

Spring 2005

Issue #17

*Outreach*



A publication of the United Brachial Plexus Network, Inc.

**CAMP UBPN 2005**

**A Capitol Place To Be**



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### *On The Cover:*

Camp UBPN 2005 is headed to Washington D.C. in September. Don't miss the excitement! See page 17 for registration materials and additional details. Capitol photo courtesy of Washington, DC Convention and Tourism Corporation.

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## President's Letter

Welcome to another issue of UBPN's *Outreach* magazine. In it you will find details about our third UBPN-organized camp. The UBPN Board of Directors is working hard to ensure that we have another fun and informative camp in 2005. The Washington D.C. area will add another dimension to the camp experience, as it will allow us the opportunity to be involved in the national political process. We challenge you to join with us this year and help to raise awareness of brachial plexus injuries on a national level. In addition, we have plans to enrich the camp experience for the children by adding educational depth to their agenda, and we will include, for the first time, the opportunity to earn Scout merit badges.

You may wonder why camp is being held in mid-September instead of Awareness Week in October, as we had originally intended. After site visits to four separate camp facilities, we found it impossible to find a site that could accommodate our needs and our schedule in October. September dates were available. However, to be able to have camp while Congress is in session, our traditional Labor Day weekend camp was out of the running, since Congress is not in session at that time.

We will have a National Rally (Sept. 15) during camp and read our National Proclamation. The rally will be held on the National Mall and will include a press conference, speakers and an opportunity for all present to participate. We will be sharing details about the rally on the UBPN web site ([www.ubpn.org](http://www.ubpn.org)) as plans unfold.

While we are certainly planning wonderful events and speakers for this Camp, I must emphasize that what previous campers have found most valuable has been the opportunity to meet others with this injury. Being able to talk with other adults, with other children, and with other moms and dads is what truly makes camp so valuable. Come and join us, I guarantee you will come away both changed and charged up by the experience.

This issue contains information about how to register for camp. We will put more details about camp speakers and events as they are confirmed on the web site. Registered campers will be receiving packets of information during the summer months.

We are also excited about offering several new items for our community to show your support of our cause. Two of our new items are bracelets and magnets. You can see examples and get additional ordering information on the back cover. In addition, we will continue sales of our "bell" items. Not only will these items allow you to proclaim your support of our community but will help us to subsidize UBPN Camp 2005.

I hope to see you at UBPN Camp 2005: A Capitol Place to Be!

Nancy Birk,  
UBPN President

2003 Camp Attendees



# The Brachial Plexus Injury Prevention Program (BPIPP): An Overview of UBPN's Newest Strategic Initiative



Prevention is better than intervention. Prevention versus intervention should always be the focus when considering obstetrical injuries. Efforts to minimize the occurrence of shoulder dystocia, or to prevent it altogether, are obviously the most logical and safest place to start.

The focus of the BPI Prevention Program is to work toward the ultimate goal of reducing the number of obstetrical brachial plexus injuries. As a newly forming program and committee, there are many tasks that must be accomplished.

The first is the recruitment of passionate volunteers who agree that this injury is largely preventable, who can commit to being contributors to the program, and who can support the position that UBPN has developed toward prevention. We are proud to acknowledge those members from our community who have graciously volunteered to take part in these important efforts. They include Lisa Muscarella (AZ), Co-Chair (lisa@ubpn.org); Richard Looby (MA), Co-Chair (richard@ubpn.org); Lisa Duncan (CA); Jennifer Engelhardt (IL); Jennie Jackson

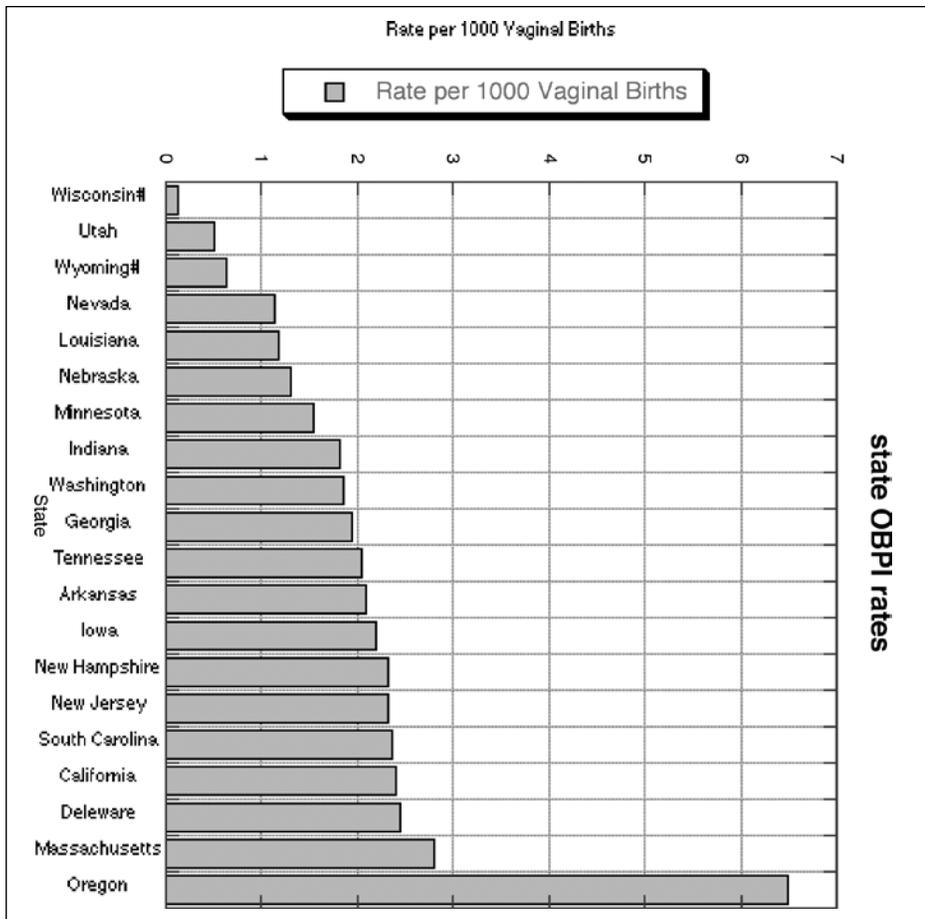
(NY); Krista Landry (CN); Kimberly Leeds (NM); and Brenda Copeland-Moore (WI).

Secondly, we need to have a baseline from which we can measure the progress and effectiveness of awareness and prevention strategies. To do so, we need to know how many babies are injured every year. We see numbers projected from 0.5 - 3 injuries per 1000 births, but where do these statistics come from? There is no mandatory database to record these injuries. In fact, absent other injuries, obstetrical brachial plexus injuries (OBPI) do not have to be reported.

However, if your child is injured and tests have to be run (such as a clavicle x-ray), then there has to be a hospital code assigned for billing purposes. Thus, when a child is released from the hospital, there is a hospital discharge record, which can allow us to identify a recorded injury. For OBPI, this code is 767.6 (an international code using the International Classification of Diseases: ICD-9).

The CDC samples this data from across the country every year. For the year 2002, there were nearly 9,000 OBPI born in the United States. Given that very few are injured outside of a vaginal birth, that is a rate of 2.8/1000 vaginal births. We believe this number to be a very conservative estimate.

We have also begun the collection of individual state data. **Table I** shows the injury rate per 1000 vaginal births for



**Table I:** State Obstetrical Brachial Plexus Injury Rates per 1000 Vaginal Births

states that offer this information free of charge. Some states do not even collect this information. Of those that do, the data is questionable, as not all hospitals reported data, and/or they only recorded primary discharge diagnosis.

There are up to 15 diagnosis codes available during discharge. For states that have recorded up to 15 discharge diagnosis codes, ICD-9 code 767.6 was found in discharge diagnosis 1-9. We continue to collect this data and seek funding to collect the data from states that charge fees. These baseline (crude) numbers will allow us to measure the effectiveness of UBPN's Awareness and Prevention efforts. Again we believe these numbers are conservative, although consistent from year to year.

We have also begun to collect references and are reviewing literature that supports our ideas on Positioning for Prevention. We have developed prevention pages on the UBPN website <http://www.ubpn.org/prevention>, which describes in more detail the circumstances that we believe lead to BPI. Our team will continue to refine our definitions, and develop literature and written media that can be used to disseminate our message for prevention.

The BPIPP team has an arduous journey ahead. We must fight to change the pervasive opinion that these injuries are an acceptable outcome of birth. We must enlighten the birthing professionals that this injury is indeed preventable and that it is unequivocally an unacceptable outcome of birth. We must also inform and educate women and the public, that birthing on your back closes your birthing canal, and that alternative positioning for labor is much safer and advantageous to both baby and mother.

These are just the first of many objectives that we must consider to improve the chances of reducing the incidence of brachial plexus injuries.

We are anxious to start making a difference, and welcome others who may be interested in joining our efforts to contact one of the co-chairs for more information. Anyone who may have special contacts that could potentially assist us in our efforts, such as media, medical, or political, are especially encouraged to contact us. ■

## 14<sup>th</sup> International Symposium on Brachial Plexus Surgeries

The 14<sup>th</sup> International Symposium on Brachial Plexus Surgeries, sponsored by Club A. Narakas was held in Brescia, Italy on Oct. 9-11, 2004. Pictured below are some of the support group representatives who attended.

*(L to R, Back to Front: Karen Hillyer, Liz Black, Neil Finney, Nancy Birk, Kathleen Mallozzi, Debbie Clark, Claudia Strobing, Peggy Ferguson)*



### Keep Outreach Coming to You!

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

You can phone in your address changes by using our toll free number at 1-866-877-7004 and leave a message, stating clearly and slowly your new address, or you can email the change to [info@ubpn.org](mailto:info@ubpn.org).

