

# Outreach

Spring 2007  
Issue #20



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#### On The Cover:

*Featured on the cover are Farren and Tanner, siblings from Arizona. Farren is one of several siblings interviewed for this edition of "Straight Talk." You can read this insightful and fun article beginning on page 9. This edition also features the accomplishments and celebrations of our community. For additional pictures and descriptions, see the complete photo essay on pages 26 and 27.*



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**UBPN, Inc.**  
**1610 Kent Street**  
**Kent, OH 44240**

Toll Free or Fax: 1-866-877-7004  
Web Site: <http://www.ubpn.org>  
Executive Editor: Nancy Birk  
Editor and Design: Kim West  
Outreach Founder: Bridget McGinn

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## President's Letter: An Update from UBPN President Nancy Birk

### **Camp**

We have been very busy at UBPN preparing for another wonderful camp. You will find information and registration in the center section of this issue. This will be our fourth UBPN-organized camp. Our first camp was in the Rocky Mountains of Colorado, our second in the Adirondack Mountains of upstate New York, and the third was near Washington D.C. at the National 4-H Conference Center. This year, our camp will be at Camp Berachah near Seattle, Washington.

As you will see in our camp information, this is the first time that we have planned a camp that is close in location to the camp coordinator. I know it will make Karen McClune's task much easier this time around, having camp in her own state. It is still a huge effort on her part, and we are grateful for the many hours, days, weeks, months and even years, that she has devoted to making camp a wonderful experience for each person who attends. I know you will enjoy this camp, which will combine the best of our traditional camp activities in a spectacular location in the Pacific Northwest with educational opportunities. Previous campers have noted that the bonding experience that comes at camp is something that is life altering, for all ages and for each member of the family.

You will be astonished to see that the cost of camp is greatly reduced from the previous camp. For a family of two adults and two children, the savings will be more than \$120 for the three night stay. We have worked hard to negotiate a price that is affordable for our campers, knowing that getting to the Seattle area will be expensive for some. We are hoping that this will allow those who have wanted to come to camp for some time to be able to finally afford it. Please register early, both to get the early bird rate which waives the registration fee, and also because we expect camp to fill up quickly as it did last time. We had to turn people away for the first time.

*continued on page 4*



UBPN President Nancy Birk (third from left), along with Claudia Strobing (first from left) and Judy Thornberry (fourth from left) attended the recent Narakas Meeting in Puerto Rico as representatives of UBPN. They are pictured with meeting organizer, Dr. Jose Borrero.

We are also pleased to announce that we have received a community grant from eBay that will completely fund our premium activities at camp – the therapeutic horseback riding, go-karts, zip line and climbing wall. We are still seeking funding for dedicated use of the swimming pool and of course, we always need funding for sponsorships, so those in financial need can come to camp.

At past camps, we have filled up the schedule with overlapping programming. In the evaluations, participants felt that this was too much activity and they emphasized that the best part of camp was the bonding experiences that they had with others. We have planned camp this year to capitalize on those kinds of experiences. We will certainly have programming that will facilitate learning about the injury but our focus will be more on what our past campers have said we need to do at camp.

## Prevention Program

Camp has not been our only focus. Our programs continue to grow stronger to meet the needs of our community. Our newest program, the Prevention Program, will undertake a new initiative to see that obstetrical brachial plexus injuries are counted and coded appropriately in each state. This will need to be a grassroots effort as we aim to oversee the efforts of each state. Stay tuned to the website for updates on this program which will be guided by program co-chairs, Rich Looby and Lisa Muscarella.

## International Brachial Plexus Surgery Symposium – Puerto Rico

I had the opportunity to speak about the role of UBPN at the 15th International Symposium on Brachial Plexus Surgery organized by the Club Narakas in San Juan, Puerto Rico. Attending with me were fellow members of the UBPN Board of Directors, Claudia Strobing and Judy Thornberry. This was the third Narakas meeting that I have attended and I have found, each time, that the doctors who are treating brachial plexus injuries are simply an incredibly dedicated group of individuals. This is not your typical medical conference, instead it is a group of colleagues getting together to discuss and argue about what is the best way to treat our specific medical condition. The doctors continually challenge each other and with such challenges, we see change and improvement. Kudos to these doctors for all that they do and not being afraid to invite support groups to participate in their discussions.

## Website

With the help of John Petit and Ryan McClune, I have been able to convert our website to a place where we can finally make changes quickly and keep it updated. Kathleen Kennedy has been overseeing the revisions to our Medical Resource Directory and we continue to add more doctors and clinics as they come in. More changes are coming and we hope to get the registry soon to a place where it will be an asset to help local support groups find people in their area.

I'll close now with my urging that you come to camp. I'd love to connect with you!

  
Nancy Birk, UBPN President

## Please Register Online

The UBPN Registry is available on the UBPN web site for your use ([www.ubpn.org/Registry](http://www.ubpn.org/Registry)). The Registry is a great way to establish contacts with others in your area and will be helpful for support group leaders.

Separate entries are provided for individuals, support groups and professionals. You can choose how much of your information will be available on the web site for the public to see. Please complete as much of the entry forms as possible, as it will help us when compiling demographic statistics that are needed to pursue grant funding. Please direct any questions about the Registry to [web@ubpn.org](mailto:web@ubpn.org).

## 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](mailto:info@ubpn.org).

## Additional Outreach Copies

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.

## 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  
almelanson@cmh.edu



## Looking for a Specialist?

The Medical Resource Directory project, located on the UBPN web site at <http://ubpn.org/medicalresources/> provides a comprehensive, regularly updated resource to aid families and individuals in their search for specialized care. Lists of BPI medical specialists including therapists are provided.

All known brachial plexus specialists/therapists were sent a questionnaire requesting information regarding their practice and experience with BPI. Responses continue to be submitted and changes are made as they are received.

## A Search With Benefits

What if UBPN earned a penny every time you searched the Internet? Well, now we can!



GoodSearch.com is a new search engine that donates half its revenue, about a penny per search, to the charities its users designate. You use it just as you would any search engine, and it's powered by Yahoo!, so you get great results.

Go to [www.goodsearch.com](http://www.goodsearch.com) and enter United Brachial Plexus Network as the charity you want to support or visit UBPN's home page ([www.ubpn.org](http://www.ubpn.org)) and click on the GoodSearch button. This will take you to the search engine and our cause will already be filled in. You can even download a tool bar that will sit at the top of your browser screen.

Just 500 of us searching four times a day will raise about \$7,300 in a year! Be sure to spread the word to all your friends and family!

## eBay Awards Grant to UBPN

eBay Foundation recently awarded a CHAMPION A CHARITY grant of \$2,500 to UBPN. The grant was made possible as a result of Josh Birk, an eBay employee, who "Championed" funding for our organization. Funds will support Camp UBPN 2007.

eBay Foundation's CHAMPION A CHARITY program encourages employees to become involved with and advocate funding for nonprofit organizations that work to improve the quality of life for all. A competitive program through which grant decisions are made by an employee committee, eBay Foundation CHAMPION A CHARITY grants are only made to organizations recommended for funding by eBay employees.



Josh Birk, an eBay employee, is the son of UBPN President Nancy Birk. Thank you Josh for championing our cause!

## New UBPN Program for Youth Announced

Hello! My name is Joshua Aten. I am 17 years old. I have an obstetrical brachial plexus injury on my right side. I think it is important that kids and teens have a voice within the Brachial Plexus community and I want to work to make that happen. I have been assigned by the UBPN Board of Directors to oversee the creation of a task force within UPBN. Its name is Outreach for Kids and Teens. It is dedicated to kids and teenagers with obstetrical brachial plexus injuries and traumatic brachial plexus injuries. The role of this group is to find ways for kids and teens to participate in the BPI community. This includes coming up with programs for the upcoming camp in Auburn, Washington. This group is very new and needs members. If anyone is interested, feel free to contact me at [atenhouse1@gmail.com](mailto:atenhouse1@gmail.com).

# What is a Brachial Plexus Injury?

The term Brachial Plexus Injury (BPI) refers to an injury to the complex set of nerves that control the muscles of the fingers, hand, arm, and shoulder. The nerves originate at the spinal cord and are formed in 3 trunks located in the upper shoulder: the upper trunk from spinal cord segments C5 and C6, the middle trunk from segment C7, and the lower trunk from segments C8 and T1.

## Other Terms for BPI

Terms used to describe a BPI include Erb's Palsy (an upper trunk injury), Klumpke's Palsy (a lower trunk injury), Brachial Plexus Palsy, Erb-Duchenne Palsy, Horner's Syndrome (when facial nerves are also affected), and "Burners" or "Stingers" (usually associated with sports-related brachial plexus injuries). Torticollis is another term sometimes used in conjunction with brachial plexus injuries.

## Types of Injuries

Injuries to the Brachial Plexus can involve:

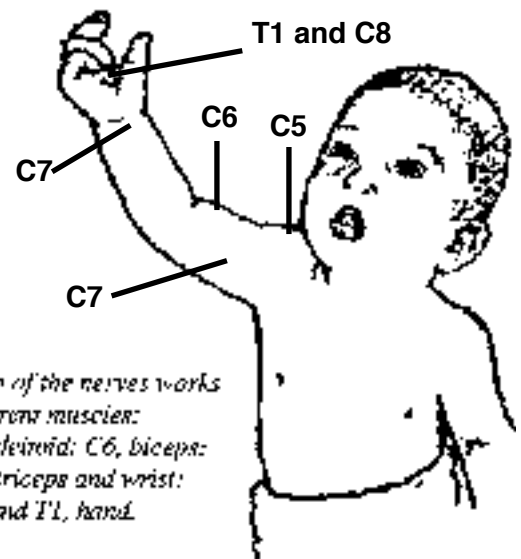
1. tearing the nerve from the spinal cord (an avulsion)
2. tearing the nerve but not at the spinal cord (a rupture)
3. scar tissue where an injured nerve has tried to heal putting pressure on the nerve and disrupting signals to the muscles (a neuroma)
4. stretching but not tearing of the nerve where the nerve is able to heal itself (a praxis). This is a temporary condition where the muscle regains complete function.

