, and 7% wore an assistive device while playing. Twenty-five percent of parents feared that their child would be injured in their primary sport and thirteen percent in their secondary sport.

continued on page 20

Table 1. Sports Participation in Study Patients

Type of Sport	Number of patients who participated
Soccer	31
Baseball/Softball	27
Basketball	27
Swimming	10
Football	10
Dance	10
Rollerblading	7
Skiing	6
Martial Arts	6
Gymnastics	5
Tennis	4

Table 2. Level of Sports Played by Study Patients*

Highest level played	Percent of Study Population
recreational	46%
town league	31%
school league	8%
high school	3%
professional/national	2%

* This level of participation and achievement is similar to children without BPBP.

3 Strikes

■ *Laury Hale*

The scene: a Little League baseball field, mid-summer evening. All the familiar signs are there: arms crossed tightly at the chest, firm set to the mouth, rigid stance – and that’s just my husband. I remind myself to loosen my grip on the “baseball Mom” chair and enjoy the banter with the other parents. Our son Eric tucks his glove under his right arm, and gets down to the business of pitching. I’ll confess to general ignorance of the game, but here is what a well-trained parent’s eye sees: a pitch, followed by an in-field grab, followed by a first base out – all done with the left hand, some amazing Jim Abbot-style glove switching and a little right-hand assist. Parents are jumping out of chairs and hooting, kids are running to the mound and my husband Bob and I share a quick nod above the mayhem.

In the weeks of this very special summer league, Eric was a stand-out player. The coaches were exceptional, the kids were great and Eric looked forward to every game. What we didn’t expect was what happened off the field. Parents of other players would pull us aside and tell us our son was inspirational. Both coaches from our

continued on page 24



Eric Hale



The Use of Chinese Acupuncture in Brachial Plexus Injuries

■ *Andrew Grubbs, MD*

I first saw John (the name has been changed to protect his privacy) at the age of 12 following an admission at the local Children's Hospital for depression. His mother had contacted me in desperation to see if acupuncture could do anything to help her son.

John had experienced a left-sided brachial plexus injury at birth and despite several surgeries, extensive physical therapy and multiple medications he still experienced significant pain on a daily basis. This pain had led to depression and problems with anger management. John required home schooling due to the pain control issues.

Classical Chinese acupuncture works on the theory that all people have energy or "Qi" (pronounced "chee") that flows through a series of channels over and in the body providing this energy to the internal organ systems. An individual is healthy if the channels are open allowing the Qi to flow smoothly throughout the body. Any obstruction or blockage of the flow of Qi can result in illness, pain or loss of function of a part of the body. A blockage can occur as a result of direct trauma, a prolonged illness, worry, stress or even some medications such as steroids.

The goal of Chinese acupuncture is to re-establish the flow of Qi to a particular channel, organ system or part of the body. The resumption of the normal circulation of Qi can alleviate pain and aid in the return of function to the involved body part.

There are several ways to open a channel and re-establish the flow of Qi in Chinese medicine. The most consistent effect is obtained by the use of acupuncture needles. These needles are stainless steel, pre-sterilized, one-time use only needles. They are very fine gauge (30-34 gauge). These needles are inserted into well identified points on one of the major 14 channels on the body. It is also possible to try using a technique known as cupping to activate the points on the channels. The cups look like miniature glass fishbowls. The technique is done by pricking the skin quickly with the point of a needle and then inverting a glass cup that has been warmed inside over the area pricked by the needle. The cup creates suction over the acupuncture point that stimulates the point and the channel. The third technique that may be appropriate, is the use of a Chinese herb known as moxa. This herb comes wrapped in fine paper like a large cigar.

The tip of the moxa stick is lighted and held 2-3 inches above the surface of the skin. The heat from the burning herb penetrates deep into the tissues of the body activating the acupuncture points.

All of the acupuncture channels in the arms meet at a single point at the base of the neck. The goal of acupuncture treatment in brachial plexus injury is not only to open the channels of the involved arm, shoulder and neck but also to balance the flow of Qi between both arms and shoulders. This means that whatever treatment is used in the involved arm must be used in the opposite arm.

Chinese medicine also looks at issues involving the emotional well-being of the individual. People dealing with significant trauma and pain over an extended period of time will use up or deplete their Qi. This decrease in Qi will cause problems with the functioning of the internal organ systems. John presented to the office with depression and anger management issues in addition to his chronic pain. Most forms of depression in Chinese medicine are related to deficiencies of the Qi of the Heart. Anger and frustration are related to problems with the functioning of the Liver. Working to correct the imbalances in these organ systems can improve the overall health of the individual.

The initial treatment plan used with John focused on using cupping on points of the back to help control his emotions and to strengthen the organ systems of the body. Over the next several weeks, John did begin to feel more comfortable in the office and allowed needles to be

placed in his arms, shoulders and neck. By the fourth week of treatment, he had stopped most of his pain medications and his mother had noticed fewer complaints of pain and more smiles. He continued to show improvement emotionally and physically during the remainder of the treatment course.

It is usually recommended that an individual complete a course of treatment consisting of 10-12 treatments. At the completion of the course of treatment, most practitioners suggest a break in treatment of 3-4 weeks during which there may be signs of continued improvement. The break is followed by a re-evaluation and possibly a second course of treatment.

The unfortunate aspect of acupuncture treatment is that most insurance companies either do not cover the cost of the treatment or reimburse such a small percentage of the charges that it makes it difficult for the practitioner to provide that treatment at that price. One of the challenges to the brachial plexus community as well as others is to find a way for these services to be covered.

It was quite amazing to see John improve each week. Each individual is unique and not all results will be as gratifying as those experienced by John. However, acupuncture is an option not to be overlooked for those suffering with the long-term effects of a brachial plexus injury.

Andrew D. Grubbs, MD received his medical training at the University of Cincinnati College of Medicine. He obtained his board certification in Internal Medicine and also has experience in Emergency Medicine, Internal Medicine private practice, pharmaceutical research medicine, and geriatric long-term care medicine. Dr. Grubbs formally trained in Classical Chinese acupuncture through the University of Southern California under the instruction of Anita Cignolini, a practitioner of Chinese acupuncture for over 30 years. Dr. Grubbs currently resides in Cincinnati, Ohio where he practices general Chinese acupuncture. For further information, visit his web site at www.AcuMD.com or he can be contacted by calling 513-642-4001.

Key Points From The National Center for Complementary and Alternative Medicine (NCCAM)

Acupuncture originated in China more than 2,000 years ago, making it one of the oldest and most commonly used medical procedures in the world.

It is important to inform all of your health care providers about any treatment that you are using or considering, including acupuncture. Ask about the treatment procedures that will be used and their likelihood of success for your condition or disease.

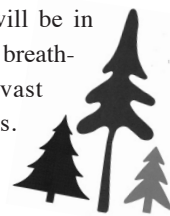
According to the 2002 National Health Interview Survey--the largest and most comprehensive survey of complementary and alternative medicine (CAM) use by American adults to date--an estimated 8.2 million U.S. adults had ever used acupuncture, and an estimated 2.1 million U.S. adults had used acupuncture in the previous year.



Health care practitioners can be a resource for referral to acupuncturists. More medical doctors, including neurologists, anesthesiologists, and specialists in physical medicine, are becoming trained in acupuncture, TCM, and other CAM therapies. In addition, national acupuncture organizations (which can be found through libraries or Web search engines) may provide referrals to acupuncturists.

Join the UBPN Family Tree

Camp UBPN 2007 will be in a setting surrounded by breath-taking mountains and vast stands of evergreen trees. Especially to a visitor, these beautiful trees make a profound impact and they are the most immediate image one brings away from a visit to the American Northwest.



At the last Camp in Washington D.C., we created a fundraising project and formed a paper doll chain with the dolls sponsored both by folks who came to camp and by many who could not come but wanted to participate in some way.

For this next camp, you can join us by participating in our Family Tree project.

We have produced die cuts of several evergreen tree patterns (to match our UBPN Camp 2007 theme). Children will carry the trees into the closing event of Camp, creating a virtual forest. As we did at the last Camp, we will recite the name of each sponsor, along with the sponsor's city and state.

The evergreen trees will be decorated by children at camp during the arts & crafts sessions.

You can sponsor a tree for only \$1 per tree. Funds raised will help to support the arts and crafts at Camp. Why not sponsor a tree for every member of your family?

Send your check to UBPN at 1610 Kent St., Kent, OH 44240 or you can pay via PayPal (www.paypal.com) by indicating donation@ubpn.org in the email address requested on that site. Include in the comment section who the sponsors are, your city and state, and let us know if the donation is being made in honor of someone. We will include all information on the back of the evergreen tree. If you like, send in a photo that can be incorporated into the tree itself (the head must not be larger than 3/4 inch).

We will include photos of this event in *Outreach* and we will also publish a list of tree sponsors.

Let's see how big a forest we can make! How many times can we circle the room?

UCSF-Led Study Suggests Link Between Psychological Stress and Cell Aging

The following press release from the University of California, San Francisco (UCSF), has direct bearing on our families. We all know we feel increased stress. This research not only validates that mothers of chronically ill children feel more stress but reveals how that stress adds to the aging process.

Increasing scientific evidence suggests that prolonged psychological stress takes its toll on the body, but the exact mechanisms by which stress influences disease processes have remained elusive. Now, scientists report that psychological stress may exact its toll, at least in part, by affecting molecules believed to play a key role in cellular aging and, possibly, disease development.

In the study, published in the November 30 issue of Proceedings of the National Academy of Sciences, the UCSF-led team determined that chronic stress, and the perception of life stress, each had a significant impact on three biological factors -- the length of telomeres, the activity of telomerase, and levels of oxidative stress -- in immune system cells known as peripheral blood mononucleocytes, in healthy premenopausal women.