## Mayo Clinic's Brachial Plexus Team Uses Novel Approaches to Attempt to Restore Hand Function

■ *article reprinted with permission from the Mayo Clinic Neuroscience Update*

The brachial plexus is a complex network of interconnecting nerves that innervate the arm from the shoulder to the hand. The C5 through C8 and T1 spinal nerve roots form the basis of the brachial plexus.

Injury and lesions to the brachial plexus are fairly common and arise from a variety of causes. Traumatic lesions are typically caused by high-speed motor vehicle accidents, such as those involving motorcycles and snowmobiles. Perinatal cases occur in 1 in 2,000 births and are often related to shoulder dystocia. Other causes include tumors, irradiation, and nerve entrapment.

In traumatic lesions, critical motor function in the shoulder, elbow, wrist, and hand may be lost, and sensation in the fingers impaired. Incapacitating pain may also result from stretching or rupture of the nerves of the brachial plexus or avulsion of the nerves from the spinal cord. Lesions in the upper trunk (C5 and C6) result in the loss of shoulder and elbow flexion, whereas injuries to the lower trunk (C8 and T1) impair hand function. Injuries to the complete brachial plexus paralyze the entire upper limb.

Whatever the cause, these injuries can inflict severe disability in the shoulder, elbow, and hand. "In addition to the physical problems, patients may also have considerable psychological distress and economic hardship," says neurosurgeon Robert J. Spinner, MD. "The good news is that recent advances in the diagnosis and operative management and the depth of our multidisciplinary Brachial Plexus Clinic neurosciences team all work together to improve func-

tion and ease the patient's psychological distress."

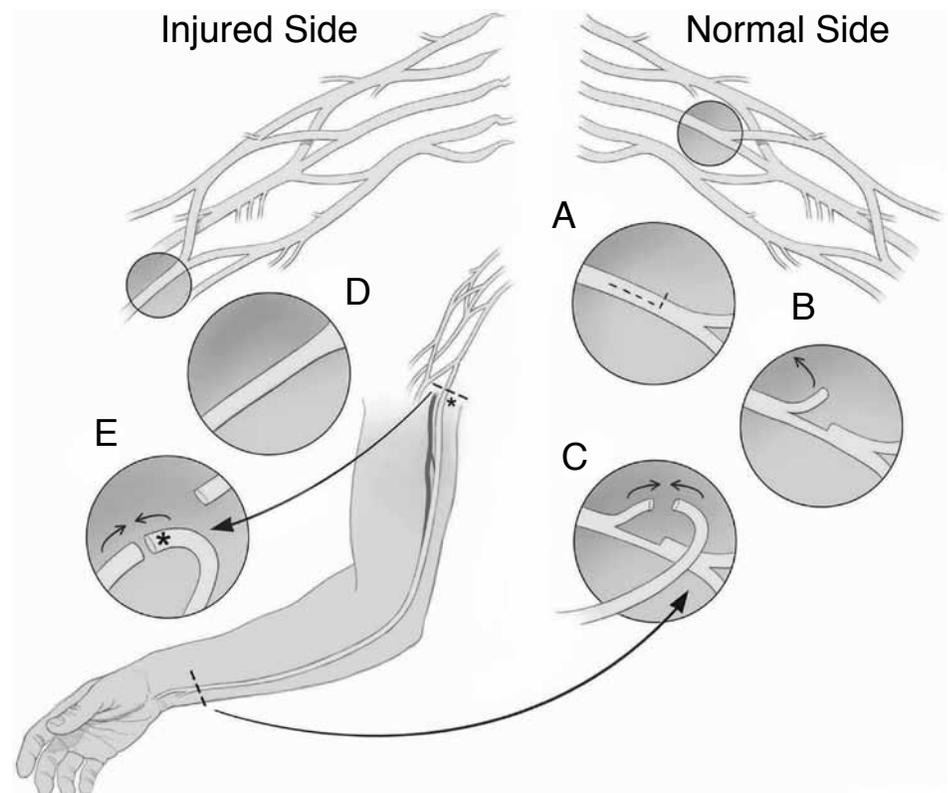
Adds neurologist C. Michel Harper, MD: "Communication and coordination of patient care across medical and surgical specialties clearly enhance the care, outcome, and satisfaction of our Brachial Plexus Clinic patients."

### Mayo Clinic's Interdisciplinary Brachial Plexus Clinic

The interdisciplinary Brachial Plexus Clinic at Mayo Clinic in Rochester addresses the complex problems of pa-

tients who have brachial plexus lesions. Specialists from several areas—neurosurgery, orthopedic surgery, neurology, radiology, physical medicine and rehabilitation, physical and occupational therapy—work cooperatively to design a treatment and recovery plan that is unique to each patient. It is the mission of the Brachial Plexus Clinic to help patients recover as much painfree function and quality of life as possible.

The team of surgeons that evaluates each patient also operates together. Having performed more than 100 procedures



**Figure 1.** Half the C7 nerve from the brachial plexus on the normal side is selected (A) and used (B) to power the injured side. A vascularized ulnar nerve graft from the injured side is reversed and connected to the donor C7 nerve on the normal side (C). The other end of the ulnar nerve graft is then connected to the median nerve on the injured side (D and E). This complex technique potentially allows patients with severe brachial plexus injuries to regain sensation in the hand and movement in the fingers on the injured side. Illustration courtesy of Mayo Clinic Neuroscience Update.

in 2003 alone (including 25 contralateral C7 transfers and 30 free-functioning muscle transfers in the past 2 years), this team has extensive experience and expertise to provide state-of-the-art care for patients with brachial plexus injuries.

Says Dr Harper: "The multidisciplinary approach is absolutely essential when evaluating and treating patients with complicated brachial plexopathies. Each patient is evaluated by a neurologist with a special interest in peripheral nerve disorders. The same team of neurologists performs all necessary electrodiagnostic studies — both preoperatively and during surgery — to help the surgical team make critical decisions regarding localization, prognosis, and treatment options for the patient."

### Treatment Options

The diagnosis of brachial plexus injury can be established soon after injury. Evidence of complete root avulsion indicates early surgical intervention is necessary, and the sooner it is undertaken, the better the outcome. Waiting longer than 6 months for surgery is not advisable because the cumulative effects over time of muscle atrophy, motor end plate degeneration, and neuronal death contribute to inferior outcomes.

### Surgery

Surgical options include neurolysis for neuroma in continuity, nerve repair for lacerations, and nerve grafting to bridge gaps that result from traumatic ruptures, tumor excision, or severe stretch lesions (which do not conduct impulses across the lesion). Nerve regeneration is slow, however, occurring at a rate of approximately 1 inch per month.

### Nerve Transfers

When direct nerve grafting cannot be performed or is less likely to provide a satisfactory result, transfer of "expendable" uninjured nerves allows the rapid recovery of key muscles. Nerves can be moved from an uninjured portion of the

*continued on page 36*

# The Mayo Experience

■ *By Ellen Bramblett*

My son, John Floyd, suffered a brachial plexus injury more than two years ago when he was fifteen. John is an avid and competitive cyclist. The summer before his accident he was thrilled to go with a group of local cyclists to the Tour de France and spend a week cycling the same daily Alpine route as the race competitors. His life truly revolved around cycling.

In November 2002, John was hit by an SUV while on a training ride in Atlanta, Georgia. His injuries included a concussion, a broken left arm and leg, and as we learned while in the hospital, nerve damage to his left arm. Most of you can relate to the initial confusion upon hearing the term "brachial plexus injury" for the first time. Since nerve avulsions are relatively rare, we were convinced that the pain John experienced once he woke up from his concussion was a positive sign, indicating that the nerves were already healing — whoops.

### EMG one month later, no activity

After the EMG, we began to realize that this was much more serious than we originally thought. At the same time we were completely overwhelmed — John was dealing with severe neurological pain; ongoing appointments with a pain specialist to find a "recipe" to at least partially control the pain; trying to better understand the injury; learning to use a wheelchair; and handle schoolwork from home.

That's when I discovered upbn.org. The site has been a godsend, providing not only a wealth of useful information but also a place to receive much needed emotional support. I registered in early 2003 and have posted close to 300 times since. Early on, the posts were mostly questions for which I received quick and useful answers. After John started getting muscle movement, I began to post answers to other people's questions — usually strongly encouraging them to consider the Mayo Clinic in Rochester, MN for treatment.

### The Mayo Clinic in Rochester, MN

Following advice to get three medical opinions, I made appointments for John at what are generally considered to be the "big three" clinics. As luck would have it, the Mayo appointment came first. We arrived for our consultation, thinking we'd hear what they had to say, go to the other appointments and then make our decision. In the end we were blown away by our entire Mayo Clinic experience.

We visited with the primary doctors with different specialties, who work together



Following several surgeries at the Mayo Clinic to treat his traumatic brachial plexus injury, John Floyd continues practicing his love of competitive biking.

*continued on page 37*

## The Use of Kinesio Tex® Tape as an Adjunct to Treatment For Children with Brachial Plexus Injury

■ *By Trish Martin, PT*

**K**inesio Tex® tape is an elastic, cotton tape with an adhesive backing developed by Dr. Kenzo Kase in 1973. Dr Kase felt that muscles and other tissue could be treated by outside assist and developed a new type of tape. Kinesio Tex® tape can be used as an adjunct to treatment for the infant with brachial plexus injury. Therapy goals and use of Kinesio tape differ for the infant and older child. A thorough evaluation of the infant to assess specific areas of weakness, abnormal movement patterns, and alignment concerns is essential. Diagnostic tests to determine boney alignment and innervation are also key in determining primary concerns and targeting treatment areas.

Kinesio® tape may be used to support a weakened muscle, limit hypermobility in a specific area, facilitate optimal alignment for improving the effectiveness of a muscle group, and provide stability proximally to maximize grading and control of movement. Specific muscle imbalances can be minimized through the use of Kinesio tape. For many techniques, Kinesio tape is applied origin to insertion to facilitate or support a muscle and insertion to origin for a fascial release or acute injury.