Denervated muscle can cause imbalances resulting in muscular and skeletal deformities in the elbow and shoulder. Also, the development of the affected arm can be compromised resulting in a shorter limb.

Injuries to the Brachial Plexus can result in full to partial paralysis of one or both arms with a temporary or, when the nerve cannot completely heal, a life-time injury. While compromising muscle function and the ability to grasp, extend, and reach with the affected limb, the injury can also affect physical appearance.

## How Injuries Occur

The Brachial Plexus can be damaged in a number of different ways including accidents involving high impact conditions (automobiles, motorcycles, snowmobiles, sports) but most brachial plexus injuries occur during birth with a condition called Shoulder Dystocia (SD). The baby's shoulder becomes "stuck" against its mother's pubic bone changing the otherwise normal delivery into an emergency situation. Various SD

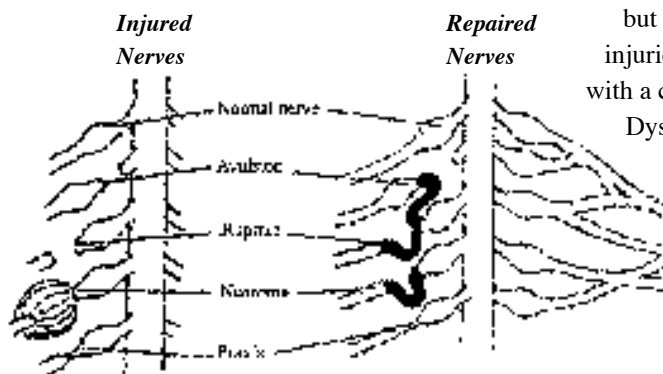


maneuvers may be used to complete the delivery; but, in the process, excessive force can be applied to the baby's neck and head resulting in stretching and/or tearing of the Brachial Plexus nerves.

More than one Brachial Plexus trunk can be injured in any of the above conditions, resulting in unique set of nerve injuries for each individual. Thus, diagnosis of the injury requires a careful neurological examination by a brachial plexus specialist to determine which nerves have been affected and the severity of the injury. Such diagnosis should be completed as soon as possible.

## Medical Treatment

Brachial plexus injuries are treated with neurosurgery to repair damaged nerves (primary surgery), surgeries to transfer tendons and muscles thereby improving functionality (secondary surgery), physical therapy (PT) to improve strength and range of motion, and occupational therapy (OT) to deal with issues of every day living.



A nerve may be grafted if there is a rupture or avulsion. Sometimes the surgeon must remove a section of nerve because of scar tissue. Then, a nerve graft is used to reconnect the ends of the nerve.

*continued on page 23*

# Dr. Saleh M. Shenaq, 1948-2007

*It is with great sadness that we note the death of Dr. Saleh Shenaq, a pioneering and caring doctor who will be greatly missed by all who knew him. UBPN asked Dr. Maureen Nelson, a friend and colleague of his, to write a memorial tribute.*

The death of Saleh Shenaq, MD, is a huge loss for the brachial plexus community professionally, and for many of us, personally. The medical community has lost one of the most accomplished plastic surgeons in the world. Dr. Shenaq was recognized internationally for the care of children and adults with brachial plexus palsy as well as other areas of plastic surgery. He published over 100 professional articles and 29 book chapters, and presented extensively, both nationally and internationally, mostly related to the treatment of brachial plexus palsy. He also taught dozens of physicians who came from around the world to study under him in the operating room.

Dr. Shenaq had been Professor and Chairman of Plastic Surgery at Baylor College of Medicine in Houston and was the long time Plastic Surgery Residency Program Director there, directing the education of scores of physicians until 2005. At that time he went into private practice, including international care, mostly in his homeland of Jordan. This gave him great satisfaction, particularly in caring for indigent children, who otherwise would have had no treatment options.

Dr. Shenaq was an excellent physician. I can tell you from working with him in the operating room that he

was also an amazing surgeon, who demonstrated meticulous technique with precision and attention to the smallest of details. This was dramatically exemplified for me, one day, when he was performing a major musculotendinous transfer to all five fingers of a hand to give finger flexion. I was growing impatient as he

spent over thirty minutes positioning, testing, removing, and realigning the tendon on ONE finger three separate

times, each of which looked good to me, until he finally got the perfect position and alignment when he pulled the tendon to make the finger move.

It was awesome to see the difference between what I thought was good versus what he knew he could make the finger do. He had the vision, persistence, skill and dedication to get as close to perfection as possible no matter how difficult the procedure or how long it took.



Dr. Shenaq and Dr. Nelson

Dr. Shenaq was always studying new techniques and approaches and enthusiastically educating all of us – his residents, fellows, colleagues, patients and families, about medical advances and the reasoning behind them. It was always exciting to hear his thoughts on the potential for improvement in arm function, whether it was by surgical or non-surgical treatment.

I have personally learned a tremendous amount from Dr. Shenaq, medically and otherwise. He was a caring, compassionate, and funny friend as well as a devoted husband and father who loved to talk about his family. His concern for humanity was demonstrated

to me in a wide range of ways, from his strong but gentle recommendation to a Central American immigrant cab driver (after he and I had presented together on brachial plexus palsy at a national meeting) about the importance of a cab driver's choice of a gift for his wife for their upcoming tenth wedding anniversary, to his thoughtful education of patients and their families about treatment options, to

his amazing parental-like care of his residents and fellows.

It was an honor to know Dr. Shenaq and to work with him. I think that he, Dr. Rita Lee, and Dr. Jack Laurent (the other founding members of the brachial plexus team) are all together plotting something amazingly good for children up in Heaven right now.

I will always treasure and admire this spectacular physician, plastic surgeon, and human being who happened to be my friend.

*Maureen Nelson, MD*  
Carolinas Rehabilitation



Dr. Shenaq at one of the many BPI gatherings he attended.

## From Our Community...

Such sad news. I can only hope that other doctors will fill the void for BPI kids.

How sad he was a great doctor and a kind and funny man...

This saddens me very much, what a great man to dedicate his life to helping children/adults with our injury... This truly saddens me and my thoughts and prayers go out to his family and all whom he helped.

I feel a great deal of sadness over his passing... He will be greatly missed.

How sad for his family I want to extend my deep sympathy to them.  
He is a big loss to the BPI Community...



# Spontaneous Recovery Research by the Doctors at Leiden University Medical Center

*One of the strategic goals of UBPN is to get an accurate and realistic count of incidence and prevalence of brachial plexus injuries. The most recent medical article that addresses the issue of permanence or resolution of obstetrical brachial plexus injury is by the brachial plexus team at Leiden University Medical Center at Leiden in the Netherlands.*

*The following abstract is for the full text of an article published by Drs. Willem Pondaag, Martijn J.A. Malessy, J. Gert van Dijk and Ralph T.W.M. Thomeer in **Developmental Medicine and Child Neurology** 2004 46: 138-144. We have received permission to print the abstract but not the full text of the article. Full text of the article is available via local public or university libraries, through Inter Library Loan if they do not carry the journal.*

## Abstract

The natural course of obstetric brachial plexus palsy (OBPP) is generally considered to be favourable, with complete or almost complete recovery stated to occur in over 90% of patients. The validity of this presumption is important if one is to ensure that patients are treated appropriately, that parents of OBPP infants receive accurate information on prognosis and that a standard is set for epidemiological comparison of different treatment modalities.

In order to obtain a scientifically – based outcome figure we performed a systematic literature review of the natural history of OBPP. In such a systematic review, all the available literature is explored to identify papers that were published in medical journals throughout the world, and to evaluate the scientific quality of these papers. In this case, the MEDLINE database was used to search for papers published from 1966 to 2001. Four quality criteria were applied.

1. The study design should be prospective, and not retrospective. This means that the study does not look back in time, but patient cases are collected from a specified moment onward. In prospective studies patient cases are less likely to get overlooked (inclusion bias).

2. The study population should be constituted on a demographic basis. Results based on referrals to specialized centres or on hospital records may be biased by selection towards more severe cases.

3. Follow-up should be sufficiently long and complete. Three years was considered as the minimum, because the end stage of recovery might take up to three years, and secondly, the neurological investigation of younger children is difficult to measure. At least 90% of the patients should be available for follow-up.

4. Assessment of the end stage of recovery should be accurate and reproducible, preferably using a specialized pre-defined assessment

protocol, and not imprecise classifications like ‘good’, ‘fair’ or ‘incomplete.’ Each of these four items scored one point.

A total of 1,020 papers were screened using title, keywords and abstract, resulting in 76 papers for evaluation. Thirty-four articles failed to meet any quality criterion. Thirty-five papers received one point, seven received two points. None of the reports gained more than two points. The studies that most closely matched our quality criteria reported an incomplete recovery in 20 to 30% of children. This does not mean that 20 to 30% of children need surgical correction, just that their function is not ‘normal.’

From this systematic literature review, it can be concluded that the quality of the studies that investigate the natural history of OBPP is poor. Therefore, the often-cited excellent prognosis for this type of birth injury cannot be considered to be based on scientifically sound evidence. The rate of spontaneous recovery in OBPP may be worse than is generally believed.