Telomeres are DNA-protein complexes that cap the ends of chromosomes and promote genetic stability. Each time a cell divides, a portion of telomeric DNA dwindles away, and after many rounds of cell division, so much telomeric DNA has diminished that the aged cell stops dividing. Thus, telomeres play a critical role in determining the number of times a cell divides, its health, and its life span. These factors, in turn, affect the health of the tissues that cells form. Telomerase is an enzyme that replenishes a portion of telomeres with each round of cell division, and protects telomeres. Oxidative stress, which causes DNA damage, has been shown to hasten the shortening of telomeres in cell culture.

The results of the study -- which involved 58 women, ages 20-50, all of whom were biological mothers either of a chronically ill child (39 women, so-called "caregivers") or a healthy child (19 women, or "controls") -- were dramatic.

As expected, most women who cared for a chronically ill child reported that they were more stressed than women in the control group, though, as a group, their biological markers were not different from those of the controls. However, in one of the study's key findings, the duration of caregiving -- after controlling for the age of the women -- proved critical: The more years of care giving, the shorter the length of the telomeres, the lower the telomerase activity, and the greater the oxidative stress.

Moreover, the perception of being stressed correlated in both the caregiver and control groups with the biological markers. In fact, in the most stunning result, the telomeres of women with the highest perceived psychological stress -- across both groups -- had undergone the equivalent of approximately 10 years of additional aging, compared with the women across both groups who had the lowest perception of being stressed. The highest-stress group also had significantly decreased telomerase activity and higher oxidative stress than the lowest-stress group.

"The results were striking," says co-author Elizabeth Blackburn, PhD, Morris Herzstein Professor of Biology and Physiology in the Department of Biochemistry and Biophysics at UCSF. "This is the first evidence that chronic

psychological stress -- and how a person perceives stress -- may damp down telomerase and have a significant impact on the length of telomeres, suggesting that stress may modulate the rate of cellular aging."

The link from mind to body

"Numerous studies have solidly demonstrated a link between chronic psychological stress and indices of impaired health, including cardiovascular disease and weakened immune function," says lead author Elissa Epel, PhD, UCSF assistant professor of psychiatry. "The new findings suggest a cellular mechanism for how chronic stress may cause premature onset of disease. Anecdotal evidence and scientific evidence has suggested that chronic stress can take years off your life; the implications of this study are that this is true at the cellular level. Chronic stress appears to have the potential to shorten the life of cells, at least immune cells."

While it is not yet clear how psychological stress impacts telomeres, the team suspects stress hormones may play a role.

The next investigative steps

A next step in the research will be determining if prolonged psychological stress has an impact on telomeres in other types of cells, such as cells of the lining of the cardiovascular system.

The scientists also plan to further examine the impact of prolonged psychological stress on immune system cells, which mount the body's healing response to wounds, and defenses against illness. When the immune system needs to rev up, it produces more defense cells, which requires high levels of the telomerase enzyme, in order to maintain

telomere length, thus allowing for additional rounds of cell division. The current study suggests that, for people under chronic stress, the telomerase activity of their immune cells might be impaired.

The current study represented a one-time snapshot of the biological markers in the women. Both the caregivers and controls were given a standardized 10-item questionnaire assessing their level of perceived stress during the previous month, and measurements of their objective stress (caregiver status, and duration of caregiving stress) were collected. The data was then correlated with the indices of cell aging (telomerase and telomere length).

The team is now conducting a long-term study in which the length of telomeres will be measured repeatedly in participants to test whether the rate of telomere shortening in individuals with higher reported levels of stress is actually faster than in those with lower reported levels of stress.

If the findings bear out, there would be numerous implications for clinical intervention, says Epel. The effect of prolonged psychological stress on telomeres presumably takes many years, which could make it possible to intervene. The team wants to carry out clinical trials to see if stress reduction interventions, such as meditation, yoga or cognitive-behavioral therapy, would increase telomerase activity and telomere length -- or slow the rate of telomere shortening -- in individuals.

At this point, there is not a routine test for assessing telomerase activity or telomere length in cells, and scientists are years away from knowing enough about the correlation between chronic psychological stress and these biological markers to proceed in this direction.

However, if the evidence that telomere length is a risk factor for disease becomes more established, it's possible, the scientists say, that prematurely shortened telomeres might some day be a traditional health-risk factor, such as high LDL cholesterol. And if this were the case, drugs that activated the telomerase enzyme just enough to forestall over-shortening of telomeres might be administered.

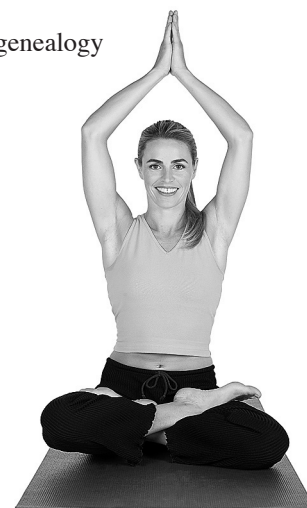
Co-authors of the study were Richard M. Cawthon, MD, PhD, Department of Human Genetics, University of Utah, who also served as a co-senior author; Jue Lin, PhD, UCSF Department of Biochemistry and Biophysics; Firdaus S. Dhabhar, PhD, Department of Oral Biology, College of Dentistry, Molecular Virology, Immunology and Medical Genetics, College of Medicine, Ohio State University; Nancy E. Adler, PhD, UCSF professor and vice chair of psychiatry, and Jason D. Morrow, PhD, Department of Medicine and Pharmacology, Vanderbilt University School of Medicine.

The study was funded by the John D. & Catherine T. MacArthur Foundation, the Hellman Family Fund, the Steven and Michele Kirsch Foundation, the Burroughs Wellcome Fund Clinical Scientists Award in Translational Research, the Dana Foundation and the National Institutes of Health.

Stress Busters

How do you manage stress? What helps you to cope with the difficult task of managing all the worries of everyday living along with the burden of a child with a brachial plexus injury? We asked members of our UBPN Board of Directors (who range from moms & dads of both traumatic and obstetrically injured to folks with the injury themselves) what they do to manage stress in their lives. Here are some of their suggestions:

- having fun with the kids, just letting imagination flow
- have a pedicure or manicure or BOTH
- turn up the music and sing and dance
- play with the family pet
- paint
- go running
- eat chocolate
- baking, cooking
- read a good book
- take a drive, alone in the car, with the music turned up
- walk with the one you love, or go alone
- take an extra hot bubble bath, with candles
- use a Jacuzzi/hot tub at night, with the moon and stars
- pause to take a few deep breaths and stretch
- take action and find a way to be productive about something I find stressful or upsetting
- take unneeded stuff to Goodwill or local charity
- get a haircut or new style
- escape, whether it be a short drive or weekend away
- garden
- watch movies
- work on crafts
- watch old movies
- scrapbook, work on family genealogy
- get a massage
- tai chi or yoga
- metal detecting
- play an instrument
- compose music
- clean out a closet
- humor and laughter
- exercise
- volunteer
- go shopping
- play sports



Straight Talk From Those Who Live It Each Day: BPI Dads Share Their Experiences with Rich Looby, UBPN Vice President

Rich Looby was inspired by a panel at the last Camp in which BPI fathers shared their stories and discussed issues of concern to them. He brought together a panel of both OBPI and TBPI dads for this issue's Straight Talk series and thanks Robert Morgan, Tom Purnell, Bernie Kirkland, and Jeffrey Landry for opening up their hearts to us.

Rich: Tell us something about yourself and how and when your child was injured.

Robert: I am Robert Morgan and my son, James, was injured on November 22, 2003. He was riding an ATV and lost control and hit a tree head on. His head hit a tree and the handlebars caught him under the arm stretching his head, neck, shoulder and arm.

Bernie: My name is Bernie Kirkland. My son, Matthew, now 5, was injured at birth in October 2000.

Jeff: I'm Jeff Landry. Our daughter, Ella, was injured during the delivery in September of 2001 when her shoulders were stuck and the doctor twisted and pulled on her neck.

Tom: I am my wife's husband and my child's dad. I enjoy fencing, running, and photography. I work with computers at a website that is still in business and making a profit in spite of the Internet crash.

My wife was always interested in home births. With home births, it's a more personal experience. In fact, we were going to have an underwater birth in a giant portable tub at home. We had friends who had home births with no problems. We did have concerns about doing the birth at home except, we live two minutes away from a hospital. We even asked our midwife about her experiences and if she ever had any complications. After our questioning, we were more confident in our choice. After all, our midwife had numerous pictures of the kids she helped birthed in her office. Our child would be born in

the room we set aside for him. We figure these would be great memories to start our family.

The birth seemed to be going fine without any hassles. In short, my child got stuck (shoulder dystocia), the midwife pulled, and he was injured. Afterwards, we learned that our midwife was in legal disputes over her license about a child that died during a childbirth she performed.

Rich: Before your child was injured, did you have any experience with disabilities?

Robert: No, I have never had any personal experiences with disabilities.

Tom: I had no experience with disabilities at all.

Bernie: Only limited experience. My daughter started Pre-1st in September, 2000 and was shortly diagnosed with a learning disability and ADHD.

Jeff: I worked as a special education aide for four years as well as coaching Special Olympics for two years. So,

yes, I did have experience with disabled children.

Rich: After the traumatic birth (or accident), were you immediately aware of the BPI injury?

Robert: Not immediately. I knew at the scene of the accident that something was obviously wrong, because he could not move his arm or hand or shoulder and he did not feel it at all either. After several tests were done at the ER, the doctors diagnosed a BPI, but because of all the swelling, they were unsure of the exact nerve damage.