Infants with brachial plexus injuries often develop disuse atrophy of specific muscles as reinnervation occurs. The Kinesio tape can be used to promote optimal alignment and prevent prolonged over-lengthening of weakened muscles. Kinesio tape also provides sensory input to mechanoreceptors in the skin to facilitate improved awareness.

The tape is latex-free and can be worn for 4-6 days continuously before removal. The tape is applied to the adhesive backing with a 10 percent stretch and can be stretched to 40 percent longer than the resting length. Kinesio Tex® tape comes in beige, red, blue and black and widths from one inch to three inches.

Kinesio tape is worn for 24 hours a day and can be worn for several days in a row. Skin integrity needs to be monitored and time out of the tape may be needed to allow the skin to “breathe.” Tape is removed during bath time and canola oil or lotion may be used to assist in removal.

Parents are often instructed in the application of Kinesio tape, as well as the removal process.

The accompanying pictorial will demonstrate some of the ways Kinesio tape can be used as an adjunct to therapy.

---

*Patricia (Trish) Martin, P.T. is a physical therapist specializing in the treatment of infants and children with orthopedic and neurological involvement as well as in lower extremity biomechanics, casting, splint fabrication, and taping. Trish received a Bachelor of Health Science degree from the University of Kentucky in 1980. She worked at MetroHealth Medical Center and has continued in pediatric private practice for 23 years. She is NDT trained in pediatrics (1988). Trish has been a course assistant to Beverly Cusick courses on lower extremity biomechanics splinting and casting since 1990. Trish has been taping for twelve years and using Kinesio Tape for eight years. She became a Kinesio Taping Instructor in 2001 and teaches courses on Kinesio taping and taping for alignment in children and adults. Trish is currently Manager of Satellite Therapy Services for the Cleveland Clinic Children’s Hospital for Rehabilitation. Contact: PMartin827@aol.com*



1. A thorough evaluation needs to be initiated, including volitional and spontaneous movement, asymmetries, range of motion limitations, and reflexes.

Alignment and movement patterns need to be assessed in supine, sidelying, prone, and (if appropriate) in sitting.

Determine which movement’s components are present and which are diminished or absent.

The involved arm needs to be assessed to determine resting position, active movement, and range of motion restrictions and limitations.

Vascular status, including indications of swelling and discoloration, needs to be assessed.



2. Initially a tape “patch” is applied to an area of the trunk (often upper back) to allow assessment of skin reaction to tape. A barrier, like a light coat of Milk of Magnesia, is applied under the tape to protect skin. Allow barrier to dry prior to tape application.

This patch is removed by the parents in 4-6 days and skin reaction is assessed. If parents note increased irritability or skin redness around tape, patch may be removed earlier.



**3.** At the next therapy session, Kinesio Tape® may be applied to facilitate middle and lower trapezius to aid in shoulder stabilization and to decrease shoulder elevation. Tape is applied from origin to insertion.

Kinesio Tape may also be applied to the tight upper trapezius, insertion to origin, to decrease elevation, but skin is often more fragile in this area, with fascial restrictions.

Tape should not be applied to both upper and lower trapezius.

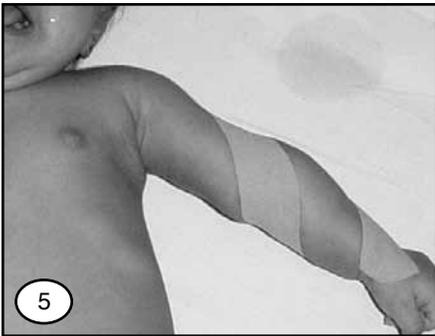


**4.** Torticollis, a tight neck with rotation toward one side, is often seen in conjunction with brachial plexus injury.

Congenital muscular torticollis (CMT) refers to a condition caused by idiopathic fibrosis of the sternocleidomastoid muscle that restricts movement and pulls the skull toward the involved side and rotates toward the opposite side. (Yu CC, Wong FH, Lo LJ, Chen YR. "Craniofacial deformity in patients with uncorrected congenital muscular torticollis: as assessment from three-dimensional computed tomography imaging". *Plast Reconstr Surg.* 2004 Jan; 113(1):24-33.)

Positional torticollis is a term used to define asymmetric head position, often accompanied by plagiocephaly.

**4a.** Kinesio tape can be applied to the over-lengthened sternocleidomastoid muscle, usually on the opposite side of the brachial plexus injury.

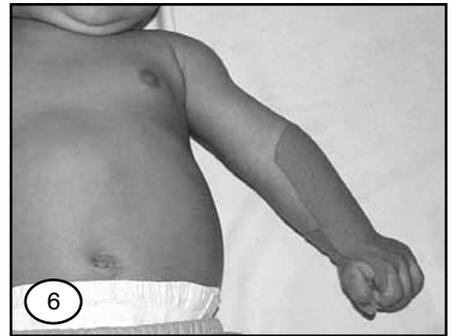
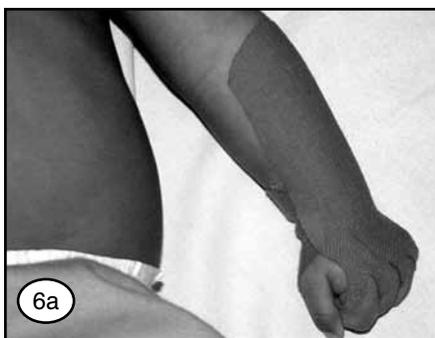
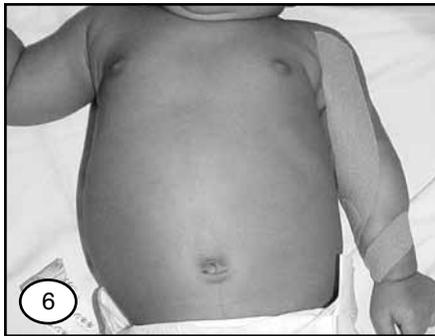


**5.** Kinesio Tape® can be applied in a serpentine fashion along the radial wrist, forearm and upper arm.

In tape application, consider age-appropriate developmental skills and movements required to obtain these skills.

For example, the infant will bring hand to mouth before the use of elbow extension for weight-bearing.

For this reason, the tape is often applied to wrap around anterior to the elbow.



**6.** Tape is applied to facilitate wrist radial deviation (away from pinky side of hand), forearm supination (palm up), elbow flexion (bending) and shoulder flexion (lifting off the surface).

**6a.** A "button-hole technique" may also be used to provide sensory input to the hand and facilitate wrist extension.

Kinesio Tex tape comes in beige, red, blue, and black colors. The use of colored tape is encouraged, as this also provides additional visual input toward the involved arm as it moves into the visual field.



**7.** The Kinesio tape is often removed by parents the day before a therapy session. The therapist needs to continually reassess movement patterns to determine which taping technique will be the most beneficial.

Achievement of developmental milestones and use of tape to facilitate age appropriate skills must also be considered.

**8.** Bilateral hand skills, with supination and symmetrical manipulation skills, are facilitated.





**9.** Scapular position needs to be assessed and Kinesio tape applied to provide proximal stability and improved alignment. Scapular mobilization and myofascial release techniques may need to be done prior to taping.

**9a.** Taping is followed by functional activities to promote use of extremity in more optimal alignment.

**9b.** In this case, lower and middle trapezius are taped, followed by weightbearing and weightshift activities in prone.



**10.** Grading of movements in all positions is a primary goal.



**11.** The use of Kinesio tape to support the forearm in neutral supination in weightbearing, assists to elongate tightness on the ulnar side of the wrist and allow for stability in manipulation with the radial side of wrist and hand.

**12.** The use of Kinesio tape to support the forearm in neutral supination in weightbearing, assists to elongate tightness on the ulnar side of the wrist and allow for stability in manipulation with the radial side of wrist and hand.

**13.** Reaching antigravity and fine motor control in sitting are facilitated with Kinesio tape.



**K**inesio Tex® tape can be used in conjunction with other therapeutic interventions. In NMES (Neuromuscular Electrical Stimulation), it is beneficial to determine electrode placement prior to tape application, as electrodes cannot be used effectively over the tape. The electrode placements are marked and the tape is applied to other areas, or around the electrodes. If TES (Threshold Electrical Stimulation) is used, the tape can be used on other body parts or tape can be used when TES is off. For example, if TES is used for eight hours during the night, the Kinesio tape can be applied daily after the TES unit is removed. Kinesio Tex tape can be used under splints and orthoses, as well as under the ARK brace and Theratogs.

In conclusion, the use of Kinesio Tex tape as an adjunct to treatment can be beneficial in working with children with brachial plexus injuries. Techniques can be modified depending on innervation, sensory concerns and movement patterns to aid in the attainment of optimal alignment and attainment of developmental milestones. ■

# Brachial Plexus Injury from a Rehabilitation Perspective

■ *Steven R. Cooley, CRC, CVE, CCM, CLCP  
Fellow, American Board of Disability Analysts*

Vocational Rehabilitation focuses on interventions which maximize the residual functional capacity of an individual who has incurred impairment. The rehabilitation goal is to maximize independence through securing and maintaining substantial gainful activity. When an adult has incurred an impairment, interventions are comparatively of short duration. However, when the impairment is a birth injury, the role of the specialist is more properly “habilitation” than rehabilitation and the associated interventions take place in the context of the child’s developmental process. To reach the rehabilitation goal of maximum functioning, the process must be ongoing, frequently reassessed, and highly individualized.

Although there is a wide range of functional outcomes among children who have incurred a brachial plexus injury, reduction in the use of the affected extremity is expected. The more common outcomes are some limitation in range of motion, strength, and dexterity. Often the affected limb is relegated to a secondary “helper hand” role.

Vocationally, the potential negative impact of an upper extremity impairment can be substantial. The upper extremities are involved in tasks such as gripping, applying torque, driving, lifting, carrying, pulling, pushing, reaching, handling, fingering, manual and finger dexterity, etc. Approximately 88 percent of the most common occupations and a significant portion of the most common activities of daily living involve use of the upper extremities.