*The Leiden University Medical Center serves as a tertiary referral center for nerve lesions in the Netherlands. They hold a weekly multidisciplinary out-patient clinic with representatives of the Department of Neurosurgery (Malessy, Thomeer and Pondaag), Department of Orthopedic Surgery (Nelissen), a child physiotherapist (Hofstede), occupational therapist (Campagne) and a rehabilitation specialist (van Wijlen, de Boer). They perform nerve surgery to treat obstetric brachial plexus lesions approximately 40 times per year. To date, they have surgically treated over 350 children with obstetric brachial plexus lesions. In two other publications, they reported on results for shoulder function and hand function.*

*Pictured at left: The Team at Leiden University Medical Center: (from left to right) Willem Pondaag, Martijn Malessy (neurosurgeons), Kees de Boer (rehabilitation specialist), Sophie Campagne (occupational therapist) and Prof Rob Nelissen (orthopedic surgeon). Members of the team who are missing in this photo: Prof Ralph Thomeer (neurosurgeon), Sonja Hofstede (child physiotherapist) and Rietje van Wijlen (rehabilitation specialist).*



## Straight Talk From Those Who Live It Each Day: Siblings Chat with UBPN President Nancy Birk

*This issue's Straight Talk panel celebrates the diversity of our families as we turn to the siblings of those with brachial plexus injuries. They are male and female, with ages ranging from 7 to 71, and from all walks of life, and they live from Alaska to New York; but what they have in common is that each one is a sibling of someone with either a traumatic or obstetrical brachial plexus injury.*

**Tell us about yourself and also about your sibling with a brachial plexus injury:**

**Tina:** My name is Tina, and I am 22 years old. My sister, Amy, has a brachial plexus injury. I am a new mom; so I stay at home with my baby at the moment. Amy is going to college to be an occupational therapist.

**Raymond:** My name is Raymond and I am the older brother of John who has an obstetrical brachial plexus injury to his right arm. I am 71 years old and a retired civil engineer. My wife and I live in Sammamish, Washington.

**Aaron:** I am 27 and my brother, Ryan, is two and a half years older than me. We grew up in Seattle, and when I was 14, we moved to Alaska. Ryan and I never really got along all that well before the injury. We never really had all that much in common. He moved out of the house pretty soon after high school and after that, we seldom spoke or saw each other. He never really enjoyed the Alaskan weather and took the first chance he got to leave. I am still here in Alaska and couldn't see myself living anywhere else.

**Mary:** I am the youngest of three children and the only girl in the family. I am 61 years old and grew up in an era that I believe was more kid-friendly than today. My brother John was the middle child. He was one of my "big" brothers. I think we got along the way most siblings did. Sometimes we did and sometimes we didn't. I was the little sister who was too young to play with any of his friends. We lived in a neighborhood with lots of kids of all ages and we had the run of the neighborhood. It was safe then to play outside. We had fun and great times when we were growing up.

**Farren:** My name is Farren and I am 19 years old. My brother, Tanner, is a typical 6 year old – energetic, silly, playful, and loveable. He definitely knows how to make me laugh. Tanner is all boy. At least once a day, I get tackled to the floor by him. As for me, I am currently attending Northern Arizona University and majoring in Exercise Science.

**Julia:** I am seven years old and in first grade. My favorite kind of animal is a dog. My sister's name is Kailyn. She is nine and in fourth grade. Her left arm has the brachial plexus injury.

**Gavyn:** I am a 24-year-old single father, the little brother to a 26-year-old sister with a traumatic brachial plexus injury. I am very outgoing (the most out of us three kids, some might say) as is my sister Courtney. We have always had a special bond that no one else has ever had or understood. A big part you need to realize about Courtney is that she was a little town girl who moved to



John with his siblings Ray and Mary and their mother, Fanny.

the big city and conquered it, with a great job, school, a load of good friends, and a real life. When she would visit home from Detroit, she had new shoes, hair, car, eyes, clothes and all of the other accessories and luxuries that a small town girl would dream about having from a big city. Then, she was becoming a manager, going to college, losing all kinds of weight from going to the gym, spending \$200 to get her hair done and living a very nice life for a young girl with divorced folks and a small town upbringing.

**Barry:** I am the second child out of four. I am four years older than my sister Judy, who has an obstetrical brachial plexus injury.

**Nicolette:** My name is Nicolette. I am 14 years old and in eighth grade. My sister Juliana is seven and in second grade. I am the oldest and Juliana is the youngest of four kids. We live on Long Island, New York. We have a lot in common – for one thing, we are both athletic.

***When did you realize that your sibling had an injury that affected how they used their arm/hand?***

**Tina:** I suppose it was when I was very young, about four or five, I guess.

**Raymond:** John and I are four years apart and I do not remember being aware of his injury until he began physical therapy treatments and daily home exercises. My mother, along with John and I, made a weekly one-hour trip each way to the physical therapy office. In addition, my mother had to exercise John's arm at home daily. I remember the therapy sessions being very stressful for John and the home exercises were probably as hard on my mother as they were on John.

**Aaron:** Ryan was living in Virginia and I was in Alaska. I remember I was sleeping one morning and all of the



Judy and her brother, Barry.

sudden, I heard my mother scream “WHAT!” I woke up and ran to her. She had the phone to her ear and she said that a hospital called and told her that Ryan had been in an accident, ‘please hold.’ I think that was the longest 30 seconds of my mother’s life. I was 18 at the time. The next few months were a bit stressful. My mother went to Virginia to take care of Ryan for a month. Then it was my father’s turn for a month. After that, it was my turn.

I was with my brother for about two weeks of the month I was scheduled to stay and it was almost always a constant fight with him. I didn’t realize how scared I was that I saw my brother in pain all the time and there was nothing I could do about it. Unfortunately, the only way I could handle it was to fight with my brother about every little thing. I left early and went back to Anchorage and we didn’t speak for about two years. I still heard everything that was going on through my mother.

I remember when we did finally talk. I had finally come to terms with the fact that I had not handled the situation very well and apologized. Ryan understood and was glad I had understood. He never really apologized to me for it, but I can understand that. No matter how hard it was for me, it was nothing compared to what my brother was going through.

**Mary:** My parents made every effort to treat all three of us kids the same. John had an arm that didn’t work properly, but the expectations were the same for him as for my oldest brother and myself. We had loving parents who provided the best life they could afford for us. We didn’t have a lot

of fancy things – no car or TV. Respect and discipline were expected. I didn’t think any differently of John than I did of my oldest brother Raymond.

**Farren:** Immediately after my brother’s birth, I knew something was wrong. As a newborn, Tanner’s right arm was limp, and had to be pinned to his shirt. At that moment, I knew he was injured, but we were all unaware of the extent of his injury. Watching Tanner struggle and grow with a brachial plexus injury was, and is, an amazing and heart-wrenching experience. Throughout all the experiences, we, as a family, have been through; I wouldn’t change any of it. I love Tanner so much, and I believe in my heart that he will be the strongest and healthiest boy, mentally and physically. Of course, if I could go back in time, I would push that doctor out of the way and deliver my brother myself!

**Julia:** When I was four, I knew she had an injury, because her arm didn’t look the same as her other arm. I had to go with her when she had therapy.

**Gavyn:** I first realized that my sister was faced with this disability shortly after a horrific car accident that she was involved in.

**Barry:** I probably realized when I was about 14 or 15 that my sister had something wrong with her arm. At that time, until about 10 years ago, I did not know the seriousness of it.

*continued on page 19*

Gavyn and his sister, Courtney





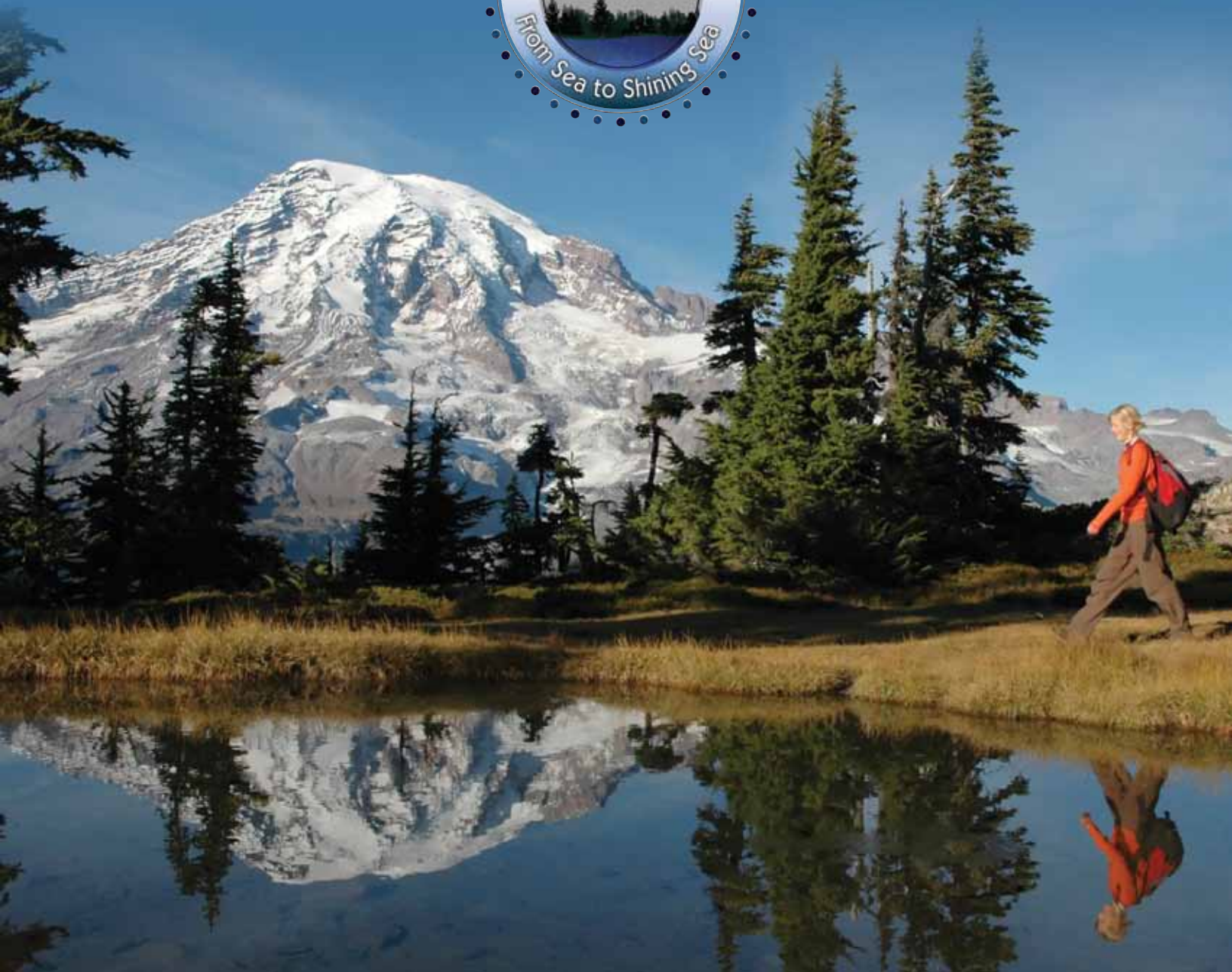
# CAMP UBPN 2007

## From Sea to Shining Sea

Camp Berachah

Auburn, Washington

August 31-September 3





# Welcome to Camp UBPN 2007!

*By Karen McClune, Camp Coordinator and Member, UBPN Board of Directors*

With each camp we have visited different regions of the U.S. This year, my husband David and I are so pleased that we found a camp in our own beautiful state of Washington, the Evergreen State with some of the most beautiful trees in the world.