Jeff: Not fully aware. The neurologist stated it was Erb's Palsy, but told us right before we left the hospital that it would go away in a few weeks.

Tom: We didn't know what was really wrong. Our midwife told us we should see a pediatric doctor and suggested one to see. She mentioned he had a limp arm, but 'it would get better.' The doctor told us what was wrong and that started us on our BPI journey.

Robert Morgan is 38 years old. He is married to Priscilla and has two children, Jessica (age 19) and James (age 13). He grew up and still resides in Bakersville, N.C., a very small town in the Western N.C. Mountains. Robert works with his parents and his brother in a family owned and operated business, the Morgan Oil Company. His hobbies are sports, mainly football, baseball and softball, and he has coached little league sports for 15 years. He also enjoys antique cars and trucks which he take to shows, and fishing and spending time with my family. He is also a member of the Bakersville Masonic Lodge #357 where he serves as the senior deacon and belongs to the Oasis Shriners and is a member of his local Baptist Church.



Bernie: Yes, but I was unaware of what the injury was formally called or what the extent of the injury was.

Rich: *How did you feel when you found out about the BPI injury?*

Bernie: We were told by the nurse taking care of my son that he wasn't moving his arm. The first thing I asked was if it was serious and if he would get the movement back. I was told 'yes.' We were told to keep the arm protected and immobilized.

It wasn't until a couple of weeks later when we saw a pediatric neurologist that I was informed of the severity and extent of the injury. At that time, I was told of the possible long-term effects and the permanence of the injury.

I was devastated after hearing this. I was afraid of the unknown and wondering how my son would do over time. I wondered how he would be treated and I was crushed to know that we, as a family, would most likely have a tough time ahead of us. All I wanted was a "normal" life, free of any extra obstacles.

Tom: For me, it doesn't make a difference. My child was born with this injury. It's a part of who he is now. My goal is to help him learn about his injury (his difference), and how to live like a normal child.

Of course, my boy is only two. I don't know how my feelings will change in the coming years when he becomes more active.

Jeff: Nervous, sad, and extremely angry with the people involved with the situation.

Robert: I was shocked. It took a few months to really grasp what it was and what the doctors were telling us. They did not really tell us a lot at first. What we learned, we basically found out on our own when my wife researched it on the internet.

When we took James back for a follow up, we had a lot of questions for the doctor. Even then, we still did not quite realize this was for life – that it would totally change his life. He would

Tom Purnell is 33 years old and shares his life with son Joshua and lovely wife Kate in Santa Clarita, California. He works for an online company programming for their website. His hobbies include photography and period fencing.

never be even close to 100 percent recovered, and did not realize the other medical complications he could possibly have throughout his life because of it.

Rich: *What were your immediate fears for your child?*

Jeff: After learning the full extent of the injury I was afraid that she would have no use of her left arm.

Robert: I guess my immediate fear was if it doesn't get any better, will the doctors have to amputate. How will James physically and mentally cope with that and if not amputate, how will he manage the rest of his life with only one arm and hand?

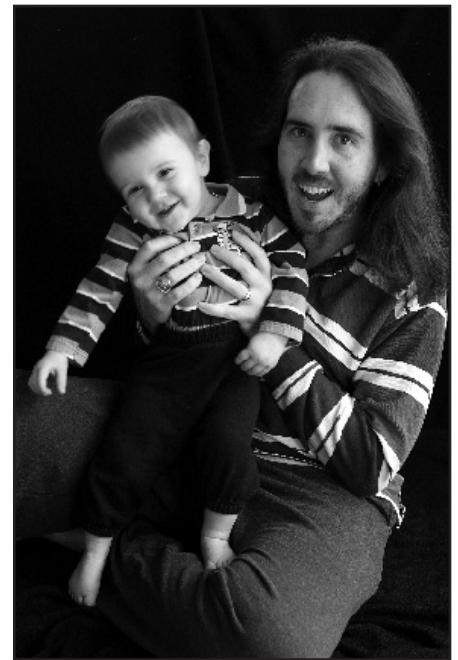
Bernie: There were two immediate fears that overcame me. One was how would he function without the use of one arm. The second was that he would be different.

Tom: That he'd run into the street after his favorite ball and our neighbor who drives home chaotically would run over him like a speed bump.

Rich: *How involved did you become in the medical decisions in regards to the injury?*

Tom: My wife has done all the research on doctors and treatments. She keeps me informed of all these matters. However, we both make the decisions. We're well aware that we made a mistake trusting our midwife; we're not about to make the same mistake twice. We always research the doctors we talk to and get second opinions to help us make decisions.

Robert: I have always been involved in the medical decisions for James. I got involved in the best way I knew how. I have always been to his doctors appointments and at his side through every test he has had and there have



been a lot. I go to his physical therapy appointments and ask a lot of questions trying to understand, questioning different opinions from different doctors and therapists. My wife, our daughter, and James's grandparents and uncles have been very involved also.

Bernie: I was 100% involved and my wife and I make all decisions together.

Jeff: Very involved. Anything to benefit my daughter is number one for me. My wife makes sure to keep me up to date with any treatments or studies that could help Ella.

Rich: *How did the care of the injury affect your time? Your employment?*

Bernie: I had to miss time at work for appointments and his first surgery. I had just started my job and had to miss most days without pay.

Jeff: It took a lot of time for traveling to doctors and other specialists and/or appointment for therapy. Play time when she was an infant turned from play to therapy time. With employment it means taking the necessary time off for appointments, whether it would be a few days, or leaving work early.

Robert: The caring for James and his injury has affected my employment. I work a full time and a part time job. I

continued



Bernie Kirkland and his wife, Kelly, have two children, Jamie (10) and Matthew (5). He grew up in a small Pennsylvania suburb just south of Philadelphia and now resides in Millville, NJ, where he works as a construction inspector and surveyor for a civil engineering firm. He enjoys spending time with his family, watching Red Sox baseball and NASCAR, fishing, hunting, and reading. The Kirklands just bought their first home last May, and Bernie says that most of their time (and money) goes toward home improvement projects.

was out of work a lot in the first year of his accident. Doctor appointments, therapy, school meetings, and because I work for my family-owned and operated business, my mom, dad and brother had to pick up my slack at work while I was out. It affected our business as a whole. It affected us financially.

Tom: There was no effect on my employment. Luckily, my wife is able to stay at home and do some consulting on the side. My boy has a very active schedule and my wife is able to make sure he is at all his appointments. With the help of the government, my boy does physical therapy two times a week. He is also enrolled in swim classes and gymnastics.

Rich: How did the injury affect the dynamics of your family?

Bernie: It was a huge shift for us. We had just found out about our daughter's disability and now were faced in dealing with both at once. We went from "normal" lives, to having to now deal with two disabilities. Unfortunately, our daughter's problem took a back seat to Matthew's injury. It was unintentional but still had an effect on her. She was six years old and was used to getting all the attention. But now with Matthew's injury, he got most of the time. It really had a dramatic effect for the first two to three years after the injury as our son had two surgeries.

Tom: The injury made us aware of our medical situation. We are more forward with doctors and always push for what we think is right. This is our only child (for now), so there are no problems with other children being neglected.

Jeff: It changed a lot in the beginning. My wife and I were very stressed. My older daughter missed a lot of quality time with us on a whole. She had to see her sister wearing splints and casts at too young of an age where she couldn't understand exactly why.

Robert: James' injury has affected the whole family. We are stronger than ever. We have pulled together to do what's best for each other, so that as a family, we can do what is best for James.

In the beginning it was a little more tough, everything concerning James' accident/injury took up so much of our time and energy with hospital stays and appointments. It was very tough on our teenage daughter. For a while we were not able to do the usual activities as a family and had to do things that James could be comfortable doing. Our daughter felt, at times, left out. Maybe she even felt a little jealous and that we were 'hovering' over James a little too much. As they both get older, it seems to be balancing out. Jessica does not cut him any slack, and treats him (most of the time) as if nothing's wrong with his arm. James seems to appreciate that.

Rich: What currently are your biggest concerns for your child, your family and any other children?

Jeff: That she will get a better range for her arm and be able to do whatever she wants without problems or feeling

different. And, of course, for them both to be as happy, healthy, and fulfilled as possible.

Robert: My biggest concern for James is right now to continue on with his medical treatment to try to regain as much use of his arm and hand as he can. And to try to not let it overcome him in such a way that it effects his schooling or effects him emotionally or physically more than that it already has.

Of course, I am very concerned about what he will do and how he will do it when he gets out on his own. What types of jobs are available to him and there's always the concern of his mental state. A lot of times, people become very depressed over things they can and can not do as a adult. We will be behind James in whatever he chooses to do, he just may have to adjust to doing it a little differently than everyone else, as he already has now.

My concern for the family is that we can and will always stay close, open and communicate with each other. That we try not to let James' injury rule our lives, and basically that my wife and my health stays well enough, and our jobs continue on because the financial part of all of this has definitely put a serious strain on us all.

Bernie: My biggest concerns now are maintaining the progress my son has made and making sure he lives a normal life. I don't want him to feel different.

My biggest concern for my family is making sure we enjoy all the things in life we should. I try to focus on all the positives in life, and not be bogged down with the problems that coincide with a BPI.

My biggest concern for my daughter, now 11, is that she realizes she is just as loved and important as Matthew is. The

Jeffrey Landry is 29 and lives in Waterbury, CT with his wife, Krista, and two daughters, Hannah (age 7) and Mariella (age 5). He grew up in Naugatuck, CT and currently works for the family construction company, and is waiting on his real estate license to begin a real estate profession. His hobbies include music, art, sports, going to the beach and doing fun things with his girls.



first 2-3 years I know were tough on her because she was young and most likely thought that we loved our son more because he received more attention.