When the impairment is a birth injury, it may also impact developmental processes. Social stigmatization is a realistic concern. The child may be unable to participate in certain recreational activities and feel socially isolated. The sense of “being different” may suppress the development of self-esteem. Some families become somewhat overprotective, which may inhibit emotional maturity, assertiveness and self-reliance. Such issues may combine with physical limitations to negatively impact school performance and social development.

On the positive side, children are remarkably adaptive and with the appropriate services and support, may be able to function at a much higher level than would be typical of someone who incurred the same impairment in adulthood. With such an injury, there are numerous interventions, products, and services which may be beneficial in helping the child maximize their capabilities, while minimizing or ameliorating the negative impact.

Many services are available without cost via the public sector. However, the quality, distribution, and delivery of public sector services are very uneven. In some areas, public sector services are quite good. However, in many areas the opposite is true. Public sector services must be responsive to a large volume of patients and are subject to budgetary constraints. Consequently, it is not unusual for patients to have to wait longer for services, than they would through private sector providers. The budgetary constraints often impact the frequency,



nature, and/or quality of services provided.

Accessing public sector services can be difficult. There are frequently complicated, bureaucratic application procedures and approval processes that result in extended delays in service delivery, or even denial. To maximize residual functional capacity, supplementation or replacement of public services with private sector services, may be beneficial.

From a vocational perspective, education is one of the most important interventions when a child has incurred a brachial plexus injury and merits being addressed individually. Many children with brachial plexus impairments will remain unsuited for occupations that are dependent upon bilateral upper body strength, e.g., construction, many skilled trades, and many driving/operating occupations. They may also have difficulty with occupations requiring bilateral dexterity such as assembly, keyboarding, etc. Educational attainment can help reduce loss of labor market access.

The key to educational attainment is to begin planning early. Educational development starts long before a child ever enters school. With all the various medical and therapeutic needs, not to mention confused emotions and stress, that frequently arise in the child’s early years, it is all too easy for educational

*continued*

enrichment to get squeezed out. Having a realistic, workable plan, to ensure that educational needs are not inadvertently neglected, can reduce a great deal of family stress.

**P**sycho-educational evaluations are also useful, at the appropriate developmental ages. They can determine if learning problems exist which might impede academic attainment and identify appropriate interventions. They also provide the parents with an ally in developing an appropriate individual educational plan when the child enters the formal educational system.

Parents face difficult decisions when their child is ready to enter school. It is important that the child function as normally as possible and learns to deal with their impairment in a positive manner. For many, the public school system is appropriate. Many public schools strive to meet the needs of all children. Unfortunately, not all do.

The school environment should be fully investigated. There are certain standards which help in assessing the school, such as a class size and/or student teacher ratio and the overall size of the school. The basic rule of thumb is, smaller is better. The awareness and attitudes of administration and teachers regarding the needs of an impaired child are also important clues. Unfortunately, there is no cut and dried formula for deciding what is the best route for the impaired child. Every child is different and every school is different. The basic goals should be to identify the environment which will allow the child to function, feel normal and included, while maximizing educational attainment and providing a safe learning environment. It is important to assure the right environment and that the child does not get “lost

in the crowd.” Private schools may be a consideration.

From a rehabilitation perspective, it is important to remember the child’s impairment does not just impact the child, but the whole family. Meeting the medical and therapeutic needs of the child can demand extensive time and energy. Sometimes, it becomes necessary for the family’s schedule to revolve around issues related to the impairment. Parents may be overextended and/or overstressed. Siblings may feel displaced. There may be a tendency to be overprotective and often there are unresolved emotions. Often the family members find themselves subordinating their needs and desires to serve the needs of the impaired child. The family is potentially the most important asset in maximizing residual functioning. Unaddressed family strain can be counterproductive from a vocational and rehabilitation perspective. The needs of the entire family must be met to ensure the maximum outcome for the child who has incurred the brachial plexus injury.

A Life Care Plan developed by a Certified Life Care Planner (CLCP) may be beneficial in aiding the family and child in meeting their needs. A Life Care Plan is a dynamic document based upon published standards of practice, comprehensive assessment, data analysis and research, which provides an organized concise plan for current and future needs with associated costs, for individuals who have experienced catastrophic injury or have chronic health care needs (Combined definition of the University of Florida - Intellicus Annual life care planning conference and the International Academy of Life Care Planners)

In simple terms, a Life Care Plan identifies and defines intermittent and ongo-

ing goods and services which may be required to maximize the child’s residual capabilities and quality of life, restoring the child as closely as realistically possible to a normal level of functioning. The plan is developed in coordination with the physicians, therapists, teachers, and other professionals involved in the habilitation process. It is highly individualized and starts with an assessment of the child and family needs. It is constructed with the awareness that needs change over time and in accordance with various developmental phases. Even the best constructed plan should undergo periodic review and is always subject to revision.

A well-developed plan should be designed to maximize independent functioning. A plan needs to foster a “can do” attitude and help the individual develop confidence in their ability to overcome barriers and be self-reliant. This is especially critical when planning for young children.

A quality Life Care Plan will be designed to encourage the child to develop safe compensatory strategies where possible, instead of others always doing things for them, while being aware each child develops at their own rate and some compensatory strategies may be beyond their functional maturity and should be delayed to avoid frustrating the child. For example, don’t expect your two year old child to be able to button his/her shirt properly, with or without impairment.

A quality plan can take part of the burden off the family and reassure them they are doing the best for their child. It can help to clearly communicate the needs and appropriate interventions to all involved and the Life Care Planner or Case Manager can serve as an independent advocate for the child.

The Life Care Plan is also a valuable tool in litigated cases to identify future needs and associated costs.

Early involvement of a Certified Rehabilitation/Habilitation Specialist can help the families of children with brachial plexus impairments reduce stress, navigate the service delivery systems, serve as an advocate, and maximize positive outcomes for the child and family. ■

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*Steven R. Cooley is a Nationally Certified Rehabilitation Counselor (CRC), Certified Vocational Evaluator (CVE), Certified Case Manager (CCM), and a Certified Life Care Planner (CLCP) who has been providing services to people with disabilities for over 20 years. He is based in St. Petersburg, Florida.*

*On March 23, 1999, Mr. Cooley testified before the U. S. House of Representatives, Subcommittee on Health and Environment, Capitol Hill, Washington, D.C., regarding the Work Incentives Improvement Act of 1999 (H.R. 1180) and Social Security reform. The Ticket to Work Program was passed and now enables recipients of SSDI to return to work and retain Medicare benefits.*

*Mr. Cooley also was a guest presenter at the 2003 UBPN Camp in Silver Bay, New York.*

# Birth Trauma and Its Aftermath: Post-Traumatic Stress Disorder

■ *By Cheryl Tatano Beck, DNSc, CNM, FAAN*

Post-traumatic stress disorder (PTSD) was first identified in the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) in 1980. The first persons to be identified as experiencing PTSD were Vietnam War veterans. At that time, in order for a diagnosis of PTSD to be made, the event needed to be considered beyond the range of usual human experience. In 1994, the DSM-IV broadened what is considered a traumatic stressor to include an event that can involve actual or threatened death or serious injury. The physical integrity of a person or others can be threatened. The person experiences extreme fear, helplessness or horror.

The DSM-IV does not specifically list childbirth as an example of a traumatic stressor, but it certainly can qualify as one (Beck, 2004a). The prevalence of PTSD due to birth trauma has been reported to range between 1.5% (Ayers & Pickering, 2001) to 6% (Ménage, 1993). Some risk factors for PTSD due to childbirth identified in the literature include high level of obstetric intervention, emergency cesarean delivery, perception of inadequate care during labor and delivery, premature or high-

risk infants, painful labors, and feelings of powerlessness.

What could happen during the child-birth process that could be so terrifying that a mother develops PTSD? What a woman perceives as a traumatic birth may be viewed quite differently from the perspective of clinicians. Margaret Wolfe Hungerford was an Irish born 19<sup>th</sup> century romance novelist. She first coined the phrase “beauty is in the eye of the beholder” in the 1878 novel *Molly Bawn*. In a study of birth trauma, I discovered that beauty is not the only phenomenon that lies in the eye of the beholder; birth trauma does also (Beck, 2004a). A traumatic birth in the eye of a mother may be viewed as just another routine delivery for labor and delivery staff.

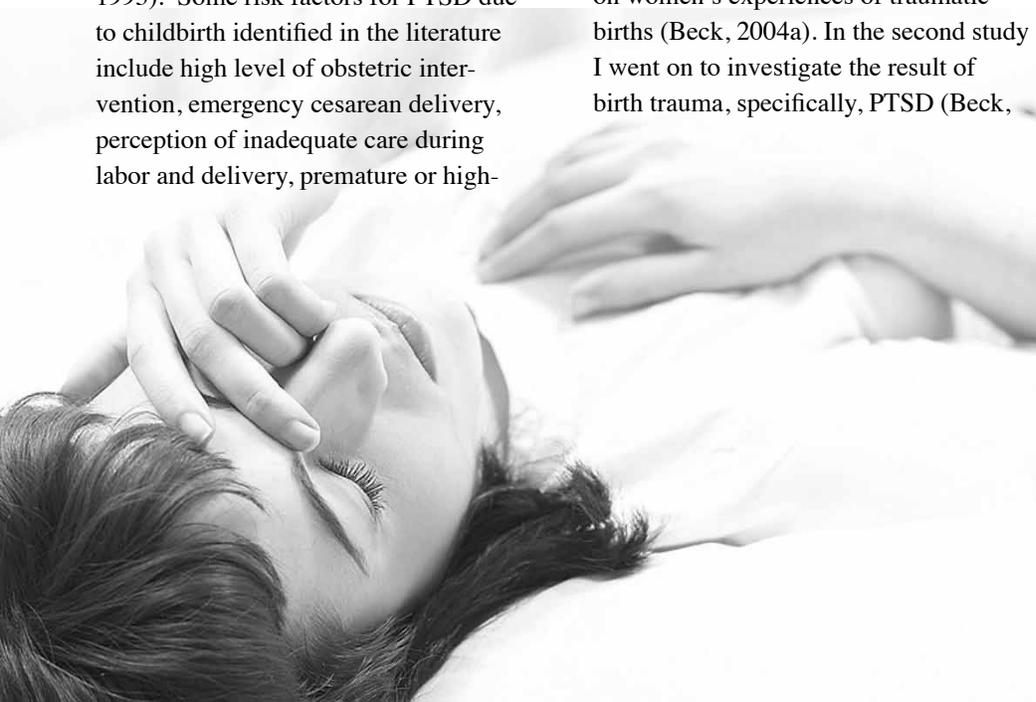
In this article I will be discussing the findings of two qualitative studies I have conducted. The first study focused on women’s experiences of traumatic births (Beck, 2004a). In the second study I went on to investigate the result of birth trauma, specifically, PTSD (Beck,

2004b): What is it like for mothers to suffer with PTSD due to a traumatic birth?