Camp begins on Friday, August 31 and ends Monday, Sept. 3. It will be held at Camp Berachah, a Hebrew word meaning "Valley of Blessing." Camp Berachah is located in Auburn, Washington, and is surrounded by a forest of beautiful trees.

We have many fun activities and educational programs planned for every member of your family. We are still finalizing speakers and activities, so visit the camp message board for the latest information as it develops:

<http://www.ubpn.org/messageboard/>

After registration and check in on Friday afternoon, we'll have our first opportunity to experience Camp Berachah food. Food is served family style at your table and to get more, all you have to do is raise your hand! After dinner, we will have a speaker from the Camp to answer questions about therapeutic horseback riding. Camp Berachah has horses on site and there will be opportunities to participate in this therapy. A social gathering will follow and will allow everyone to meet new friends and catch up with old friends.

Saturday morning will be the therapist panel and in the afternoon we will have a sports clinic. That evening, we are very excited to bring back Professor Cheryl Beck as she continues to share her investigations into Birth Trauma and Post Traumatic Stress Disorder and how it has affected our community. She is very interested in hearing your stories and, if you are willing, possibly incorporating them into her research.

Right after breakfast on Sunday, our camp photo will be taken, with the medical panel following. That

afternoon will feature the always popular roundtable discussions.

Sunday evening we will resume our camp tradition of roasting marshmallows and making smores. We will again close camp with a ceremony celebrating the accomplishments of our campers and the children will assist us as we grow a forest of trees.

At the last camp, we created a fundraiser project and formed a paper doll chain with the dolls sponsored both by campers and by many who couldn't attend but still wanted to participate in some way. This year we have produced die cuts of several tree patterns, which match our camp theme. The trees will be decorated during arts and crafts and the children will create a forest of "trees." Each tree costs \$1 and the name of the sponsor, city and state will be recited during our closing event. For more information, please see the Family Tree Project article on page 15.

In addition to these many activities, we will use the heated indoor swimming pool, indoor climbing wall, an outdoor climbing wall for the little ones, zip lines, putt putt golf, Frisbee golf, and more. Josh and Heather Birk will be overseeing the Arts and Crafts, which will be available throughout the weekend for all ages. We will provide childcare for the therapist panels, doctor panels and the roundtables.

The one question I am continually asked is, "why should we attend camp?" As I wrote in my last camp message, come for the camaraderie, come for the information, come and make new friends. Camp will bring you closer to other families and individuals, who truly understand what you are experiencing. You may meet someone else for the first time with this injury and that is such an amazing experience. Children with this injury will realize how normal they are as they see others the same age. You can listen to adults that have lived with brachial plexus injuries for over 60 years and learn what you and your child can achieve. Those with a TBPI will learn what other TBPIs have gone through and see what they have accomplished.

My husband, David, and I attended our first camp in 2001, when our son Ryan (who has a TBPI) asked us to meet him in Colorado. We have made everlasting friends and have attended every camp since. I want to thank the Board of Directors for asking me to coordinate camp again. It is always a privilege working with them, as we bring our community together.

Please mark your calendars now, fill out the registration form on page 18 and send it in as soon as possible.

I look forward to meeting each of you August 31 – September 3. See you at Camp Berachah!

*Karen McClune, Camp Coordinator*





# Camp Schedule

(Tentative)

Thank you for your interest in Camp UBPN 2007 – a camp for families and individuals with brachial plexus injuries. One of UBPN’s goals has been to move the Camp setting around the country in an attempt to optimize as many different locations as possible to enable more to attend. Last year, our Camp was held near Washington D.C. at the National 4-H Youth Conference Center. This year we move across our vast country, from the Atlantic Coast to the Pacific Coast, from “Sea to Shining Sea,” as our Camp will be held near Seattle, Washington at Camp Berachah. Camp Berachah, which means ‘Valley of Blessings’ in Hebrew, is located in the midst of a forest grove in Auburn, Washington. It is just a short drive from the Seattle/Tacoma airport.

Join us over Labor Day Weekend for a wonderful opportunity to make new friends and reacquaint with old friends, as we gather together for our fourth Camp (UBPN Camp is held only every two years) and learn more about what it means to live with brachial plexus injuries from medical professionals and from each other.

## Friday, August 31, 2007

3:00 – 6:00	Check In
6:00 – 7:30	Dinner available
8:00 – 9:00	Presentation about Therapeutic Horseback Riding
9:30 – 11:00	Evening Social
11:00	Quiet Time

## Saturday, Sept. 1, 2007

8:00 – 9:00	Breakfast available
9:30 – 11:00	Therapist Panel
11:00 – 12:00	Free Time (a list of possible activities will be provided, including planned arts & crafts for kids)
12:00 – 1:00	Lunch available
1:30 – 3:30	Premium activity (these include go karts, zip line, etc.)
4:00 – 5:30	Sports Clinic
5:30 – 6:30	Dinner Available
7:00 – 9:00	Concurrent session – Cheryl Beck Sharing the Impact of Birth Trauma & Injury: Open Group Discussions for Mothers
7:00 – 9:00	Concurrent session – Planned activity and Arts & Crafts available for Kids
9:00 – 11:00	Evening Social
11:00	Quiet Time

## Sunday, Sept. 2, 2007

8:00 – 9:00	Breakfast available
9:30 – 10:00	Camp Photo
10:00 – 11:30	Medical Panel
10:00 – 11:30	Arts & Crafts available for kids
11:30 – 12:00	Free Time
12:00 – 1:00	Lunch available
1:30 – 3:30	Premium activity
4:00 – 5:15	Roundtable Discussions
5:30 – 6:30	Dinner available
7:00 – 9:00	Town Hall Meeting around the Bonfire (Camp awards ceremony)
9:00 – 11:00	Evening social
11:00	Quiet Time

## Monday, Sept. 3, 2007

8:00 – 9:00	Breakfast available
9:00 – 11:00	Pack & say goodbyes

*Please check out by 11*

# Camp Cameos

*I cannot find words to really describe the healing and wholeness I received attending Camp 2005. It was my first camp after finding UBPN in 2004 at the age of 65. It also gave me such JOY in*

*many ways. One was seeing children of all ages with bpi's smiling and coming out of their shells. Another was to see their eyes lighting up when coming next to someone else with an injury similar to theirs & their compassion when seeing someone with more severe injuries than their own.*

*Boy do I wish there had been a camp like UBPN's when I was young. I would like to think it would have helped everyone in my family too in many ways, especially my mother. The support of other bpi adults and the endless conversations and sharing of information and life experiences with moms, dads and most of all teens made me feel that my life is useful after all. AND you can't beat hugs in person, finally, not just in cyberspace!*

**Carolyn Jenkins, 68, LOBPI**



Carolyn Jenkins and Joanie Boyko

*The first time I heard of UBPN was in 2005. I was not alone anymore! There was a whole organization of*

*people with arms like mine! I learned that there would soon be a camp for UBPN members and their families. There wouldn't be another camp for two years, so if I wanted to meet others with this "rare" birth injury face to face, and not just on the message boards, I had to act fast, and go to this camp. I was a woman on a mission.*

*Unfortunately, once I got to camp, my natural shyness took over. I was overwhelmed by the number of people who were at this camp, and I didn't meet too many of them. Yet I would still say that, for me, the most important aspect of Camp UBPN was getting to meet others with brachial plexus injuries and make new friends. The second most important aspect of Camp UBPN was deciding that no matter how difficult it would be for me to get on a horse and ride it, I was going to do it, and I did! This was a personal victory for me, because I had two previous chances to ride a horse.*

*If you come to Camp UBPN, you might not meet me, but you will meet a wonderful group of people and make many friends. I urge you to come.*

**Joanie Boyko, 58, LOBPI**



*The UBPN Camp of 2005 was one of the greatest experiences I have ever had. I was able to meet new people and learn new things. Going to the UBPN Camp would be one of the best things you can do if you are new with the injury or even if you've had it for a while.*

**Caralyn Cox, 16, TBPI**





*I have gone to camp for as long as I can remember. It is really fun and I look forward to it every other year. I enjoy meeting new people and staying in touch with them. While at camp I like to do all of the planned activities like when we went to Mount Vernon two years ago. I LOVE the facilities that we stay in – there is always something fun to do in them! Going to camp also gives you a reason to travel throughout the country.*

**Elyssa Kanter, 14, OBPI**

*Last year was the first time we went to camp and our first time being up north. We live in Baton Rouge, Louisiana. The scenery was absolutely amazing on the way to and from camp. While at camp, we had a chance to meet so many wonderful people. My daughter, Zavian, actually got to see and meet people that actually look like her, no matter what color. She bonded really well with the other kids – especially the boys! Camp gave Zavian, Paul (her daddy) and me the chance to mix and mingle with others, to talk about what we have experienced as both parents and the injured. IT WAS WONDERFUL! The best thing about it was that it was wonderful to have so many people from different ethnic groups come together for one cause. I loved it! See you in '07!*

**Zaidra, Zavian's (4, OBPI) mom**

## Join the UBPN Family Tree!

At the last Camp in Washington D.C., we created a fundraising project. The project was a paper doll chain formed by dolls sponsored both by those 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.