Tom: My biggest concern is if he'll be able to do the things he wants to do. I'm sure he'll be bullied in school. We'll have to handle that when the time comes. I can only try to instill confidence in him and teach him how to defend himself. I'm not too concerned about the family. In the end, his birth brought and continues to bring us closer together.

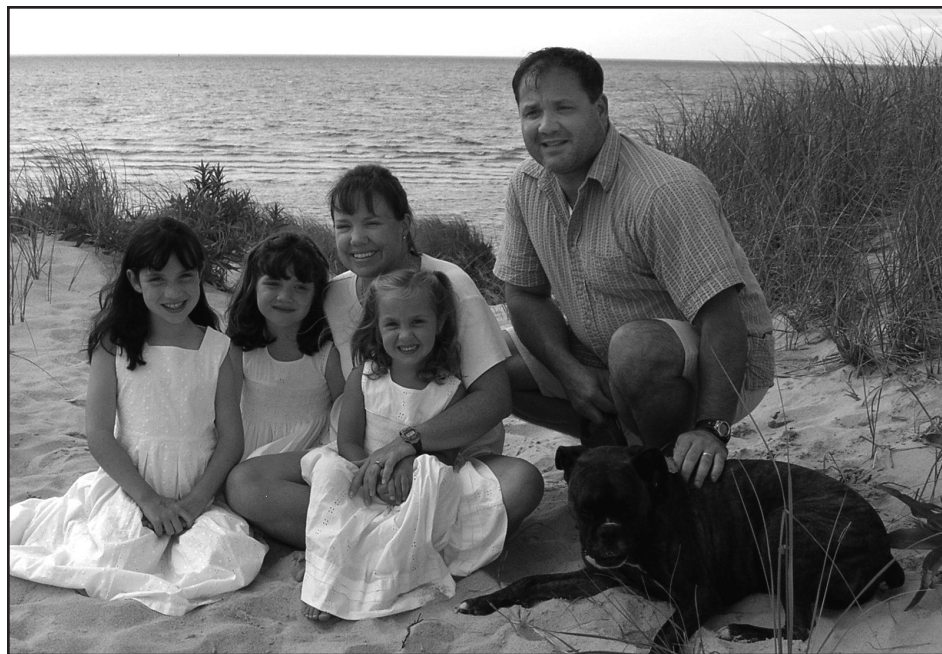
Rich: *Do you feel there is a benefit in regards to your child's development because of this injury?*

Bernie: Yes. He has learned to know what it is like to have to overcome the problems associated with a disability. He also knows what it is like to be different; however, it doesn't affect him negatively and he realizes that he has certain limitations yet remains strong and without fears.

Tom: Oh yes! There are so many things he is doing now because of this injury. We have traveled across the country finding good doctors (We went through five before we found the doctor we liked). He's been to Boston and Philadelphia. He is involved in swimming and gymnastics. I didn't get to do these things as a kid. It's also a humbling experience and it will make him a better adult in the end.

Robert: Sadly, in a way, yes. James' injury has made him a more mature and responsible child. He thinks differently, acts differently. He is more conscious of his decisions. Yes, James has benefited from it, but we continually weigh the 'pros and cons' of what it's cost him too.

Jeff: No injury is a benefit. She is a very outgoing and strong willed little girl. To say that doing things differently, or having to adapt, affects anything in that regard is too early to tell, but I doubt it anyway.



The Looby Family from left: Kailyn, Julia, Lisa, Sarah, Rich, and Boxer dog, Roscoe.

Rich: *What hopes do you have for your child?*

Jeff: That this injury or its long term effects never get in the way of her doing what she wants in life.

Bernie: The same hopes as every other parent. I want him to succeed at every task he takes on. I want him to live a normal life unaffected by his injury. I want him to grow and live a productive and fruitful life. In fact, I want him to live a better than average life. I dream of him coming to bat at Fenway Park in Boston as a Major League baseball player and the most important part is that no one will look at him any differently or view him as disabled.

Robert: That he can come to terms with his injury in a positive way. Keep a positive attitude, strive to do his best in school and hope that whatever he chooses to do with his life that it's something he enjoys doing and can do it well. I hope he will always have the 'never give up' attitude that he has, and things will be as normal for him as possible. And that people will not look at him on the outside and judge him or not give him a chance. The biggest hope of all is that he continues to walk with the Lord and let Him be his guide.

Tom: All the hopes a father can have for his child.

Rich: *What story about your child most inspires you?*

Robert: There's not only one story, but there have been many. The last two and a half years! James himself is an inspiration with all his determination and his witnessing to other kids. Sometimes they wonder why he doesn't feel more sorry for himself, and once he was asked by a friend "how can you be so upbeat all the time?" James answered, "The Lord helps me."

Tom: He seems too young at this point to inspire me. I am just inspired to work harder and support my family because of him.

Jeff: How before during and after her surgery she was a trooper. She calmed me down, and never missed a step.

Bernie: There isn't one particular instance. Honestly, he inspires me everyday with the way he handles himself and the way he doesn't let anything get him down with regards to his injury. At the age of five, he has gone through a lot, more than most adults. He has dealt with two surgeries,

continued on page 25

My Experience with TBPI and Severe Chronic Pain

■ *Christopher L. Janney*

After living with a traumatic brachial plexus injury and the severe chronic pain associated with it for nearly four years, I am only now beginning to understand the ramifications of my injury and the diverse, permanent impact it has had on my life. What I hope to do here is offer insights from my very personal journey that might allow a fellow sufferer some solace, useful information, and basic support, so that their path to even slight relief might be shorter and smoother. I will endeavor here to give a raw and honest portrayal of my path with this injury. Although some of what I share may seem gruesome or overly descriptive, this is the one angle I wish someone would have shared with me from the start.

Since the onset of my injury, I have had to learn not only about how to live with the reduced mobility and utility of my limb, but also about an entire universe of adverse effects for which life did not prepare me. I have had to learn what the word “pain” can really mean; I have had to learn about the impact of depression on pain and vice-versa; I have had to learn to write left-handed and to face the constant rage of losing the use of my dominant arm and hand; I have had to learn about the very complex and potentially dangerous role of pain medication; I have had to learn about the insidious nature of chronic pain in one’s life; I have had to formulate a new self concept in response to so much that before seemed simple and second nature to me. This is not to say that my life before this was a limited or cloistered one. In fact, my life previous to injury was far from that!

I am the youngest of three very daring and athletic brothers. This essentially

meant a childhood of broken bones, constant scrapes and bruises, and innumerable trips to the emergency room. My youth set me up to be familiar with the concept of injury, pain, and recovery. I have a vivid memory of being about twelve and watching a National Geographic program on television about some indigenous tribesmen that would pierce their cheeks with long steel rods. I remember the amazement and admiration I felt watching this man’s incredible self-discipline and control. At that time, one of the ways of “out doing” my brothers was by being the ultimate risk taker. So naturally after watching my kindred spirit with his metal rod, I thought, ‘wow, if I could stick a pin through my arm I’d totally out do them!’ So, I did it. Further details aside, let’s just say it was an important lesson about the role of the mind in experiencing and moving through pain.

Examples about my experience with pain go on from there. When I’ve rattled off the litany before, it sometimes seems so excessive that I can hardly believe it myself. I had broken 16 bones by the time I was 21, I’ve been stabbed three times, shot, and survived bladder cancer.

The cancer was removed via my urethra, which then had to be scoped every six months for ten years until I earned a clean bill of health. My spectrum for experiencing and describing pain was obviously very broad.



Chris Janney while on a ski trip in Tahoe, CA.

In the many medical visits since my injury, I have had to offer this brief history about my relationship with pain because I wanted the doctors and specialists to understand that an eight on the pain scale of 1-10 meant something very different to me than it might to someone else.

The pain associated with my brachial plexus injury blows away anything that I thought I knew about pain. This pain can be so intense that I cannot talk, breathe, or think. I often forget what I was talking about

mid-sentence. I’ve had to ask someone speaking to me to “shut up, just stop talking,” so I can concentrate on dealing with the surge of pain. The pain could even be exacerbated by the sound of speech. My hypersensitivity to sound is very similar to the hypersensitivity that my hand has to touch – which can be so raw and intense as to make even the softest of cotton feel like razors dragging through my fingers. My pain comes in wild flurries, like a Molotov cocktail exploding in my brain with burning gas spreading all over and torching my mind and senses. Somewhere in between this fiery hell comes the sharp sensation of gardening shears slicing down the center of my fingers, over and over.

I’ve spent countless hours reworking my definition of the entire concept of pain. I’ve had to counteract the confusing questions of whether pain is just a form of perception or if it is a tangible, “real” thing. In some hours I’d struggle with the question of ‘Can it be

fake? If the injury is healed, then why can't the pain be gone?' Or, 'Maybe if I just tell it to go away enough, eventually it will.'

I know that pain is one of mankind's basest emotions and without it we'd soon die. Because I know this, my "new" pain was even more confounding. How could I expect to fight something that is hardwired in to every cell of my being and designed to elicit a specific response of "fight or flight"?

What I slowly figured out was that I'd have to learn to give myself some space between the input (the pain) and the impulse to react. What I am now slowly discovering is that this "space" is the key to my daily perseverance. I have discovered that the magic that lives within that space is choice! Pain is not the choice, but rather, suffering is. I figured out that no matter what I could say about the pain, and how to define it or experience it, the only thing I could actively and immediately impact was whether I would live "suffering" from it. Today, I hope that this lesson will be key to improving all aspects of my life, not just my relationship to pain.