Both of these studies were conducted over the Internet with the help of Trauma and Birth Stress (TABS), a charitable trust in New Zealand ([www.tabs.org.nz](http://www.tabs.org.nz)). (See the sidebar on the next page.) TABS was founded by five mothers who had experienced traumatic births, to support women who have also experienced birth trauma. TABS’ other mission is to educate clinicians and the lay public about PTSD due to childbirth. Forty mothers from around the globe participated in my research. These women lived in the following countries: New Zealand, Australia, United States and the United Kingdom. Over the Internet, mothers sent their stories describing their experiences of birth trauma and the resulting PTSD due to those traumatic births. I analyzed the mothers’ stories to identify common themes or patterns that described the essence of their experiences. First, I will share with you the mothers’ powerful descriptions of their birth trauma. Next, I will describe what it is like for these women to experience PTSD due to these traumatic births.

## Birth Trauma

Four core components or themes were involved in mothers’ stories of birth trauma (Beck, 2004a). The first theme was called “To care for me: was that too much to ask?” As one mother shared, “I am amazed that 3 ½ hours in the labor and delivery room could cause such utter destruction in my life. It truly was



like being a victim of a violent crime or rape” (Beck, 2004a, p.32). Perceived lack of caring by labor and delivery personnel during such a vulnerable time resulted in turning the birthing process into a rape scene for some women. Mothers felt alone, abandoned, and stripped of their dignity.

As one mother shared, “The labor care hurt deep in my soul and I have no words to describe the hurt. I was treated like a nothing” (Beck, 2004a, p.32).

One woman who experienced a postpartum hemorrhage remembered, “I had a major bleed and started shaking and I couldn’t stop. I heard the specialist say he was having trouble stopping the bleeding. I was very frightened, and then it hit me. I might not make it! I can still recall the sick dread of real fear. I needed urgent reassurance, but none was offered” (Beck, 2004a, p.32).

Theme 2 was “To communicate with me: why was this neglected.” During traumatic births, women often felt invisible because clinicians failed to communicate with them. The following excerpt from one woman’s story powerfully illustrates how a clinician merely communicating with her and explaining to her what was occurring could have prevented her birth trauma:

“The doctor turned on this machine that sounded like a swimming pool pump. He proceeded and hurriedly showed me the piece that was to be inserted into me. It was chrome metal and extremely large in circumference. Next thing he begins to pull on this hose, which was the extension of the suction. He gritted his teeth and pulled. I felt sick. On the end of this machine was our baby’s head. He used every ounce of his male strength to pull the baby out. I was horrified. I started to imagine, and any minute now a head will come out, ripped off from its body. I was really in shock. He had his foot up on the bed, using it as leverage to pull. All of a sudden, the loud sucking machine made an even louder noise, and it broke suction. The doctor fell back and nearly landed on his bum. Blood came spurting out

## Trauma and Birth Stress (TABS)

■ *by Sue Watson, TABS Chairperson*

Originating in New Zealand, TABS or Trauma And Birth Stress, is a charitable trust that serves as a support group for mothers and an education group for health professionals. We have in common stressful and traumatic pregnancies or births that affected our lives negatively for months or years afterwards.

We formed TABS because of the need to make PTSD known as a form of mental illness that can happen following childbirth, but quite distinct from the Baby Blues, Post Natal Depression (Post Partum Depression) and Post Natal Psychosis.

Early in 1998, five of us, Carolyn, Kiri, Narelle, Sue and Toni, came together via the correspondence page of the New Zealand Little Treasures magazine as a result of two letters, the first by Toni, the second by Narelle, asking women who had had PTSD to make contact with each of the writers. Thus, TABS began! We are now the face of over 450 women who have made contact with us since then.

Since 1998, the four of us who are Auckland-based have spoken about PTSD to over 5,000 people, with the most recent being a 3-hour workshop presentation at the New Zealand College of Midwives and a Keeping Birth Normal Conference. These presentations have been to professional and lobby organizations of various stakeholders in the maternity sector. In addition, we have brought our concerns before senior government officials, and have been warmly received.

We have contributed material and articles to a number of mass media publications, as well as receiving some unexpected publicity when magazines from the same publisher shared their sources! In 2001, one of our members appeared on TV’s 20/20 Program in a segment about maternal mental health following the publicity surrounding the sad events in the Andrea Yates case. All of these have brought us into contact with mothers affected by PTSD.

We published a regular newsletter, and circulated a pamphlet about PTSD. These publications have been an encouragement and a support for many women. Due to time constraints, a web site has replaced the newsletter. We update the site quarterly. We welcome contributions from both within New Zealand and around the world. Our current focus is a new study by Professor Cheryl Beck of the University of Connecticut.

Our income is comprised of grants, donations, and any payments we receive for our literature and presentations to health professionals. If you would like to donate to TABS to help us continue in our work, please send your check made payable to TABS, PO Box 18002, Glen Innes, Auckland, New Zealand.

[www.tabs.org.nz](http://www.tabs.org.nz)

of me, all over him. That was it for me. I thought he’d ripped the head off. He then swore and said hurriedly, ‘Get the forceps.’ I can still remember the feeling of him ripping the baby out of me. It was the most awful unnatural devastating feeling ever. Well, finally, out came this baby. I was, by this state, still stuck in my own private horror movie, visualizing my baby being born dead with half of its head missing. The pediatrician

was standing beside the doctor, and I assumed that he would take the dead baby away. But, much to my horror and surprise, the doctor pulled out this blood red baby and threw it onto my tummy. (Beck, 2004a, p.33)

The third core component of birth trauma was the perception of inadequate care. Theme 3 was labeled “To provide safe care: you betrayed my trust and

*continued*

I felt powerless.” When admitted to labor and delivery, women had confidence in the labor and delivery staff that they would provide safe care. Mothers entrusted both their own lives and those of their unborn infants into the hands of these obstetrical providers. When the women perceived that the care they were receiving was inadequate or unsafe, this ignited terror in them. Compounding this terror was the feeling of powerlessness the women experienced. They had no control over rectifying this potentially dangerous situation.

“The end justifies the means: At whose expense? At what price?” This was the fourth component of birth trauma. Women who had suffered through a traumatic birth felt like their experiences were pushed into the background. As long as the outcome of a healthy baby had occurred, no one, not family, friends, or clinicians wanted to dwell on the mother’s birth trauma. The mother was told to just get over it and move on,

As one mother painfully revealed, “I was congratulated for how quickly and easily the baby came out and that he scored a perfect 10! The worst thing was that nobody acknowledged that I had a bad time. Everyone was so pleased it had gone so well! I felt as if I had been raped!” (Beck, 2004a, p.34)

## PTSD Due To Childbirth

In describing what it is like to endure

*“Women suffering with PTSD had a tremendous need to talk about their traumatic births but their family, friends, and clinicians quickly became tired of listening.”*

PTSD due to birth trauma, analysis of mothers’ stories revealed the following five essential themes or components of this devastating disorder: “(1) Going to the movies: please don’t make me go!, (2) A shadow of myself: Too numb to try and change, (3) Seeking to have questions answered and wanting to talk, talk, talk, (4) The dangerous trio of anger, anxiety, and depression: spiraling downward, and (5) Isolation from the world of motherhood: Dreams shattered” (Beck, 2004b, p.220).

The first theme dealt with the constant bombardment of flashbacks during the day and nightmares during the night. Mothers with PTSD frequently used the image of loop tracks imprinted on the brains. The distressing memories of birth trauma or their “movies” were uncontrollable. These movies stuck on replay kept mothers focused on the past unable to enjoy their present role as a new mother. As one woman admitted, “I live in two worlds, the videotape of the birth and the ‘real’ world. The videotape felt

more real. I lived in my own bubble, not quite connecting with anyone. I could hear and communicate, but experienced interaction with others as a spectator. The ‘videotape’ ran constantly for 4 months” (Beck, 2004a, p.219).

Nightmares were just as distressing as flashbacks for mothers with PTSD. One mother had an “agonizing forceps delivery” without any pain medication. She reported experiencing, “extraordinarily realistic nightmares”. “Like Lady Macbeth, I became terrified of sleeping! I would go without sleep for about 72 to 96 hours. I always knew I’d have to fight the nightmares again. I was scared that this time I wouldn’t have the strength to fight; it that it would succeed in destroying me” (Beck, 2004a, p. 219).

The second theme highlighted how mothers with PTSD viewed themselves as only a shadow of their former selves. They felt numb, detached, and for some, they actually dissociated. One mother who had an emergency cesarean delivery and postpartum hemorrhage recalled that right after delivery she felt her head floating above the rest of her body. Another woman who had been terrified by the multiple insertion attempts of her epidural said that once she got home she’d wake up each morning not able to feel anything. She’d drag herself through each day. She admitted having the hardest time trying to overcome a feeling that she was dead.