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.

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](http://www.paypal.com)) by indicating [donation@ubpn.org](mailto: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

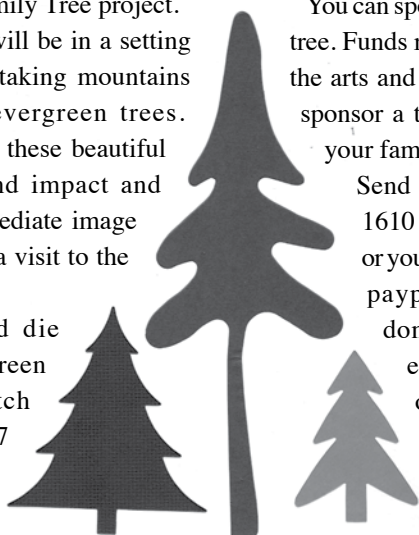


Paper-doll fundraiser from Camp 2005

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 ¾ 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?



## About the Camp Location

Camp Berachah is one of the largest camp and conference facilities in the Pacific Northwest. Originally operating in the 1960s as a Christian commune, it has lived several lives, and now functions as an independent ministry. It provides facilities to local, regional and national guest groups, and annually meets the retreat needs of more than 20,000 people and 300 groups. While many of these groups have a Christian focus, in keeping with the mission of this particular camp, they extend their facilities to groups like ours, which are secular in nature and not affiliated or associated with any religion.

Camp Berachah is located in a heavily wooded area in Auburn, Washington, within 40 miles equidistant from both Seattle and Tacoma. Our group will have exclusive use of Hillside, which has two large conference rooms in the center, with floor to ceiling windows, overlooking the vast cedar trees of the camp. The guest rooms fan out in two directions on two levels from the conference rooms. This will make it very convenient for campers to move to and from the various sessions.

The campus features an incredible amount of activities. Through the grant that we have obtained from eBay, we are able to offer to our campers some fun activities that we have not had at any other camp, that include go-kart racing, and a zip line. We will also have indoor heated swimming facilities and therapeutic horseback riding.

To read and learn more about the facility, visit the Camp Berachah website at: <http://www.campberachah.org/>

## Why not combine Camp with a Family Vacation?

For some of you, Camp may be a journey, possibly to a part of our country that you have never visited before. You are in for a delightful experience because the Pacific Northwest is truly full of magnificent beauty and there is much to see and explore. If you, or your family, are combining Camp with a family vacation and staying a few days before or after Camp, these are some websites that will give you some travel information and help you plan a memorable trip.

<a href="http://www.seattle.citysearch.com">www.seattle.citysearch.com</a>	<a href="http://www.seattle.com">www.seattle.com</a>
<a href="http://www.seattlesouthside.com">www.seattlesouthside.com</a>	<a href="http://www.citypass.com">www.citypass.com</a>
<a href="http://www.goodsearch.com">www.goodsearch.com</a>	<a href="http://www.seattlecenter.com">www.seattlecenter.com</a>
<a href="http://www.spaceneedle.com">www.spaceneedle.com</a>	<a href="http://www.seattlemuseum.org">www.seattlemuseum.org</a>

You can also click on 'guides and maps' on the Washington state tourism site ([www.experiencewa.com](http://www.experiencewa.com)) to have printed information sent to your home. Consider using [www.goodsearch.com](http://www.goodsearch.com) (described elsewhere in this issue as a fundraiser for UBPN) if you are searching the web for something specific or looking for lodging.

Come enjoy what the beautiful Northwest has to offer!

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# Camp Donation Form

UBPN wants every family to financially be able to attend Camp. We count on donations to help UBPN, Inc. underwrite the Camp program so we can offer a unique camp with diverse and professional speakers and programs. We currently offer three ways to donate for camp. The first is to donate to the 2007 Camp UBPN Sponsorship Program. These funds will be used to help families attend the 2007 camp via scholarships (see the form on page 17.) Secondly, a fund has been established by the Kanter family for future scholarships. And third, is the donation to help UBPN, Inc. underwrite expenses for this year's camp.

Please consider donating to one or more of these programs. Any amount is welcomed and appreciated.

All donations are tax-deductible.

***Please consider contributing to one or more of these important camp funds. Tax-deductible. Any amount is appreciated.***

- |  |          |
|--|----------|
| <input type="checkbox"/> Donation to UBPN Camp 2007 Sponsorship Program                            | \$ _____ |
| <input type="checkbox"/> Donation to The Kanter Family Camp Fund For Future Camp UBPN Sponsorships | \$ _____ |
| <input type="checkbox"/> Donation to underwrite program and expenses at Camp 2007.                 | \$ _____ |

*Thank you for your donation.*

*Return this form with a check made payable to:*

***United Brachial Plexus Network, Inc., 1610 Kent Street, Kent, OH 44240.***

*Please designate the appropriate program name in the memo section of your check.*

# Camp Sponsorship Application

UBPN is committed to providing funds to be made available for low-income families otherwise unable to afford the full cost of attending camp. While we plan on helping as many families and individuals in need as possible, please note that we anticipate that funds will be limited. Priority consideration will be given to first-time applicants. Thereafter, all other applicants will be considered.

Sponsorships will be awarded based on demonstrated need, using the U.S. Government Poverty Guidelines (at 200% to reflect what the government and most charitable organizations consider low-income) as our main determining criteria. **On a separate sheet of paper** we ask that each applicant provide us with an explanation of other factors (related to brachial plexus injuries) influencing their current financial situation.

Sponsorships will be awarded to one individual affected by a brachial plexus injury. If the person injured is a child, one adult will also be sponsored. Sponsorships will cover full payment of costs associated with camp to include: registration fees, camp lodging, all meals, and, in some cases, assistance with transportation needed to get to Camp Berachah from your home. UBPN can provide a personalized letter indicating that the recipient has been awarded a sponsorship to camp to help in individual fundraising efforts related to transportation costs.

If your family or individual income falls at or below the guidelines at right, or if you are currently facing serious financial challenges, please complete an application for consideration of sponsorship.

## FOR OFFICE USE ONLY:

Date application received \_\_\_\_\_

Date sent to review committee \_\_\_\_\_

### Annual Income

1 Family Member: \$19,140

2 Family Members: \$25,660

3 Family Members: \$32,180

4 Family Members: \$38,700

5 Family Members: \$45,220

6 Family Members: \$51,740

7 Family Members: \$58,260

8 Family Members: \$64,780

For each additional person, add \$7,172

### To Apply for Sponsorship:

1. Complete and sign the Income Self-Certification Form.
2. Enclose a letter on a **separate sheet** explaining other financial factors.
3. Return with the completed Registration materials postmarked no later than July 1.

## Income Self Certification Form

I, \_\_\_\_\_, hereby certify that I am requesting Camp UBPN 2007 sponsorship consideration from the United Brachial Plexus Network, Inc. for attendance at camp to be held August 31 - September 3.

My annual income is \$\_\_\_\_\_ and my family size is \_\_\_\_\_ person(s).

I hereby certify that the foregoing statement is true. I will show income receipts upon request.

Applicant's Name: \_\_\_\_\_ Date: \_\_\_\_\_

This application is for: ☐ Child with BPI ☐ Adult with BPI

If application is for Child with BPI, please print family last name here \_\_\_\_\_.

Address: \_\_\_\_\_

Phone Number: \_\_\_\_\_ E-mail: \_\_\_\_\_

Fax: \_\_\_\_\_ Signature: \_\_\_\_\_

*Also, include a separate sheet of paper that explains other factors (related to brachial plexus injuries) influencing your current financial situation.*



# Registration & Fee Calculator

*This calculator is a guide to assist you in determining your camp costs. VISA, Mastercard, American Express, and Discover credit cards will be accepted via Pay Pal. Personal checks will also be accepted. Please include a \$100 non-refundable deposit with your registration form. The balance of your camp fees will be due before August 1. Deposits will be applied to camp fees. Checks should be made payable to UBPN, Inc. Please include "camp deposit" on the memo line. Upon receipt of deposit, you will receive a complete camp registration packet.*

Contact Name: \_\_\_\_\_

Additional Campers:

Address: \_\_\_\_\_

Name & Age: \_\_\_\_\_

City, State, Zip: \_\_\_\_\_

Name & Age: \_\_\_\_\_

Phone: \_\_\_\_\_

Name & Age: \_\_\_\_\_

E-mail: \_\_\_\_\_

Name & Age: \_\_\_\_\_

Name & Age: \_\_\_\_\_

I will be paying by:

☐ Check

☐ Credit Card

☐ \$100 Deposit Only

The balance will be due before August 1, 2007.

Credit card payment will be accepted online through Pay Pal <<http://www.paypal.com>>. Our payment address is **camppayment@ubpn.org**.

☐ I wish to pay for my entire camp stay at this time.

☐ **Registration Fee** (Registration fees are waived if application materials and deposit are postmarked by June 30, 2007!)

Number of persons in your family age 4 and older: \_\_\_\_\_ x \$15 = \$ \_\_\_\_\_

☐ **Three Night Stay - (Friday - Monday)**

☐ Room (each room sleeps up to four): \_\_\_\_\_ x \$195.00 = \$ \_\_\_\_\_

Adult Meals (ages 11 and up): \_\_\_\_\_ x \$65.00 = \$ \_\_\_\_\_

Youth Meals (ages 7-10): \_\_\_\_\_ x \$65.00 = \$ \_\_\_\_\_

Meals for children 6 and under are free

☐ **Day Use Only**

For locals or those lodging off-site. Includes meals. Children 6 and under are free.