One important influence in this thinking has been the writing of Viktor Frankl, a holocaust survivor who wrote Man's Search for Meaning. Frankl describes how some people in the camps had an internalized sense of purpose attached to their "suffering" which he thinks contributed to their ultimate survival. For some reason this hypothesis has really resonated with me and made a serious impact on the way I look and my experience with chronic, severe pain. In his book, Frankl writes:

"Dostoevsky said once, 'There is only one thing I dread: not to be worthy of my sufferings.' These words frequently came to my mind after I became acquainted with those martyrs whose behavior in camp, whose suffering and death, bore witness to the fact that the last inner freedom cannot be lost. It can be said that they were worthy of their sufferings; the way they bore their suffering was a genuine inner

achievement. It is this spiritual freedom - which cannot be taken away - that makes life meaningful and purposeful."

Even with this newfound understanding about pain and "suffering," I cannot gloss over the fact that the road has been long and this new perspective slow in coming. I can easily say that this "new" kind of pain nearly killed me. It fueled a depression like nothing I ever imagined for myself. Pain became my great isolator; it forced me into an immediate withdrawal from the outside world. I had a hard time being the guy in a room or in a group who had to grunt or grit his teeth every few minutes. I found it difficult to think about anything else beyond pain and nearly impossible to translate this experience to even my nearest and dearest. I was not sleeping well, eating was a chore, and I couldn't write, never mind the more exotic tasks like getting dressed, taking a shower, or cooking.

The inability to find a reference for this pain or any validation from those closest to me, and from even some of my caretakers, was probably the most unexpectedly difficult part. If there is anything I would say to someone who is newly facing this pain that I think can help right away, it is simply to acknowledge them and say, "I know this kind of pain doesn't make sense, but I know it is real; you are not alone and you are not imagining it."

Medicating Pain

Initially, I found that pain medications were very helpful and supportive in terms of facing the reality of my injury. Naturally, the surreal experience of surviving a traumatic injury, combined with the paralysis of your dominant hand and arm, was a lot to deal with, and the indescribable pain just made matters worse.

The medications were important in terms of giving me a break and a chance to sift apart the bombardment of hyper-intense physical and emotional feelings. I stayed on them for nearly three years – a fact I now regret to some degree. I

think I would have most benefited from them for only six months. The greatest problem I see now with the length of time I was on the medications was their collective effect on my depression, which I actually think then created a cyclical effect on the pain and my experience of it.

I know that each person's experience is unique, and I encourage pain sufferers to forge their own plan for a life managing pain, but I feel very strongly that we must all exercise caution when choosing to stay on pain medications indefinitely. I think it is of prime importance to educate yourself and to have due diligence when making the decisions to get on and stay on pain medications.

Not unlike my familiarity with pain, I have also had a deep familiarity with the power of human emotion and its impact on quality of life. My education, training, and experience as a working actor in Hollywood has fine-tuned my "emotional instrument," and like my pain awareness prior to injury, I thought I knew myself and the possible range of my emotional state. Yet again, with the advent of this injury, I learned something new. The injury itself, the pain accompanying it, and the depression of loss and isolation rendered me suicidal. I was so deeply despondent that I thought about suicide nearly 30 times an hour – all day, every day. I lost my fire and spark for life. I lost my capacity for hope or optimism. I had very little ability to see the value of friends and family, or to nurture those connections.

Looking back, I think that this numbness to life was a side effect of the medications. Yes, I was experiencing some pain relief, but I was also sitting in the passenger seat of my life. I think the drugs flattened my spark and ability to fight and the survival instinct that had served me throughout my life was missing. My awareness of this change in my nature depressed me further.

I spoke frankly and openly about my serious contemplation of suicide, much to the horror of my family. I did

research on different methods of dying at one's own hand. I made timelines and schedules about when might be the best time to go. I eventually made a pact with my family that I would agree to live at least until the three year anniversary of my injury. I also made a silent pact that if I were to commit suicide I could only do so after being free of pain drugs for at least six months. Herein began the steps to a new direction in my story with pain.

It took some heavy duty re-educating and re-programming to even begin slowing down my suicidal thoughts. I knew that if I was ever going to get off the medications I would need serious help.

I was fortunate to learn about the Bay Area Pain and Wellness Center in Palo Alto, CA, which I credit with providing me the right kind of information and support that anyone with this injury should have. My time at the clinic ignited my ability to even contemplate a med-free life. At this center I learned about the relationships between pain and depression, nutrition, sleep, exercise, and meditation. Through rigorous daily exercise, guided meditations, nutrition classes, and paying attention to my sleep habits, I slowly gathered the tools to redirect my interpretation and response to pain. The most significant element however, was just the basic camaraderie. Meeting professionals who understood and other people who also lived in pain, to whom I could describe my intense and strange feelings, was such a necessary boost to me. I was not alone and I was not imagining it!

It was the first time in the years since the onset of my injury, that I felt I might have any control in my experience, not just my understanding, of this pain; that I could be free of the empty suffering that came with this pain and no longer be just a slave to it. This exposure and structure allowed me to find the courage to eventually get off the medications.

I finally got off of all the pain drugs. The process of withdrawal was awful, but only second to the initial accident that left my right (dominant) lung,

chest, shoulder, arm and partial hand paralyzed. Withdrawal from Methadone threw me into a state of perpetual nausea, headaches, and body tremors for weeks and weeks to come. It was much worse than I'd imagined it would be. And now that the medication that blanketed my whole neurological system to protect me from the pain was gone, I was left with the constant biting/gnawing/burning/crushing pain that so often made me wish I were never alive.

An unexpected positive aspect quickly emerged though; as I experienced increased pain by getting off the meds, I realized that I also got back my mind, and with that, the will to fight! While on the pills, I had lost the "fight" in me and not believing it was the drugs that were responsible for its departure, but my own failure to overcome circumstance and depression, I seriously and continually considered taking my own life.

A Clinical Pain Trial

Another fortuitous thing happened around the same time. Last December I was supposed to be climbing the mountains of Nepal for one month. I wanted to get as far away from my world as I possibly could on the third year anniversary of my accident. To my dismay, in the weeks before the trip while trying to prepare my severely out of shape and atrophied body for the ordeals of climbing snow covered mountains up to an altitude of 18,000 feet, I threw out my back. I had to face a frightening possibility – being stuck in my home, alone, on my anniversary, and having to face the upset of how my once rich and fulfilling life had changed so drastically just three years before.

Two days before the anniversary, as I wallowed in the dread of the very real possibility of being home alone for my third anniversary and on Christmas, I was bestowed with another twist of fate. I visited Stanford University's website to find contact information for some of the doctors I had worked with. I came across a notice seeking participants for an ongoing clinical trial on pain reduction.

Clinicians were taking real-time functional magnetic resonance imaging (fMRI) scans of the brains of chronic pain sufferers, and relaying the scans, in real time, via 3-D goggles to the patient while inside the MRI machine. They were essentially using a three million dollar bio-feed back machine to study whether people were able to "see" and then manipulate their own pain levels.

At the very least, I could spend the anniversary doing something to move forward and deal with the pain hurdle of having a TBPI. I called and asked if they still needed participants. They did and asked me to come the next day. I packed my bags and made the six-hour drive that night.

I learned that there are two main regions of the brain responsible for our perception of pain (the rostral anterior cingulate cortex and the limbic system). The fMRI is able to detect blood flow through those regions of the brain. To put it simply, if you can control the blood flow, you can control the pain. I also learned the differences between the physical awareness of pain and the emotional context of that pain. The emotional response to pain has a great deal of impact on how we experience it physically.

When you are in the machine, the feedback is relayed in one of two ways. One way is with an image of your brain and the blood circulating through it's pain regions. The other, is with a computer generated scene of three fires set on a beach at night with the ocean in the background, each fire represents one of the pain centers of your brain. The more fire visible meant more blood was flowing through those areas. This fire imagery worked best for me.

Before I was scanned, they made a plastic mesh mold of my head so that it could be bolted down to the retractable fMRI table to hold me steady so clear images of my brain could be taken. Then physiological system monitors were placed on my body to detect blood oxygen levels and blood pressure. This insured that I wasn't effecting the

outcome of the scans by my breathing levels. Each round of scans was about twenty minutes in length, and we sometimes did more than a few rounds back to back.

My first instructions were to try and be aware of the relationship between the size of the fires and my current pain levels. This was to be done by a total pain immersion experience. I was to concentrate on the minutest details of the pain that rages through my arm and then imagine it consuming my whole body.

As soon as I drew my attention to the raw burning of my hand, and how much I hated it as it spread up my arm and into the rest of my body, the three fires on that beach began to roar! The more I focused, the higher the fires would reach. I could make the screen inside my goggles fill with fire.

That was a strange and surreal, yet ultimately empowering moment. I realized that if I could make those areas of my brain light up, then I could very well quiet them down. This was a huge personal victory. Now I had some kind of impact on what had been an uncontrollable torment eating me alive. Remarkably, as soon as I felt the glee from this new achievement, the flames died down to coals of a spent campfire.

For the next two weeks I would stay with my brother and his family in San Francisco, making the daily drive south to Stanford University and for three to four hours climb inside this machine, which I prayed might hold the answer to the riddle that was psychologically crippling me.

As I spent more time getting to know how to “control” my brain, my spirits began to lift. At long last, I was empowered. Never before had I considered that if I learned how to concentrate on and increase my pain, I might be able to concentrate on feeling good and alleviating the pain.

I had forgotten all about the impending anniversary and felt fortunate not to be traveling abroad, but to be right where I was. Until then, losing the functional use

of my arm, yet living in severe pain was confounding in its futility. The time at the pain trials finally made me feel like this accident and the pain might have a purpose, and my life an objective, that as a part of the scientific trials, my injury and thus my life might be of some value after all.