The third theme focused on the intense need of women suffering with PTSD to find answers, to know the details of their birth trauma. Some mothers were obsessed with reading obstetrical textbooks to try and answer their questions. Other women made repeated visits to their ob-



*Cheryl Tatano Beck, DNSc, CNM, FAAN is a professor at the University of Connecticut, School of Nursing. Her Bachelor of Science degree in Nursing is from Western Connecticut State University. She received her Master’s degree in maternal-newborn nursing from Yale University. Cheryl is a certified nurse-midwife. She received her certificate in nurse-midwifery also from Yale University. Her Doctor of Nursing Science degree is from Boston University. Cheryl is a fellow in the American Academy of Nursing. She has received numerous awards such as the Eastern Nursing Research Society’s Distinguished Researcher Award, the Distinguished Alumna Award from Yale University and the Connecticut Nurses’ Association’s Diamond Jubilee Award for her contribution*

*to nursing research. Currently she serves on the editorial boards of Nursing Research, Advances in Nursing Science, Journal of Nursing Education, and Journal of Nursing Measurement. She has been a member of the Board of Trustees of Depression After Delivery-National. Currently she is on the Executive Board of the Marce Society and has been appointed to the President’s Advisory Council of Postpartum Support International.*

stetricians or midwives' offices to have their questions answered. Women suffering with PTSD had a tremendous need to talk about their traumatic births but their family, friends, and clinicians quickly became tired of listening. One mother who gave birth to twins shared, "I was so devastated at people's lack of empathy. I told myself what a bad person I was for needing to talk. I felt like the ancient mariner doomed to forever be plucking at people's sleeves and trying to tell them my story which they didn't want to hear" (Beck, 2004b, p. 221).

The trio of anger, anxiety, and depression resulted in a spiraling downward of mothers. Mothers directed their anger at clinicians, family, and at times, turned their anger toward themselves. Mothers with PTSD were also plagued with depression and anxiety. For some women, the anxiety was turned up a notch to panic.

Lastly, the fifth component addressed the destructive grip of PTSD on the world of motherhood. Birth trauma seems to put up walls between the mother and her infant. One mother painfully recalled, "At night I tried to connect/acknowledge in my heart that this was my son and I cried. I knew that there were great layers of trauma around my heart. I wanted to feel motherhood; I wanted to experience and embrace it. Why was I chained up in the viselike grip of this pain? This was my Gethsemane- my agony in the garden," (Beck, 2004b, p. 222).

PTSD also resulted in mothers separating themselves from other mothers and babies. They wanted to avoid any thing that would remind them of the traumatic births that had led to their PTSD. Women experiencing PTSD had to make a heart wrenching decision of whether or not to have any more children.

In concluding this article, I would like to take this opportunity to thank all the courageous mothers who shared with me their powerful and painful stories of birth trauma and PTSD due to childbirth. These unselfish mothers participated in this study in hopes that no other women would have to suffer a traumatic birth like they had to endure. Please remember to visit TABS' website at

[www.tabs.org.nz](http://www.tabs.org.nz). ■

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## Coming to Terms With a Childbirth Trauma

We were eagerly anticipating the arrival of our second daughter Rain. From the very beginning, we knew that Rain was going to be a large baby, so my doctor thought that it would be best to schedule a C-Section when we reached the 37th week of gestation. We were scheduled for the procedure on a Friday, but my waters ruptured on the Thursday before.

Immediately, we were off to the hospital. My husband called my OB-GYN's office to let them know that it was time. Upon arrival at the hospital, I was placed on fetal monitors, and allowed to begin the labor process that was never supposed to take place.

Several hours in it the doctor on call arrived. I stated to him that I was scheduled for a C-Section the very next day so I thought that maybe we could get that done right then. He thought that was not going to be necessary because in his opinion the labor was progressing normally and well. He's the doctor right?

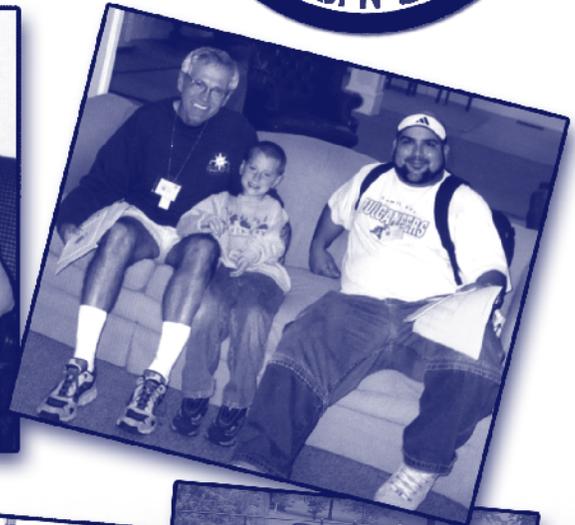
Hours went by. The pain was excruciating. I was unable to have an epidural because I have severe scoliosis. So I decided to do this without medication. Things were going along. Rain was slowly moving down the birth canal, but suddenly she stopped. Simultaneously, her heart rate fell, and there was no detectable activity on the fetal monitor. The nurse determined that I was completely dilated and rushed out to get the doctor. He came in, scrubbed up, and came to do what he had been trained to do. As he requested I started to push. As I did the pain was indescribable. I told the doctor that something is wrong because the pain was beyond belief. The

*continued on page 39*



# Camp UBPN 2005

## A Capitol Place to Be



# Join us for Camp UBPN 2005

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

It's almost here! It's time for UBPN's camp, held every two years. I am so excited about Camp 2005, this coming Sept. 15 – 18 at the National 4-H Youth Conference Center in Chevy Chase, MD, just 20 minutes outside of the heart of Washington, D.C. We will be staying in a hotel conference setting, cafeteria style, surrounded by a beautiful residential area right on Connecticut Ave. Every camp that we have held has been unique and our activities reflect a sense of place. Camp this year will be very different than past camps, as we will be taking advantage of being so close to our nation's capital, with all the educational and historic venues that such a remarkable location offers.

A highlight of camp will be our arrival day – Capitol Hill Day, Thursday Sept. 15. The day begins with families and individuals meeting with their Senators and/or Congressional Representatives, sharing with them issues related to brachial plexus injuries, and perhaps an opportunity for a photograph. Then we will gather together on the National Mall for a rally where we will celebrate a National Proclamation about Brachial Plexus Injury Awareness Week and hold a Press Conference. That day concludes with a 'Star Spangled Evening' at Mt Vernon.

Friday, September 16<sup>th</sup> is our first full day of Camp. Because we are in the D.C. area, we fortunately have been able to line up representatives from the Social Security Administration and Advocates for Justice and Education, Inc to present a morning of programs detailing SSI/SSD issues and what and how to

plan an IEP for your child. This will be followed by last camp's very popular Sibshop (this time we will also allow support group leaders to participate), a Father's workshop and an Injured only workshop. In the afternoon, we will be heading off for a Camp Field Trip to the National Zoo, home of the famous pandas.



Karen McClune and husband, David, at Camp UBPN 2003

After dinner, we will be presenting a Legal Panel. This legal panel will not feature attorneys, but rather families who have gone through litigation, including all points of view, from those who won a case, to those who settled, to those who lost. Start thinking of questions now for our panel to answer! Following this, for those with energy to spare, we will host a Washington Monuments at Night Tour. Then it is Lights Out for some rest before another full day.

On Saturday, September 17<sup>th</sup>, we are very pleased to feature Professor Cheryl Beck, from the School of Nursing at the University of Connecticut, whose article on birth trauma is on page 13 of this issue of *Outreach*. She will give a keynote address and follow it with a breakout session for the moms. For the children and dads, there will be a Sports Clinic held simultaneously with the breakout session. We are hoping to line up a major sports figure from one of the local professional teams and will announce that on our website when it happens, so stay tuned! The afternoon sessions will include concurrent roundtable discussions that focus on personal issues faced by Mothers/Daughters and Fathers/Sons, a Therapist Panel, and an

Adult OBPI/TBPI Panel. After dinner we will present a Medical Panel, with bpi specialists sharing the latest in treatment of brachial plexus injuries. Our evening will conclude with a camp wrap up – our Town Hall Meeting – with the presentation of Camp Awards, Designation of our Kid's Ambassadors, and an opportunity for you to present your ideas on how UBPN can improve, not only Camp, but also the organization.

**“Why should I come to Camp?”**  
**Come** for the camaraderie. **Come** for the information. **Come** to help make your voice heard in D.C.!

Camp will bring you closer to other families and individuals who are facing the same issues, 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 just how normal they really are as they see others the same age. You can listen to adults that have lived with BPI for over 60 years and learn what you and your child can achieve.

My husband, David, and I went to the first camp when our son Ryan (who has a TBPI) asked us to meet him in Colorado and go to Camp 2001 with him. We have made ever-lasting friends, and have gone to camp ever since. I want to thank the Board of Directors for asking me to be camp coordinator this year. It is a privilege working with them, as we bring the BPI community together for another great camp.

So mark your calendars now and join us at Camp 2005 on September 15 -18. I look forward to meeting each of you. See you at Camp 2005!

*Karen McClune,*  
Camp Coordinator

# Camp Cameos!

Dear UBPN,

I wanted to share the following written presentation Lise made to her 1<sup>st</sup> grade class in Encinitas, CA. She presented it shortly after we returned from camp as part of a "Why I am Special" day in her class. She also shared the remnants of her cast, and her bear from UBPN Camp.

Sharing her injury was a great experience for Lise and her whole class. I would recommend other parents advocate for similar opportunities at their schools so kids can be educated about why kids are different – to avoid teasing, bullying, inappropriate remarks, and misunderstandings. Kids are naturally curious – so give them the information.