■ Participating Friday night

☐ Adults \_\_\_\_\_ x \$10.00 = \$ \_\_\_\_\_

☐ Children ages 7-10 \_\_\_\_\_ x \$5.00 = \$ \_\_\_\_\_

■ Participating Saturday

☐ Adults \_\_\_\_\_ x \$24.00 = \$ \_\_\_\_\_

☐ Children ages 7-10 \_\_\_\_\_ x \$13.00 = \$ \_\_\_\_\_

■ Participating Sunday

☐ Adults \_\_\_\_\_ x \$24.00 = \$ \_\_\_\_\_

☐ Children ages 7-10 \_\_\_\_\_ x \$13.00 = \$ \_\_\_\_\_

**TOTAL \$** \_\_\_\_\_

# Straight Talk... *cont'd from page 10*

**Nicolette:** I probably realized that Juliana had an injury that affected her arm after her first surgery and when she started going to therapy.

## ***Did you feel that your parents spent or spend too much time with your sibling caring for his/her arm?***

**Tina:** I can't say that they spent too much time. She has had many surgeries and it took a lot for her to feel better. As far as more time for myself and my brother – a little, I suppose.

**Raymond:** John and I were fortunate to have wonderful parents. Looking back, I realize how much they sacrificed to help John regain as much use of his injured arm as possible. This was in the days before health care insurance and families had to bear the brunt of the expenses. I know this must have been an enormous undertaking. Our parents made every effort to minimize the effect of John's injury on our daily lives. Somehow, without really knowing it, we all shared in these efforts. Our parents were not afraid to have others know of John's injury and they never let anything get in the way of his treatments.

**Mary:** I guess I never thought my parents spent too much time with John. It was just what they did to get the best help they could for John at the time. I used to go with my mom to Physical Therapy for John. It was downtown and we had to go on the bus. It was an adventure and one of us usually got carsick. I used to think the therapist was mean to my brother when she would make him dive to the bottom of the swimming pool to retrieve small objects. My mom would explain that John needed to do those things to make his arm stronger. It was just the way things were. I never felt cheated or left out. My parents did the best they could for all three kids. John was not set apart because of his injury.

**Farren:** When Tanner was first born, my life as I knew it changed. I was used to being the only child for 14 years. I was very eager and excited for Tanner's arrival, but also scared of the changes that might occur. During the first year or so of Tanner's life, his injury did consume a lot of my parent's time. At times, I missed the "old family" but being the age I was and aware of the situation, I just wanted what was best for my brother – even if it meant spending less time with my parents.

**Julia:** No. She gets some attention when her arm hurts.

**Gavyn:** The attention that my sister received from our parents was not viewed as too much or overbearing, but obviously viewed as what was necessary for someone in her condition.

**Barry:** My parents did not spend any time with her at all concerning her arm (to my knowledge).

**Nicolette:** When I was in fourth grade, Juliana was at therapy constantly. I remember having to wake up early three days a week so my mom could make sure we were ready for the school bus; and then, when we got home, we would have to go back to therapy with her. My parents decided to stop regular therapy when it was being taken care of in school, so now they don't spend as much time on therapy as they used to.

## ***How do you help your sibling deal with the injury?***

**Tina:** My sister is a very strong person. She doesn't really need help.

**Aaron:** I wish I was able to help him. One of the few things I regret in my life was how I mishandled the situation.

**Mary:** Being the youngest, I probably wasn't much help to my brother in dealing with his arm. I do remember when he had surgery to correct things in his shoulder. I thought he was very brave to have an operation. The scar he had was like a badge of courage.



Kailyn, Sarah and Julia

**Farren:** Since Tanner is only six, he hasn't been confronted with many issues due to his injury. I can only hope that if these issues arise, he can talk to me about them. Even though he is so young, he knows how much I love him and that I am here for him.

**Julia:** I try and cheer her on the monkey bars. She doesn't need help usually with most things.

**Gavyn:** Well how much time do you have? Endless amounts of loving help have been given to Courtney. Things like the crying phone calls, the mental push to keep going, and the reassurance that she will be able to have a normal fulfilling life. On a whole different end of the spectrum, I have provided a lot of physical help as well including, helping her shave her arm pits, putting on and taking off bras, lifting any and everything, a lot of chopping and preparing was very necessary at first as well. But the thing I have helped with that has hurt the most, was in the first couple years of her injury before she was very aware or sure of herself yet. That was when she needed the most reassurance that she would one day be better; and if not physically, then mentally.

**Barry:** I did not contribute any feelings or support to my sister at all as I did not know the seriousness of it. I thought it was just a birth defect years ago growing up. I don't believe she knew about it either.

**Nicolette:** I don't help Juliana with big things like helping her move her arm in a new way; but I do help her with things like buttoning her pants and zipping her coat.

***Did you ever feel embarrassed around your peers because of your sibling's injury?***

**Tina:** Not really. My friends would ask me and I would explain what it is and how it happened and that would be the end of it.

**Aaron:** This was never an issue.

**Mary:** I never felt embarrassed by my brother. My friends never said anything about my brother's arm. We all grew up together in our neighborhood and my brother John was just one of the kids.

**Farren:** Never. The only time I was embarrassed was when my mom made me go on Dr. Phil and having students at my high school come up to me and tell me, "I saw you on Dr. Phil." But that's not really so bad – I think it was a great experience and a great way to get brachial plexus awareness out.

**Julia:** Nope. Never.

**Gavyn:** Oh no, that's my big sister. I would beat anybody up that said anything!

**Barry:** No, I did not feel embarrassed of her; however, I was more embarrassed over my older sister!

**Nicolette:** I have never felt embarrassed by Juliana but I sometimes get annoyed with my friends. I'll be talking and I'll say something like "and that thing with Juliana's arm" and they'll ask "what's wrong with her arm?" And I'll tell them – for the fifth time!

***Have you ever had to 'stick up' for your sibling at school?***

**Tina:** Maybe a few times, but my sister is a little younger than I am so we didn't really have interaction time in school.

**Raymond:** John and I played a lot of street games with the neighborhood children, like "kick the can" or "hide and seek." I remember that we all played well together and if there had been any issues because of John's injury, I would have done my best to stick up for him.



Amy with nephew, Aidan, and sister, Tina

**Mary:** I don't recall any time I had to stick up for my brother. He did cool things like winning the "Old Woody" pitching contest at the local park. And he was on the Safety Patrol at our elementary school.

**Farren:** No. And let's hope not, because the kid messing with my brother would be toast!

**Julia:** No, but she did do that for me during tag.

**Gavyn:** No, she mainly stuck up for me!

**Barry:** I did not have to take up for her. She has a very strong mind!

**Nicolette:** Since I'm 6 years older than Juliana, I've never been in school with her. But she'll stick up for herself all the time.

***How do you think having a sibling with a special need has affected you?***

**Tina:** My parents tried their best to treat us all the same but it never seemed that way to me. She seemed like she got away with more and didn't have to do as many chores as the rest of us – things like that. But in my eyes, she is just my

*In the next issue, our Straight Talk Panel will feature TBPI young adults and kids, who will be interviewed by an OBPI young adult, Amy Theis. Amy is on our Board of Directors at UBPN. She is a college student at the College of St. Scholastica where she is studying to be an Occupational Therapist. If you would like to participate in this panel, please contact Amy at her UBPN address (amy@ubpn.org).*



sister and can do anything she puts her mind to. Besides she always said that she could do everything we could.

**Aaron:** Other than helping me grow as a person, I would say it has not affected me much.

**Mary:** I think having a brother with a special need prepared me for my twin boys, who are both developmentally delayed. My parents always expected the best out of all of us according to our abilities. When my twin boys came along two years after my daughter and they developed so differently from her, I think my parent's influence kicked in. It has helped me deal with everything about my boys over the last 26 years.

**Farren:** The years of watching Tanner's injury improve through physical therapy and surgery has inspired me to become a physical therapist. I am currently majoring in Exercise Science in hopes to further pursue becoming a physical therapist. Before Tanner's injury, I had no thought of becoming a physical therapist and now I can't imagine becoming anything else.

**Julia:** Not really. But sometimes she is in the way when I am doing the monkey bars.

**Gavyn:** This situation has taught me to value life more and to also be more appreciative for what I can do and what I do have. And to be honest, it has made me question my faith as well because I could not imagine how a young girl accomplishing everything that she was could be subjected to such fate. On the other hand, her struggle and what she has accomplished has shown me more of the Lord's good work to see how she has persevered through everything that He has put in front of her.

**Barry:** It has not had any effect on me.

**Nicolette:** Of course it's had an effect on me; but she's just Juliana to me and that's how it's always going to be.

***Do you have an amusing story or anecdote that you'd like to share about your sibling?***

**Tina:** I really don't find my sisters injury amusing. She will be this way the rest of her life. What is amusing about that?

**Raymond:** One day while John was having his therapy on our dining room table, a family friend came to visit. My mother, proud of John's progress,



Farren with little brother, Tanner

proceeded to show her how far John could reach his arm up his back. At the sight of this unusual maneuver, the friend collapsed to the dining room floor in a dead faint! It took a few minutes to revive her. She was amazed at John's flexibility.

**Aaron:** Nope.

**Mary:** My brothers used to make wooden hydroplanes and drag them behind their bikes in races in the street. John used to tear up and down that street

## 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](mailto:donation@ubpn.org). *No amount is too small – all contributions make a difference.*

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I would like my donation to go toward: \_\_\_\_\_

*I would like to make a donation to UBPN, Inc. of the following amount:*

☐ \$15 ☐ \$25 ☐ \$50 ☐ \$100 ☐ Other: \$ \_\_\_\_\_

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Please make my donation in honor of:

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**UBPN, Inc., 1610 Kent Street, Kent, OH 44240**

with the best of the kids. He used to play basketball out at the hoop on the street light pole. He was just like everyone else.