While I was strapped down inside that fMRI machine I found a number of techniques to increase and decrease my pain. I was told by the end of week one, that in the two years of clinical trials, I was the most able at controlling the increase and decrease of blood flow through the brain’s pain regions. This was a great feeling, in the sense that I was doing it right, but I never experienced a pain free moment during the trial. I could reduce a two to three minute oncoming pain surge by about 80% of its wrath in about seven seconds which was an awesome feeling of achievement and possibility, but I was still in serious pain.

Even so, I was seriously affected by my success and by the sense of possibility I’d relearned through the visualizations. I partially credited my strong ability and success with the imagery work to my pre-TBPI career as an actor and my well-formed imagination. The areas responsible for pain are located like an upside down triangle in the brain; one in each opposing hemisphere a few inches inward from the temples is responsible for the actual tactile perception of pain and the third region is in the lower center of the brain and is associated with the emotional context of the oncoming pain signals. So when I would imagine a pain situation or a non-pain situation, I would place myself in an imaginary circumstance in which not only would all of my physical senses be activated, but also my emotional senses as well.

One of the my visualizations to instantly induce pain was to graphically imagine the horror of my four year-old niece being alongside me in the midst of a roasting fire, and that it was my fault that she was there, dying. I’d heighten

the emotional intensity by imagining that I could do nothing about it. With this sense of helplessness, I’d let myself be overwhelmed by the guilt of what I’d done to put her in this situation and the horror that it would never end. Like in acting, I would activate my imagination with the most specific and visceral thoughts possible, and if one didn’t work, then I’d roll on to the next in order to maintain that heightened negative emotional state. I would often come out of the fMRI machine with my face drenched with tears from my imagination. This felt strange, but again, empowering.

The visualizations then directly impacted my understanding of how to change the blood flow positively and negatively into the pain centers of my brain.

Every session in the fMRI machine started with a segment of delving into the pain experience and stimulating those pain regions of the brain. Then there would be a 30 second rest period followed by the attempt to eradicate the pain. This was my favorite part of the trials. Engaging the imagination in as much stress-free pleasure as possible, while enlisting all my senses to experience what my imagination was creating, and getting to “watch” it all with the brain scan information I was receiving back on the 3D goggles was sheer joy.

The two visual settings that worked quite well were of me flying. Here is where I’d really focus on the details and how they made me feel. Sometimes I’d be flying through the Swiss Alps in springtime: over tall fields of grass, whisking by falling leaves from nearby trees, and over meadows of colorful flowers with enchanting scents, dipping through warm and alternately cool pools of water, through the spontaneous sprinkle of a midday rain, then up closer towards the sun to warm my skin and soaring back down into green valleys again, happily somersaulting through the air as I laughed to myself.

continued on page 25

A Few of Our Favorite Things

Members of the UBPN online community were asked to share items and ideas that have been helpful to them in living with a brachial plexus injury. Helpful tips came in from both TBPI's and OBPI's and their parents. We hope you will find some new things that will enhance your everyday life.

I can't do without my shoulder bag. I bought it in Holland 17 years ago from a street vendor. It's leather and a perfect size and I've carried it with me ever since to every school and place I've worked

Henry

As a parent of a ROBPI who lives in Illinois, I cannot live without the mittens that are half gloves and half mittens. The fingertips on the gloves are cut off and the top half of the mitten flips over to cover those cute little fingers. My son is seven and they have saved tears many a morning. They are so much easier than regular gloves or mittens and he can do it himself.

Gayle, mom of Brandon

I do believe that my favorite thing in the long run of Joe getting a TBPI is the great and wonderful FRIENDSHIPS that we have both made. No gadget can help when just a good old fashioned HUG is what one needs. Everyone at the UBPN and the message boards are, without a second thought, MY FAVORITE THING!

Traci

I love my one handed can opener. It is made by Hamilton Beach. Also, my pizza/dough roller by Pampered Chef – it is made for one hand rolling.



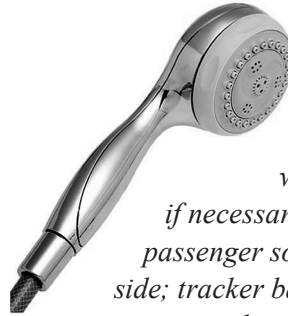
Judy

My laptop. Until I was injured, I didn't even have a computer--now it is essential.

Onepaw

I cannot live without my Handicapped Parking Card and my rubber, or soft & furry balls of the right size (depending on level of contracture or pain) for my LBPI hand.

Carolyn



Front loading washer & dryer with drawer underneath for storage; a wall oven; cutting boards with rubber handles so that they don't move while I am cutting; my suitcase with four wheels that can be pushed with one finger if necessary; a cover for my seat belt when I am a passenger so that the belt does not press on the bpi side; tracker ball mouse so that I am not constantly moving my shoulder; and shower heads that can be moved or hand held so that it is easier for me to rinse my hair.

Kath

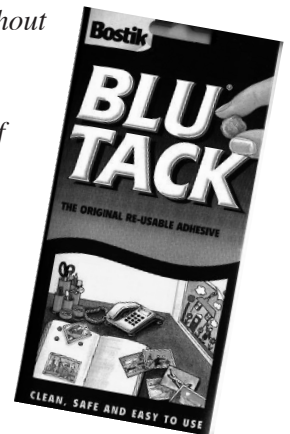
I do find that Blu Tack (<http://www.artech-electronics.com/us/products/accesso/blutack.html>)

is the best thing ever invented. Without it, I wouldn't be able to make the jewelry I make. Also, one-handed G clamps are very useful for all sorts of things.

Lizzy

I'm not BPI, but I would say SUPPORT is the thing I wouldn't want to live without.

Peggy



I recently purchased a rock replica made out of clay. It heats up like a tea bag and has different points for different areas of your body. I can use my good arm and reach around to the shoulder area of my poor arm and massage it.

Rachel

As a mom of a bpi child, we need the velcro invention; the rice bags that you can warm up in microwave to place on a cold arm/hand especially in the winter; elastic waistband on pants; most important though, we need a big sense of humor and lots of LOVE!

Louise

I am LOBPI. For many years I dealt with left bra straps that kept falling down. I found a product called, "Under Cover Comfy Straps." The package says, "Wear Comfy Straps on your shoulder to stop bra strap slippage and



ease shoulder discomfort. Discreet under clothing - place Comfy Strap on each shoulder, open flaps and position bra straps inside." They work! It stays where I put it, even when I put it out a little way in order to accommodate a more open neckline. No more falling bra straps for me! The interiors are made of silicone but don't irritate my skin.

They are made by TRULIFE of Dublin, Ireland. The web site is www.trulife.ie.

Another product I have found to be very helpful is the LIDS OFF Jar Opener by Black and Decker. I've had one for a year or two, and so far, it has always worked for me.

Joanie

Definitely my car, with power and heated seats. Also my handicapped sticker. It has been a lifesaver.

Pat

Chris' physical therapist gave him a book called "One-Handed in a Two-Handed World." After Chris looked through it, he realized he'd already figured out how to do a lot of those things by himself. He uses his feet to pick things up off the floor sometimes. The book lists certain products that can be purchased to help also. A speaker cell phone in his car is also essential – that could be an accident waiting to happen if he didn't have that.

Chris' Mom

I love my arm rest for the computer keyboard, it lets my shoulder relax and I can use a regular mouse with my right hand; an adjustable shower head makes it so much easier to rinse my hair; a lap top size keyboard makes it easier to sit in a comfortable position or lay down so my back does not hurt as badly; office type chairs with arm rests are the best for me; and a digital camera that automatically turns the pics back to the up-right position when I take the pic upside down because I am ROBPI.

Amy T

My husband built me a stand for my dryer! I have had it for several years. He built the first one for my mother. Once I saw how easy it was to get clothes out of the dryer I asked for one! Another gadget that I love is my Gizmo can opener with one-handed operation; a hand held shower is a must; and my small pig pillow. It tucks under my BP arm, right in the arm pit, while I sleep and offers support. Another shape that works well is a heart. Also, therma pads that stick to your clothing and provide heat to the area.

Joy in FL

I can't live without my cutting board with the two metal spikes in it to hold the item I'm cutting!

Carolyn from LA



The E-Z Squeeze -- this little gadget is the biz! <http://www.chefsresource.com/ezs-100-2.html>

Jacko

I love my left handed scissors. Plus, my Niwashi for gardening is fabulous, I don't know how I managed without it. If you like gardening I can't recommend this tool enough and it's available in a left handed version too. Weeding and digging are so easy with it. <http://www.niwashi.co.nz/niwashi.htm>

Jen from NZ

When showering, a long handled mesh sponge. It's a lot easier to use than a washcloth. Also, soap in pump containers or flip tops is easier than fighting with bar soap. Squeezable containers for some foods like jelly and butter that would be hard to spread sometimes are helpful, too.

Priscilla

*Hate driving without one of these:
<http://www.thehotrodgirl.com/suicideknobs.html>
or*

http://www.shrunkenheads.com/catalog/car_accessories/knobs/misc.asp

There are even custom ones that you can place your own photo inside.

Christopher



Game On!

continued from page 8

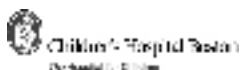
Twenty percent of children experienced an injury in their primary sport, but most were bruises or sprains/strains. Only two patients suffered upper extremity fractures: one during football, the other while rollerblading. The type, severity, and frequency of injury were not different statistically from national statistics on children.