We had a great time at Camp in NY last time and it was valuable for Lise to meet other kids her age with similar injuries.

Pam MacPhee

## **About My Arm**

*By Lise MacPhee, written at age 6*

*When I was born, my arm got stuck in my mom's stomach. I have a brachial plexus injury. My nerves ripped so the messages couldn't get through to move my arm. I couldn't do as much as you for a long time. I couldn't crawl when I was a baby. I couldn't reach or touch my nose. I couldn't hold on to a swing. I have been going to therapy for six years. I do stretches there and they give me exercises to do at home to make my arm stronger.*

*I had surgery last year when they cut me open and moved a muscle and sewed me back up. Before they cut me open, they gave me medicine to make me fall asleep. When I woke up, I had a cast on my arm and now I can do a lot more stuff like you. I can do the monkey bars now and I am really happy. I went to camp with other kids who have the same injury as me.*

I'm writing to express how wonderful our 2003 camp experience was. I can't put into words how it made my son feel. Connor has never really felt comfortable at school or with other kids. In some way he always felt a little bit different even though we try hard to make him feel like everyone else. I couldn't decide whether we should attend. I had kept my emotions contained since Connor was born. I went into denial, depression and then, of course, the anger. I felt no one could understand how I felt. Finally our family decided to go to camp not just for Connor, but also for his sister Ciera.

We met so many wonderful people. Connor always had a smile on his face. He was so comfortable and happy. He loved playing with the other kids and looked up to the adults with the same injury. He did things like rock climbing and rowing a boat, which I don't think he would have tried unless he saw someone else with his injury doing it. He watched the older boys play basketball and learned how to play softball. Now Connor plays baseball and he has joined the basketball team.

The camp experience also helped Ciera see how other siblings interact with their sister or brother who have the injury. Ciera also got to talk to other people about her feelings.

Dave and I spoke with other parents. It's nice to be around others who understand if you feel angry or sad. No one there told you that it could be a lot worse. We already know that, but it doesn't take away the hurt or sadness.

Camp inspired me to inform others about BPI. Connor has been in the paper for Brachial Plexus Awareness Week. He received a proclamation from the Mayor and was featured on TV. All things I probably would never have accomplished if not for camp.

I will never miss another camp and Connor is looking forward to going again. I encourage you to attend – it will make a difference.

Linda, Dave, Ciera, and Connor Swetof

I stumbled upon UBPN in June of 2003. August of 2003 was the second semi-annual summer camp. I was interested in going to meet others with the same injury. I thought it would be great to see the kids too – running and playing with their slings on. Was I ever wrong!

When I got to camp, I was overwhelmed. The kids weren't wearing slings at all and I was the only TPBI there with a sling on. I told my mom that I wanted to go home. She said that since we had driven from Michigan to upstate New York that we weren't going anywhere until the weekend was over. I am so glad we stayed at camp.

It was nice to sit and talk with other TPBI, something I had only done once since my accident. As we sat and compared notes on 'how we do things,' we found we could share good techniques and share experiences to avoid. For the first time since my accident, I didn't feel alone. What a great feeling!

In the evenings, after a full day of events, we would sit in this little room and talk the language of TPBI and adult OBPI. It was wonderful to be able to talk to others who understood 100% what I was talking about. My friends try to understand but they really have no idea mentally what we go through.

My mom and I listened to a panel of doctors present info about BPI. We were in the the learning stages, so it was great. I was overwhelmed at bed time but the next day I was ready to go at it again. I also heard a doctor talk about pain management – that's a huge issue for TPBI.

I made some great new friends that summer at camp, something I never imagined doing at 23 years old! I even volunteered to help with whatever I could when I got back home. I think camp is great for TPBI especially, if for nothing other than meeting people with the same injury and losing the 'alone' feeling. You have an instant bond with people who have gone through similar situations, it's nice to share the stories.

Courtney Edlinger  
Ferndale, Michigan

*As a new mom, I felt overwhelmed by all that I faced raising my daughter, Zoe, by myself. I wanted to go to camp so she could meet other kids with the same injury. I wanted to meet parents whose children had BPIs. I hoped I might be able to learn something from them. I sure did!*

*I also wanted to meet and talk with the doctors to see what we could do for Zoe. I had so many questions and wasn't finding the answers I needed at home.*

*I was very fortunate that my church had fundraisers to raise money to send me and Zoe to camp and that UBPN was able to give me a sponsorship for the rest.*

*I learned so much and met wonderful people and I can't wait to see everyone again and to meet new people at camp this September. I hope to see YOU there too.*

Kimberly Dunning and Zoe, 3 years old



Thank you for your interest in Camp UBPN 2005 – a camp for families and individuals with brachial plexus injuries. Camp will be held for the first time in a city setting, our nation’s capital, at the National 4-H Youth Conference Center, in Chevy Chase, MD. Located on Connecticut Ave., the camp is easily accessible by car (just off the beltway) or by Metro. It is close to three major airports (Reagan National, Dulles and BWI). It’s only two miles from the National Zoo and a short drive into Washington, D.C. and all it has to offer, and it is the perfect location for our National Rally, as we focus attention on awareness of brachial plexus injuries.

Join us in this wonderful opportunity for meeting new friends and reacquainting with old friends, capitalizing on educational opportunities for the children to learn about American government in action, and gathering together in an effort to learn more about brachial plexus injuries and treatment options.

# Camp Schedule (Tentative)

## Thursday, Sept. 15, 2005 – Capitol Hill Day

- 9:00 – 12:00 Families meet with their Senators/Congressional Representatives
- 12:00 – 1:00 Lunch on your own
  - 1:00 National Rally on the National Mall, Press Conference
- 2:00 – 4:00 Open Time to visit Smithsonian Museums or US Capitol or Monuments
  - 4:00 Bus leaves Rally area for Camp
- 4:00 – 6:00 Check In/Arrival
  - 6:00 Bus leaves Camp for Mt Vernon
- 6:30 – 9:00 “A Star-Spangled Evening” at Mt Vernon, including Dinner
  - 9:00 Bus leaves Mt Vernon for Return to Camp
- 9:30 – 11:00 Visit with Friends/Adjourn
  - 11:00 Lights Out!

## Friday, Sept. 16, 2005

- 7:00 – 9:00 Breakfast available
- 9:00 – 10:30 Social Security Issues (SSI/SSD) – Diana Varela (Social Security Administration)
- 9:00 – 10:30 IDEA/IEP workshop – Vanita Snow (Advocates for Justice and Education, Inc.)
- 9:00 – 10:30 Arts & Crafts available for Kids, Educational Packets/Curriculum Available
- 10:45 – 12:00 Concurrent sessions of Sibshop, Fathers Workshop, Injured Only Workshop
  - 12:00 Bus leaves Camp for National Zoo
  - 12:30 Lunch at National Zoo
- 1:00 – 4:00 National Zoo
  - 4:00 Bus leaves Zoo for Camp
- 5:00 – 6:30 Dinner Available
- 6:30 – 8:00 Legal Panel
- 6:30 – 8:00 Arts & Crafts available for Kids, Educational Packets/Curriculum Available
- 8:00 – 10:00 Washington Monuments by Night Tour
- 10:00 – 11:00 Visit with Friends/Adjourn
  - 11:00 Lights Out!

## Saturday, Sept. 17, 2005

- 7:00 – 9:00 Breakfast Available
- 8:30 – 9:00 Camp Photo
- 9:00 – 10:00 Birth Trauma and Post Traumatic Stress Disorder – Prof. Cheryl Beck
- 10:00 – 11:00 Breakout Session for Mothers – Prof. Cheryl Beck
- 10:00 – 11:00 Kid’s Sports Clinic
- 11:00 – 12:00 Roundtable Discussions (Mothers/Daughters; Fathers/Sons)
- 11:00 – 12:00 Arts & Crafts available for Kids, Educational Packets/Curriculum Available
- Noon – 1:00 Lunch Available
  - 1:00 – 2:00 Therapists Panel
- 1:00 – 4:00 Arts & Crafts available for Kids, Educational Packets/Curriculum Available
- 2:00 – 3:00 Breakout Sessions for Therapy
- 3:00 – 4:30 Adult OBPI/TBPI Panel
- 5:00 – 6:30 Dinner Available
- 6:30 – 8:00 Medical Panel
- 6:30 – 8:00 Arts & Crafts available for Kids, Educational Packets/Curriculum Available
- 8:30 – 10:00 Town Hall Meeting (Awards Ceremony, Presentation by UBPN Board, Q/A)
- 10:00 – 11:00 Visit with Friends/Adjourn
  - 11:00 Lights Out!

## Sunday, Sept. 18, 2005

- 7:00 – 9:00 Breakfast Available
  - Please checkout by Noon

## Registration Procedures

Your **Registration Form**, **Donation Form** (if applicable), **Sponsorship Form** (if applicable), and **Fee Calculator sheet**, along with your **\$100 deposit per family**, should be sent to UBPN, Inc. at:

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

Camp deposit and/or camp fees can be charged to a credit card online through Pay Pal <<http://www.paypal.com>>. Pay Pal accepts VISA, Mastercard, Discover Card, and American Express. Payment will be made to the e-mail address: **camppayment@ubpn.org**. If you plan to pay the remainder of your camp fees by check, you will be contacted following receipt of your materials to confirm the final total.

Space is Limited! We have only 75 rooms available to us at the Conference Center. The sooner you can get in your registration deposit assures you a space at camp.

Campers will receive confirmation of receipt of camp materials and will be receiving a full packet of materials once registration is received. Included in that packet will be a medical information sheet, information on how to plan for your role in the National Rally and Capitol Hill Day, camp t-shirt form, additional transportation details, and information about educational programming and curriculum for children (if applicable).

## Transportation

Attendees have many options for travel to camp. The Washington D. C. area is serviced by 3 major airports: Ronald Reagan Washington National Airport (DCA) — 12 miles to the Camp, Washington Dulles International Airport (IAD) — 26 miles, and Baltimore/Washington International Airport (BWI) — 35 miles.