**Farren:** I think one of my favorite stories about Tanner was the time my mom called me to tell me that Tanner ran into a tree. She told me that when she picked up Tanner from school, they gave her an “ouch report,” stating that Tanner needed an ice pack. Apparently, while Tanner was playing on the playground, he ran straight into a tree, which left him with a little bump on his forehead. This story makes me laugh every time.

**Julia:** My sister went sledding on her belly, and slid off the sled, and kept sliding while snow went up her coat! She was really cold and jumped around trying to get it out.

**Gavyn:** Yes. A funny time was when I was getting ready for a date and the guy was knocking at the door and I am saying “come on in and I will be right out in a minute.” I then appear out of the restroom shutting the door behind me, as he asks: “finishing getting ready?” and I reply with: “nope, shaving my sister’s armpit for her.” What a fun conversation that led to at dinner that night!

**Barry:** Ah yes – the chocolate milk shower! I learned early not to make fun of Judy (laughing with her is ok but not about her). I can’t remember exactly what I was joking with her about – maybe it was because she was always the last one ready to eat breakfast, so we would all be running late for school. Anyway, I was making fun of her slowness and she dumped a whole glass of chocolate milk on me.

**Nicolette:** Since Juliana’s balance was all messed up when she was younger, I remember her running into walls, falling down, and then she would start to laugh hysterically.

***Is there anything else you would like to share with our readers?***

**Tina:** I would hope that parents don’t treat their children with an injury such as my sister’s any different than their other children. They can do anything they set their minds to. If they need help they



Aaron and Ryan

will ask. They may not know just what they are capable of until they try. Push them to try as hard as they can and that should make them as strong as my little sister! Amy, I truly am proud of you!

**Raymond:** John is a retired mechanical engineer and an avid fisherman. His successes in life are outstanding. He has not let his injury slow him down. I am very proud of my brother’s achievements.

**Aaron:** Since this happened at a much later age than most, I would have to say to siblings that you just need to be there for them. They may ask you to do the most mundane things that they could do themselves (even with the injury) but maybe they are just struggling with their life being so different and it just takes time for them to cope with it.

That was something I was unable to do for my brother and I know now that even though he could do it, he may have other issues he needs to deal with inside before the everyday things are mentally possible.

To end things, I must say that my brother has really turned this injury into a positive thing in his life. He has really embraced it and not only learned what he can do, but also is helping others that have problems (whether it’s the same kind of injury or something entirely different.) Of all of the things he has accomplished in his life (work, home,



Nicolette and Juliana

etc.), I can honestly tell you that I have never been more proud of anyone I have ever met than Ryan. He is inspiring. And as I write this, he is on a cruise around the world, which he did NOT invite me on. But, I think I can forgive him for that!

**Mary:** From my own experience with my two special needs children, all I can say is to expect the best of your children at the level at which they perform. Discipline and respect are essential to bringing up children to a productive life and future. That is what my parents did for my brother, John.

**Julia:** I love having Kailyn as a big sister. I have a little sister too, named Sarah.

**Gavyn:** Just that I am so glad that Courtney is involved with UBPN. Before she knew it, she had been given a real job (even if it is volunteer), but it gave her some realization that she would be able to work again and a new field might just be exactly what she was lacking in her day to day life. UBPN has meant the world to her and done even more for her and for that our whole family would like to thank you from the bottom of our hearts.

**Nicolette:** Parents shouldn't treat their injured child any differently from the other children. Even though they might need more time with therapy or something like that, they are still just a kid, but with an injury.

### ***In The Next Issue...***

Dr. Michael Pearl Discusses  
Shoulder Rehabilitation

A Chiropractor Shares  
Techniques for  
Working With BPis

Straight Talk Panel Features  
TBPI Teens and Kids

A Camp Scrapbook

## **What is a Brachial Plexus Injury...** *cont'd from page 6*

### **Surgical Treatment**

Primary surgeries are usually performed 5-12 months after the injury when it is apparent that the damaged nerves are unable to heal themselves. Secondary surgeries are typically done when skeletal and muscular development has matured to the point where surgical intervention has been demonstrated to be beneficial. This may occur in ages from toddler to adult depending on the injury and the proposed procedure.

### **The Importance of Therapy**

Physical therapy is very important to strengthen partially denervated muscles and other compensating muscles to improve range of motion of the hand, arm, elbow, and shoulder. Also, PT helps to minimize contractures and "freezing" of joints due to under use. Occupational therapy is also important to help with adapting to every day activities such as tying shoes, buttoning clothing, and personal hygiene. Parental participation in PT and OT is necessary to ensure a prescribed regimen is maintained and steady progress is achieved.

### **The Importance of Medical Experts**

The importance of having experienced medical experts treat brachial plexus injuries cannot be over emphasized. The treatment objective is to achieve the maximum possible recovery and that could mean a range of surgical procedures and applicable therapies over a period of time, often years. Specialized surgical and therapy techniques are being used for BPI's with success. However, surgical procedures (both primary and secondary procedures) used with brachial plexus patients are complex; and, like any medical procedure, can have varied results. An understanding of proposed procedures and their results, use of second opinions, and confidence in the medical practitioner are important considerations for parents and injured adults before initiating a course of treatment.

### **UBPN's Medical Resource Directory**

Physicians and therapists who have registered with UBPN can be found on the Medical Resources ([www.ubpn.org/medicalresources](http://www.ubpn.org/medicalresources)) and Therapist Resources pages of our web site. These resources should be considered a starting point when searching for medical help, as there are likely other regional unregistered qualified physicians and therapists to consider. Also, the message boards of the web site ([www.ubpn.org/messageboard](http://www.ubpn.org/messageboard)) are another available resource. The advice and counsel of others who have been affected by BPI can be invaluable if only to gain a better understanding of the treatment process.

### **Volunteers Welcome!**

*Did you know that the United Brachial Plexus Network, Inc. is run entirely by volunteers? If you feel drawn to this cause and the many projects UBPN is involved in, please contact Nancy Birk at [nancy@ubpn.org](mailto:nancy@ubpn.org) or at 1-866-877-7004 to start helping now! Not only is volunteering personally rewarding, but it helps to channel the many emotions that brachial plexus injuries can invoke!*

# It's All About Technique: My Life as a Police Officer

*By Sgt. William Scott Smith*

**M**y name is William Scott Smith. I have a right obstetrical brachial plexus injury. I have always been told that I wouldn't ever be completely normal, that I wouldn't be able to tie my shoes or that I would always have to drive a car with an automatic transmission. For some reason, even when I was little, I never really believed it when people said things like that. A still small voice from deep inside me seemed to refute any negative criticism. In spite of what most people thought, I have turned this injury into more of an aggravating nuisance than a life altering disability.

For me it all began on Thursday, September 24, 1970 as the sun burned hot in an unc customary way for the fall of the year. My mother, June Imogene Smith, was in a bad way. Aside from being pregnant with me, she also suffered from high blood pressure and was a diabetic. To top it all off, she was forty years old. These factors all worked together to form a dangerous mix that would be the beginning of my life and would leave me with little chance of survival and even less chance of living normally.

The C-section that would have given me my best chance would most likely have killed my mother. Her blood pressure was too high and the decision was made to try to deliver what turned out to be a baby that weighed over eleven pounds. The battle with birth was long and terrible and the result was a right side brachial plexus injury and thirty days in an oxygen tent from umbilical cord strangulation.

Somehow I got through it. My mother had a strong faith in God and she always

believed that the best would happen.

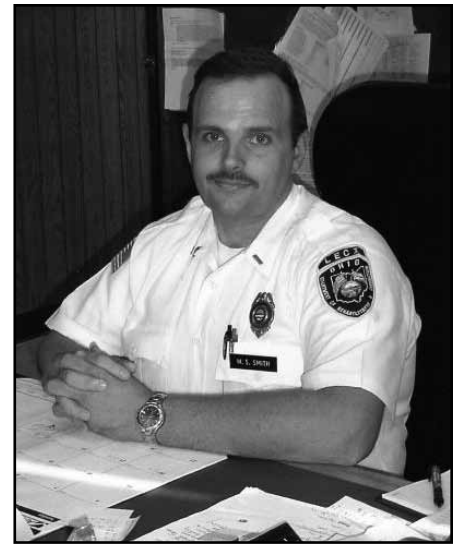
As it turns out, she was right – at least I think she was.

I can't recall when I first came to the understanding that I was "different" from everyone else. I know that it started to matter to me in the sixth grade when a fellow sixth grader called me "crippled arm." That was the first time that anyone ever looked at me with anything other than compassion and I must admit that it was a fairly bitter pill to swallow.

I found out pretty early that the world was made for people with two strong arms, and I struggled to survive by adapting to my environment. I had gone to live with my father after my mother's death - I was eight years old - and dad was not one to coddle a boy regardless of disability. This was a distinct culture shock to me, as mother had always treated me as if I might break if jostled too roughly.

My dad raised show horses and lived on a farm, so I was expected to participate in the festivities. I learned how to ride horses, bale hay and cut firewood. We also had a beef cattle herd and I learned to wrangle the young steers as well. This consisted of wrestling them to the ground and wallowing with them in their own muck until they could be vaccinated and a tag placed in their ear. Later, I would compete in bull riding at local rodeos.

I learned that I could compensate for my right BPI arm with technique. I enrolled in a Judo school as a teenager and found that I could fight as well as anyone else, so long as I took the time to develop methods of dealing with the disadvantage of being weaker on the right side.



When I made the decision to pursue a career in law enforcement, I was told that it would be impossible for me to do. At first, it seemed as if it would be because no one wanted to give me a chance to prove myself.

So, I did the only thing that I could do. I quit telling them about it. I had used my bpi arm enough that it was well muscled and strong, it wasn't obvious that it was even injured unless I let it dangle, and then it was the odd angle that gave it away. I figured out that it was almost invisible if I kept my hand in my pocket and eventually got through a hiring process with a local sheriff department in Ohio. The position was a "Special Deputy" position that didn't pay much; but at least it got me a seat in the academy.