Patients were asked to complete the Pediatric Outcomes Data Collection Instrument (PODCI), a validated questionnaire that attempts to measure functional outcomes in pediatric orthopaedics. It includes functional outcome measures of upper extremity function, transfers & basic mobility, sports & physical function, comfort/pain, happiness with physical condition, and an overall global score which combines all of the categories. The modified Mallet Classification, Toronto Score, and Active Movement Scale were also used to assess function and predict outcomes for the BPBP patients.

Overall, the results were encouraging. Patients who played sports did not have a different PODCI global score than those who did not play. Sixty-nine percent of participants had surgery at Children's

Hospital, Boston for their BPBP and showed no differences in their PODCI, Toronto, or Mallet scores compared with the normal population. The results did show that the cohort's PODCI score means for global (86.6), upper extremity (78), and comfort (84.1) scales were lower than the normal population. There was no significant correlation between the Toronto and Mallet scores and PODCI Sports scores.

Although there were differences in global function, upper extremity and comfort scores in patients with BPBP, most of the children participate in and enjoy a variety of sports. They sustain injuries at a rate similar to the general population and their surgery did not limit their participation in sports. They achieve a level of skill similar to other children. The Brachial Plexus Program at Children's Hospital, Boston hope that this study will give BPBP patients and their parents the data to make informed decisions about the risks involved in participation of certain sports. We do not advise restriction of activities, including sport participation, and leave this decision to the child and their parents.



The Brachial Plexus Program at Children's Hospital Boston is a regional, national and international referral center for children with brachial plexus birth palsy. For the past ten years, our surgeons,

nurses, and therapists have been providing comprehensive care to infants and children with acute and chronic brachial plexus palsies.

Microsurgical nerve repair and reconstruction of the less common, devastating nerve injury is performed in the first 3 to 6 month of life.

For the more common infant with a birth palsy who shows signs of significant recovery in the first six months of infancy, physical and occupational therapy is utilized to optimize outcome during the first two years of life. In older children with incomplete recovery, tendon transfers and osteotomies are commonly performed to improve function and prevent deformity.

Our center has extensive experience in all of these procedures and has published our observations and results in peer-review journals and surgical textbooks extensively in the last five years. We are more than happy to provide consultation for you and your child with brachial plexus birth palsy.

For more information about our services or to schedule an appointment or consultation at Children's Brachial Plexus Program, please contact us at:

Ph: 617-355-6021 fax: 617-739-1093

3 Strikes...

continued from page 9

team made it a point to talk to us about Eric, prefacing their remarks by saying "I know you don't like to make a big deal out of this, but..." A coach from the opposing team approached us after a game, shaking his head and smiling. "Is that your son? I haven't seen anything like that since Jim Abbot."

Our family's journey is probably similar to yours. In 1996, we happily anticipated having a new baby in the mix and a sibling for Brendan, then 3 ½. You already know how the story unfolds. A traumatic birth, a brachial plexus injury, the agonizing first weeks and finally, trying to understand everything there is to know about BPI. There is a lot of explaining to do when your child has BPI – coordinating doctors and therapists and later on, teachers, babysitters and coaches. As Eric moves through grade school, kids ask "What's wrong with your arm?" and "Why is your elbow bent all the time?" We rehearse and practice answers and before long, I overhear Eric explaining, "It's how I was born". I still "run interference" by talking with new coaches or parents of his friends. If Eric is with me, I pause so that he can explain his injury in his own words. My voice, my need to explain, diminishes each year.

Back at the baseball field, another night, another game. The umpire watches Eric warm up, then calls for a conference with the coaches. Can't let him pitch like that, he'll get hurt. Ah, maybe you should watch him a bit more, says our coach. One inning and three quick outs speaks volumes. And as for Eric – he continues to find his voice with a ball, a glove, a racquet, a hoop and any chance he can get.



Straight Talk...

continued from page 17

countless hours of therapy, splints, physical limitations yet he has soldiered on. I have always considered both he and my daughter to be my heroes because they have both stood up to whatever life has thrown at them

Rich: *What one piece of advice could you offer new fathers whose children are BPI?*

Jeff: Be patient, be knowledgeable, and don't break the OB/GYNs arm off even though it would be extremely satisfying

Robert: My advice to fathers whose children are TBPI. At first, things will be overwhelming. Be patient and learn all you can about the injury. Recovery is slow but Rome was not built in a day. Pray a lot and remember the Bible says all we have to have is the faith of a mustard seed.

Tom: Always look up your doctor's license. Always get a second opinion even if you agree with your doctor. If anything, just to assure you're making the right decision in the first place. Don't be afraid to push your doctor or ask questions. They're getting paid enough to sit through your questions and tolerate your pushing.

Remember, it's your child's injury, not yours. They'll have to deal with it the rest of their life. You only have to deal with it until they're 18.

Bernie: Remain positive and never give up hope.

Rich: *A permanent injury to the brachial plexus is a life altering event for the individual, but also has ramifications for the family of the injured. In past editions of Outreach, we have heard the perspective of Teens and Mothers. Here we have presented the Dad's point of view through answers to a series of questions. We had many other volunteers to participate, and I want to thank everyone who expressed interest. I especially want to thank these four men for volunteering their time to respond to the questions and share their thoughts about their children.*

Living With TBPI...

continued from page 21

If I ever took notice of a pain flurry in my hand, I'd immediately change the vision and move away from the sun, to a moonlit night and imagine feeling a little cold so that the fire in my hand was a good thing and that I actually needed it to heat up the rest of my body. I'd look down on the shrinking Earth knowing that all of my pain and suffering were stuck down there, far away from me, and I'd smile in relief.

I know this may seem a silly thing for a grown man to be doing in a three million dollar machine, but it was all done in the noble name of science, and my very real pursuit of pain relief and sanity. And I think it has genuinely helped me. I learned so much about the power of the mind over pain during that time at Stanford, that I still find myself resorting to some of the techniques. Try it yourself sometime; pick an image of your pain or pleasure and just go for it! I do however highly recommend that you also focus on breathing deeply when you do this; the few times when I try to employ my imagination to work through a pain surge and it doesn't work at all, its often because I am also holding my breath.

Moving Forward

Living with the complex layers of feelings and issues related to TBPI is no simple matter. Getting off pain medications is another complicated aspect as well, and requires a huge leap of faith. Unfortunately there is no way to do it fast, and it is a painful process that requires a great deal of support. I strongly recommend using the resources of organizations like the United Brachial Plexus Network, and the Bay Area Pain and Wellness Center and others closer to you, in order to bolster your awareness and your plan for living with this unique pain.

I do not profess to be an expert in anyone's experience of injury and pain, but I can firmly say that I am on intimate terms with my pain. I can offer no magic bullet for dealing with it. I do know that my entire perspective on pain and the real "meaning" of it have changed drastically since my injury. I have learned that my emotional attitude to the pain can directly impact the mechanical workings of the pain. I have learned to focus on expanding the choice, that magical space between pain and suffering. I am more optimistic than I have been in the time since my accident, but I also know that I am only just getting started. I am still going to have to learn how to make a constant effort to find moments of not being emotionally or physically consumed by pain.

My life has gotten a great deal better than it was three years ago, and I am starting to imagine that it can get better yet. It has now been almost a year without pain medications, and I am still alive. I made it to Nepal earlier this year, and have begun to think about where I might like to travel next. I am not planning my demise, nor do I still sit in the passenger seat of my life. It is true that I still experience awful pain, but I have determined that I will not simply suffer in vain from it. I have found a way to acknowledge it, breathe with it, sleep a bit more with it, have conversations with it, be in relationship with my loved ones with it, and I am thinking that there actually might be a chance that I'll actually be able to live with it.

Sample Letter to Schools

Thanks to Claudia Strobing for sharing a copy of the letter she uses to communicate with her school district about her daughter and her brachial plexus injury. All information contained in brackets would be edited to represent your child's individual situation and limitations. You may want to clarify your child's diagnosis with his/her attending physician. Personal pronouns in this document have been written as applies to a girl but obviously would need to be changed throughout for a boy.

Information on Brachial Plexus Injuries Specifically Regarding [Insert Name of YOUR Child Here]

What is the Brachial Plexus?

It is a bundle of nerves responsible for the movement of shoulder, arm, elbow and hand.

What is a Brachial Plexus Injury (BPI)?

Damage done to any or all of the nerves, resulting in loss of movement and/or paralysis of any or all parts of the arm and shoulder. This can also result in a loss of sensation.

What are the Types of Injuries?

Obstetric injuries (which [Insert name of YOUR child here] has) account for the largest portion of the injuries in children and are sustained by newborns during the birthing process. It is classified as a birth injury. A traumatic injury can be incurred via automobile accident, climbing accident, motorcycle accident or athletic endeavor. These usually occur in older teens and adults.

What are the Levels of Injuries?

Many Obstetric Brachial Plexus Injuries (OBPI) involve only a stretching of the nerves and result in minimal or no long term effects to the arm and hand. However, a percentage of those injured at birth have permanent disabilities due to severity of the injury. This involves torn (ruptured) nerves and nerves pulled out of the spinal cord (avulsed).

What is the Treatment for a BPI?

Occupational and physical therapy are the standards of care. In severe OBPI cases, parents may choose a surgical option. As brachial plexus injuries cannot be cured, surgery is an option, not a requirement. However, therapy alone may not accomplish what therapy and surgery together can do. Not all patients will choose to have surgery even if it is recommended. All types of additional therapies can be a part of treatment including: aqua therapy, horseback riding therapy, sensory integration therapy, as well as daily massage and range of motion exercises.



How Does BPI Affect Her?