At the academy, the Commander turned out to be one of the greatest men I have ever met. To his credit, he never said a word about my injury. He just rode me like a pony throughout the entire ordeal! He forced me to do pushups, run laps, and fight in scenarios. He yelled at me, he screamed at me and he hollered at me – just like he did with everyone else! He showed me, like my dad did before him, how much I could squeeze out of my bpi arm if I could set my mind to be tough and ignore the pain from my body. He did a great job of turning boys into men. I wasn't surprised to find out that he had served his country as a drill instructor in the Army!



One of his assistants, however, was of a different variety than he. This assistant told me once, in front of the whole class, that I would never pass the firearms section and that I would fail miserably during the unarmed self-defense course. This guy, whom I will not name, really caused me to gnash my teeth, and I was thrilled to find out he was one of the three men who would dress up in pads during our self defense final test.

Each student had to fight three men for two minutes in order to pass this class. If we were overpowered by them, then we failed. They were fully padded and we had to use techniques that we had been taught to defend ourselves. It was all full contact, so they could hit us and we could hit them.

When it was my turn, I tried, I really, really tried to break one of the Assistant Commander's legs with well-placed and powerful kicks. I failed miserably though because the pads were just too thick. I did pass easily and even managed to land the "Top Gun" award for being the fastest and most accurate shooter at the firing range later in the course. I was able to prove that the Assistant Commander was not gifted with prophecy and that he was also a poor judge of character.

I began work as a Special Deputy. I worked long hours for next to nothing and was soon offered a part time job as a road deputy by the then Chief Deputy who shall also remain nameless. I accepted and he said he would call me in a couple of days.

When the call hadn't come after a week, I called him. He told me that he was withdrawing his offer because some of the other deputies had voiced concerns that I wouldn't be able to defend myself in a confrontation. He had never noticed the

*"Time after time, I have been given the opportunity to meet people who would believe in me in spite of those who doubted me." -- Scott Smith*

condition before and was ignorant of it until someone told him about it, even though I had worked with him several times. Frustrated beyond belief, I quietly hung up the phone. It was the first and only case of discrimination that I have ever experienced on the job.

Shortly after being hired as a Special Deputy, I had gotten a job in a close security prison in Ohio. Working in a prison was a real learning experience for me, on top of having to learn to handle myself amongst some of Ohio's toughest inmates, I also had to learn to rub elbows with some of Ohio's toughest officers. I did well there. I learned Aikido to supplement what I had learned in Judo, joined the SRT (SWAT) team, became an armory officer and eventually worked my way up to the rank of lieutenant.

While working at the prison, I managed to land a job at a small police department where I worked part-time for ten years. I have been a police officer and correction official for well over thirteen years now.

In 2005, I took a position as a police officer at a local prestigious university. It paid enough that I was able to quit my job at the prison and the part time police department. I am currently serving as a police sergeant at that police department and I have never been happier.

When others brought me down a still small voice seemed to reassure me. Call it what you must, my inner self, a spiritual guide, instinct, etc. I won't try to change your mind, but I fully believe that, for me, it was the Holy Spirit of God speaking to me. I am a devout Christian who had often wondered

why God would leave me disfigured when everyone else was not. Often I would get discouraged and would feel betrayed by the very One that I had trusted. That is until one day when it occurred to me

that whenever times were the hardest, whenever I had hit a roadblock that I could not get past, it was at these times that the still, small voice would pipe up and give me an idea – a concept of a technique that would get me past the hard time.

Once, when I was in the police academy and it was told to us that we would have to shoot with both strong and weak hands unassisted, it seemed like the end of the road for me. I could not lift my bpi hand to eye level at all, let alone with the weight of a loaded pistol in it. When I was ready to give up, my still, small voice came though and it occurred to me that if you can't take the hand to the eye, take the eye to the hand. It worked! When I held the pistol up as far as I could, and then angled my head down to it, I was able to sight down the barrel and hit the target. That is just one example of hundreds.

I have been told that I could undergo surgery and possibly get some use back and definitely get my bpi arm to look more normal. I don't think that I am going to proceed with any surgery. I have adapted well and am happy with the way that my life has gone. Taken as a whole, I can see where through miracle after miracle, I was brought to the place that I am at today. Time after time, I have been given the opportunity to meet people who would believe in me in spite of those who doubted me. I have always excelled and believe that I may even have an answer for that question of "Why?" that I petitioned God about so many times. Why was I allowed to remain disfigured when so many others were healed and made strong?

For me, I think it is to prove what is written: "That I can do all things through Christ who strengthens me."



# CELEBRATE!

*Whether it is sitting up for the first time, bringing hand to mouth or that first bike ride, those with brachial plexus injuries always have something to celebrate. On these pages we celebrate some of the achievements of our community!*

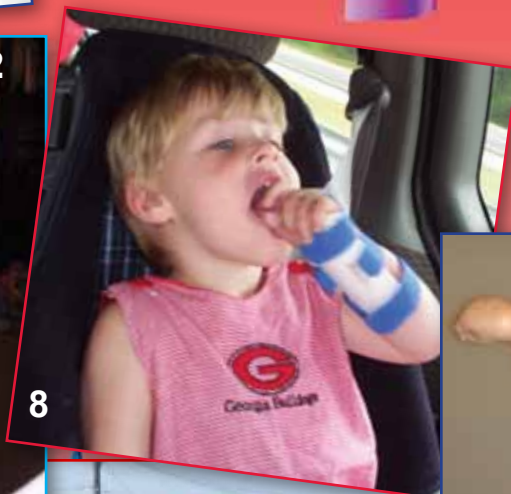
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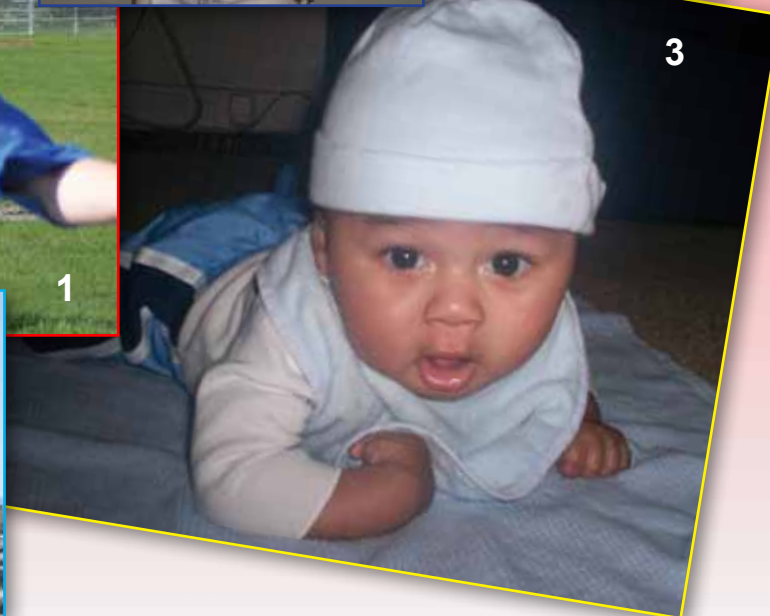
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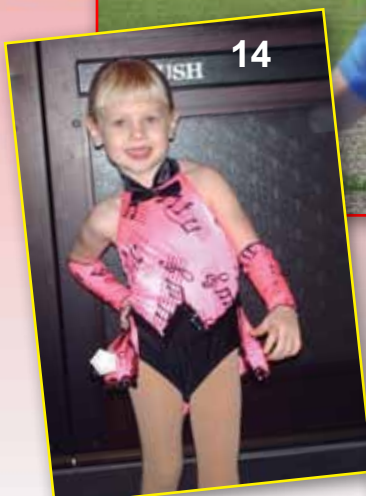


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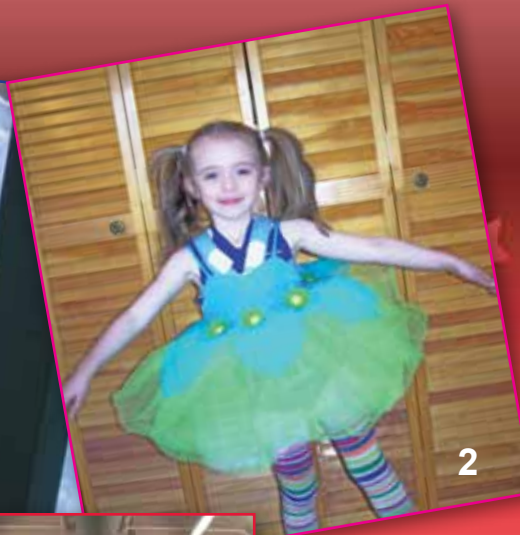
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14







1. Andrew loves playing baseball on his t-ball team!
2. Amber prepares for her upcoming dance recital at home. She's wearing TheraTogs underneath her costume.
3. Some of the accomplishments are small and incremental, yet so important. Here, Amaru lifts his head up for the first time during "tummy time."
4. Amy opens her umbrella with both hands!
5. Aubrey masters the delicate balance necessary in learning to ride her bike.
6. 'They' said Brandon would never swim, but he did it on his third birthday!
7. Brayden gets a full extension of his bpi arm playing baseball!
8. Carson reaches hand to mouth for the first time seven weeks after tendon transfers at the shoulder and wrist.
9. With a smile like that, we know that Cassidy will achieve whatever she sets her mind to.
10. Elizabeth carries the banner for her school band in a Memorial Day parade.
11. James has mastered the art of fishing one handed!
12. Jamie gets her right hand to her mouth. Go Jamie!
13. Kath, at age 65, makes the arduous climb up the Akropolis in Athens.
14. Katie in costume for her Baton Routine. Her team took first place in their competitions this season.
15. Lexi works hard to build her first snowman
16. Marcus reaches for the sky!
17. Marieke fulfils her life long dream of becoming a nurse.
18. Sarah with her karate trophy.
19. Tyler receives his green belt in karate. Black belt, here we come!

## 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](mailto: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 an 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.