Brachial plexus injuries have far reaching effects. It is now widely believed that this is not "an injury to the arm" alone but it affects the entire body. [Insert name of YOUR child here] also has Horner's syndrome, which affects her left eye (poor peripheral vision and drooping), left ear and sweat glands. In addition, [insert name of YOUR child here] has very poor sensation on the affected side and consequently suffers from sensory issues. She is sensitive to light, sound and smells; very common with a severe obstetrical injury. She would have naturally been (left/right) dominant, but has been forced to switch hands. She also may become uncomfortable in a chair and may prefer to work standing up. She may also be sensitive to light, sounds and have difficulty with required writing tasks.

What Does This Mean for [insert name of YOUR child here]?

[Insert name of YOUR child here]'s injury is considered [Insert descriptor here; for example, SEVERE, or MODERATE]. She is a [Insert side of injury] OBPI. [Describe injury, example follows. She has had three nerves fully damaged: C-5, C-6, & C-7. She also had two nerves stretched: C-4 and C-8. She has had 3 surgeries to date and will possibly have one in the Fall. She will never be fully functioning. Her injury is permanent.] Part of this injury may also be sensory.

What Can My Child Do?

[Insert name of YOUR child here] can do most everything everyone else does. She can do art projects, play with playdough, music, play on playground equipment, play sports, and swim. [Add or delete items as necessary.]

What Can't My Child Do?

[Insert name of YOUR child here] functions in a mostly one-handed world. [In the description that follows, you should add or delete items as needed for your particular situation and comfort level] She is NEVER to hang from her arms. She is NEVER to be pulled by her left arm. If you try to hold hands with her left hand, she will probably tell you to switch to her right. She is fairly accomplished in dressing and undressing, although coats are tough, she is quite independent. If she needs help with her coat, inserting the [left] arm first makes it easier.

She is capable in toilet activities and prefers to do them unassisted. She can try any sport but she will find her own way of doing things. She runs with her left arm fully extended. She has a tendency to fall and/or trip. Her vestibular system was also damaged. We have worked hard to retrain her brain and it has worked well. However, new terrain and tiredness will combine to make her prone to falls. Her elbow does not bend well, so she does a lot of activities in front of her. She will have difficulty carrying a tray of food, so she may need assistance. Her left hand is weak, so two-handed fine motor activities will be a challenge. She will not shy away from an activity, she will just try to do it one-handed. You can offer to help. Or let her do it her way.

Transportation Issues?

[Insert name of YOUR child here] will need to be carefully watched getting on and off the bus. As she can't really support herself with her left arm, she is prone to falls on the large steps of the bus. Additionally, she cannot carry her backpack on both shoulders. She can hold it in her non-injured hand or wear it over her non-injured shoulder but never on her injured side. She can use a rolling back pack.

What Can You As Her Teachers/Counselors Do?

[What follows is an example of what you could write.]

[Insert name of YOUR child here] is a wonderful child, so enjoy her. She has come out of her shell this year and is much more personable than she has been in the past. She still suffers from some shyness - three surgeries in two and a half years will

do that to you! - but gets over it fairly quickly. Ask her if she needs your help, don't just jump in and do things for her. She gets insulted by that. Her injury is not the elephant in the corner, so to speak, but we don't talk about it all the time either. You are not therapists, and I don't expect you to be. She expects you to treat her as you do all the other children. She has sensory issues, especially with her injured arm. She also has mouth sensory issues and so she doesn't like to try new things.

Offer new things to her as you do the other children, perhaps she will try something and learn to like it!

Also, please put sunblock on her injured arm if she goes outside in the sun. For reasons not fully understood, the BPI arm burns faster than the unaffected arm. Also, motor planning issues exist. So please help her get started on projects.

An Additional Note From Mom and/or Dad:

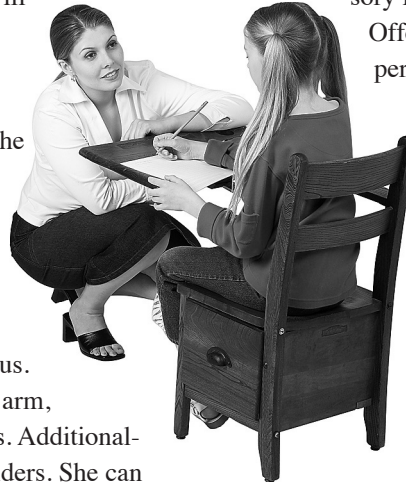
[Address any additional concerns that you may have as a parent here. One example follows.]

I cannot stress how important it is to NOT PULL ON THE LEFT ARM. [Insert name of YOUR child here]'s surgeries were designed not only with function but form in mind. Her injured arm 'looks' not unlike her uninjured arm, do not be swayed by the look. Her arm can easily be re-injured.

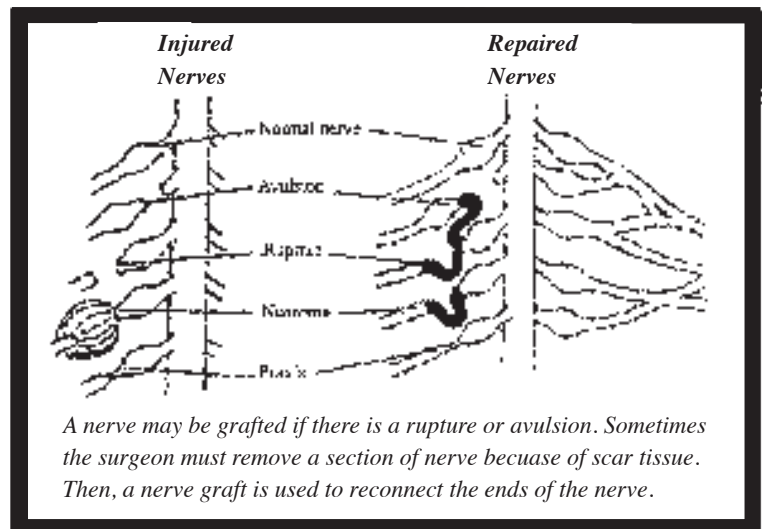
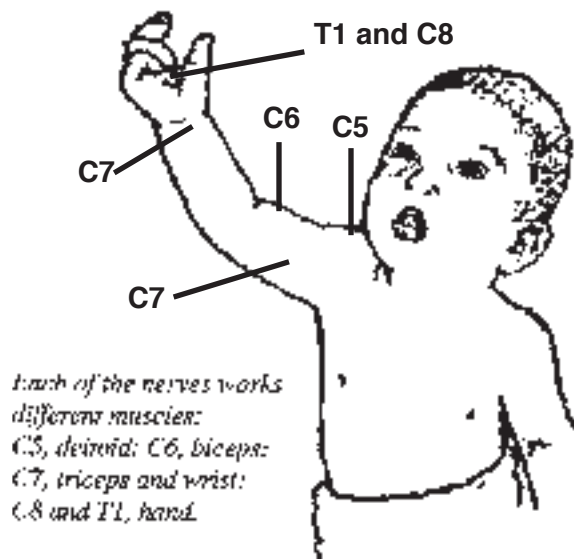
If you have ANY questions, please call me. Thanks, I look forward to a wonderful school year.

[Name of parent]

[Contact information]



For Your Information: Diagrams For Reference



Awareness Items Order Form

UBPN Gund Stuffed Puppy Dog



Quantity _____ x \$20 = _____

Ribbon Car Magnet



Quantity _____ x \$5 = _____

Reaching Out 4 BPI Bracelet



Quantity _____ x \$4 = _____

_____ Adult _____ Youth

UBPN Jewelry Ribbon Pin (Each bag includes 20 pins)



Quantity _____ x \$5 = _____

UBPN Ribbon Pins



Quantity _____ x \$10 = _____

Zipper Pulls



Stop Quantity _____ x \$1 = _____

Ribbon Quantity _____ x \$1 = _____

All prices include shipping. **Total \$** _____

Name: _____

Address: _____

Phone: _____

Please send check or money order payable to:
UBPN, Inc. at 1610 Kent Street, Kent, OH 44240

Credit card payments are also accepted through
Pay Pal <<http://www.paypal.com>>.

The payment e-mail address for UBPN is donation@ubpn.org.

Awareness Items For Sale!

UBPN Gund Stuffed Puppy Dog – \$20

UBPN has teamed with Avon Products to offer these high quality GUND puppies. Extremely soft and adorable, these puppies would make wonderful gifts for any occasion. (Not available from local Avon representatives).



Ribbon Car Magnet – \$5

This is a new item for UBPN and the UBPN community helped pick the design and colors. It will be metallic silver and blue. Funds raised will go toward the Camp UBPN Sponsorship Fund. The center part of the ribbon magnet can stay with the ribbon or it can be removed to use as a separate magnet.



Reaching Out 4 BPI Bracelet – \$4

Also a new item, these great silicone bracelets have debossed text that says REACHING OUT 4 BPI on the top portion of the bracelet and on the opposite side ubpn.org. A blue bracelet is available for adults. A youth-size (which will also fit small adult wrists) will be a marbled blue, aqua and white (see photo.)



UBPN Jewelry Ribbon Pins – \$5

The UBPN Bell Pin is a long-standing tradition. Made of die-struck pewter with nickel plating for a shiny silver appearance, this pin is not only a beautiful accessory but could provide an opportunity to bring awareness to a admirer!



UBPN Ribbon Pins – \$10 for 20 pins

These handmade ribbon pins are an economical way to show your support and bring awareness to the brachial plexus cause. Packaged in quantities of 20, these pins are an ideal way to show your support and help your friends and family show support as well!



Zipper Pulls – \$1

These **new items** can be used on zippers on coats, jackets, backpacks, suitcases – anywhere that you want to draw attention to the cause! They are easy to grip and will assist those with a brachial plexus injury with the difficulty of zipping. We are pleased to add an item that is useful to those with bpi's and also a great way to raise awareness. Please be sure to indicate on the order form which pull you prefer.