AMTRAK provides train service into Washington D. C. to Union Station. For those driving, the camp is conveniently located near the Capital Beltway, I-495. Within the capitol area Metro rail and bus service, with terminals at Reagan National Airport, Union Station, and near the Conference Center, provides quick, easy travel between major points of interest. Other choices include rental cars and taxi services. Details regarding Metro routes (also see [www.wmata.com](http://www.wmata.com)) and taxi services will be mailed upon receipt of registration materials.

UBPN will provide free motor coach transportation to and from all events planned outside of the 4-H Youth Conference Center (Rally, Mt Vernon, National Zoo). We will be unable to provide pickup and return services to airports or to AMTRAK.

## See the Sights!

If you are interested in building a family getaway around your camp experience, the area offers a variety of attractions and educational opportunities. Here are several web links to extend your stay in the Washington, D.C. area:

<a href="http://www.washingtondc.com">www.washingtondc.com</a>	<a href="http://www.washington.org">www.washington.org</a>
<a href="http://www.exploredc.org">www.exploredc.org</a>	<a href="http://www.whitehousekids.gov">www.whitehousekids.gov</a>
<a href="http://www.dcpages.com">www.dcpages.com</a>	<a href="http://www.nps.gov/nama/">www.nps.gov/nama/</a>
<a href="http://www.si.edu">www.si.edu</a>	<a href="http://www.dc.gov">www.dc.gov</a>
	<a href="http://www.washingtondckids.com">www.washingtondckids.com</a>

## National Rally

We are making plans for the National Rally to be held on the lawn of the National Mall, near the Capitol Building on Thursday, Sept. 15. We will have fuller details on this Rally as Camp approaches. The Rally itself will have a program of speakers, including a reading of the National Proclamation and it will also include a press conference.

## Capitol Hill Day

Before the Rally, attendees will have the opportunity to meet with Senators and Congressional Representatives. We will have packets prepared that will assist campers in making initial appointments. The packet will also include talking points for both adults and children to discuss topics of concern regarding brachial plexus injuries. We are hopeful that many of our attendees will be able to take advantage of this opportunity to participate in government in this special way.

## Educational Tool Kit

We recognize that for families with school age children, this camp experience would necessitate missing a few days of school. We are designing an educational component and curriculum for all ages built around the opportunities provided by our setting in the National Capital as well as Camp experiences. Materials will be provided to all families after registration. Some of the educational components can be accomplished prior to Camp.

## Kids Ambassador Program

The ambassador program is new for Camp this year. This program is designed for children of all ages to earn points while at Camp, which will qualify them for UBPN Ambassador Status. Certificates and awards will be presented at the Town Hall Meeting on Saturday night. We will also have information available to assist our Scouts (both boys and girls) in earning merit badges while at camp.

## Camp Store

It wouldn't be Camp without the opportunity to pick up an extra t-shirt or patch! We'll also have Awareness Week items available including ribbon pins, our new ribbon car magnets and those popular silicone bracelets (see back cover). Hours and location of the camp store will be printed in the official camp program.

## Adult BPI Late Night Chats

We will have a room available every evening for adult OBPI and adult TBPI to gather together. This was a huge hit at the last camp and was a great bonding experience for all who participated.

## Donation Opportunities to Help Others Attend

Wouldn't it be wonderful if everyone who wanted to attend camp could do so without having to pay? This is a goal for UBPN. We have two opportunities available for those who are able to make a donation toward our goal to underwrite the expenses for camp.

The first sponsorship opportunity addresses camp for this year. This is the **UBPN Camp 2005 Sponsorship Program**. Donations are accepted by UBPN on behalf of those who wish to underwrite the expenses for others to attend Camp 2005 at the National 4-H Youth Conference Center. The second sponsorship opportunity is an ongoing fundraising effort toward UBPN Camp Sponsorship – the **Kanter Family Camp Fund**. Donations made toward this sponsorship will not be utilized for this year's camp, but will be deposited and allowed to grow for future camps. The goal is to raise enough money to withdraw the interest to cover future camp sponsorships, while reinvesting the principle. It is from this fund that we hope to one day underwrite camp tuition for anyone with a BPI who wishes to attend.

For additional details and to make a donation, refer to the form on page 22. All amounts are welcome.

# Not From the United States?

Not from the US? Then you might be thinking, "why should I go to camp?" At first glance, it may seem that this camp is going to focus solely on gaining political acknowledgment in the United States; however, it's going to be much more than that. In the days that follow the Rally, campers will experience the charm of a seemingly out-of-the-city camp; while in actuality, the hustle and bustle of our nation's capitol sits a mere 10 minutes down the road. Come join us, whether you're from California or New Zealand, Canada or Italy, to share in the camaraderie with other families who cope with brachial plexus injuries on a daily basis. Learn from the experts by attending the fabulous educational programs, and explore ways in which self-esteem and self-confidence can be enhanced in a supportive and encouraging setting.

# About the Camp Location

The National 4-H Conference Center is one of the most modern, comfortable, and efficient residential-training facilities in the Washington, D.C. area. Opened in 1959, the Conference Center has been continuously expanded and modernized through the generous support of corporate, foundation, and individual donors. And, it is the only facility in the D.C. area focused specifically on youth.



The Conference Center is located in a quiet, campus-like setting on 12 acres in Maryland, one mile from the nation's capital. The Conference Center offers excellent year-round meeting accommodations complemented by the area's numerous resources and learning opportunities. More than 35,000 youths and adults stay at the Conference Center each year and represent a broad range of interests. In addition to 4-H groups, educational and professional associations, government agencies, churches, schools, youth groups, Extension groups, and community organizations all use the Conference Center.

The campus features a high energy recreation room, Cyber Cafè, basketball and volleyball courts and comfortable lounges. The Conference Center is ADA compliant and is equipped to help guests with disabilities. Guests will appreciate the convenient access to public transportation for trips to nearby shopping, restaurants, and churches, or to downtown Washington and historic sites.

To read and learn more about the facility, visit the National 4-H Youth Conference Center web site at: <http://www.4hcenter.org/>

# 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 2005 Camp UBPN Sponsorship Program. These funds will be used to help families attend the 2005 camp via scholarships (see the form on page 23.) 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.*

- Donation to UBPN Camp 2005 Sponsorship Program \$ \_\_\_\_\_
- Donation to The Kanter Family Camp Fund For Future Camp UBPN Sponsorships \$ \_\_\_\_\_
- Donation to underwrite program and expenses at Camp 2005. \$ \_\_\_\_\_

*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 DC 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 June 1.

## Income Self Certification Form

I, \_\_\_\_\_, hereby certify that I am requesting Camp UBPN 2005 sponsorship consideration from the United Brachial Plexus Network, Inc. for attendance at camp to be held September 15 - September 18.

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 be also be accepted. Please include a \$100 non-refundable deposit with your registration form and fee calculator. The balance of your camp fees will be due before August 1. Your deposit will be applied to your 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 and further directions.

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

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

\$100 Deposit Only

The balance will be due before August 1, 2005.

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 15 2005!)

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

**Three Night Stay - (Thursday-Sunday)**

*Includes food, lodging and bus transportation to group activities. Children 3 and under are free*

Double Room (price includes two individuals): \_\_\_\_\_ x \$357.50 = \$ \_\_\_\_\_

Price for each additional person (up to two additional): \_\_\_\_\_ x \$82.75 = \$ \_\_\_\_\_

Single Room (price includes one individual): \_\_\_\_\_ x \$289.75 = \$ \_\_\_\_\_

*This room will sleep one person and a child under three.*

**Additional Night Stay - (Wednesday)**

*Includes Thursday morning breakfast only. Children 3 and under are free*

Double Room (price includes two individuals): \_\_\_\_\_ x \$90.50 = \$ \_\_\_\_\_

Price for each additional person (up to two additional): \_\_\_\_\_ x \$13.25 = \$ \_\_\_\_\_

Single Room (price includes one individual): \_\_\_\_\_ x \$82.85 = \$ \_\_\_\_\_

**Day Use Only**

*For locals or those lodging off-site. Includes 3 meals per day and bus transportation to group activities.*

Participating Friday (ages 4 and older): \_\_\_\_\_ x \$35.00 = \$ \_\_\_\_\_

Participating Saturday (ages 4 and older): \_\_\_\_\_ x \$35.00 = \$ \_\_\_\_\_

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

# An Overview of Social Security Disability

■ *Marc Sussman, Attorney at Law*

**S**ocial Security Disability is a program of the federal government designed to provide a cash benefit and medical insurance to the disabled. To simplify this complex subject, this article will cover the two basic types of benefits, although there are other benefit areas.

## Disability Insurance Benefits (DIB)

In order to qualify for DIB, the person must prove disability and that the disability began during the time the person was covered for the benefits.

Coverage is determined by looking at the person's work record and determining whether through that employment the person paid FICA taxes. If the person making the claim worked steadily and regularly at covered work (paying FICA taxes), then the person remains covered for five years after the last day worked. This is often an important factor to consider because the injured person making the claim might not be able to prove disability as of the date when he or she stopped working, but may be able to prove disability a year or more later.

## Supplemental Security Income (SSI)

This is a program for the disabled poor, whether they have worked for many years nonstop; never worked a day in their lives; or worked at something between those extremes. In consider-

ing whether the person is sufficiently poverty-stricken, the Social Security Administration considers all assets and all income, including the income of a spouse.

## Defining Disability

Congress defines disability as the inability to do any job for more than a year on a full-time basis that would be consistent with the person's age, education, and work experience.

The definition of disability is the issue that decides most claims, and is the part of the case with which an attorney can provide the most help.

The definition of disability can be interpreted differently depending on how old the person is, schooling, and the kind of work the person did in the last fifteen years. In many situations, the crucial factor in a case will be the kind of work the person did, especially the skills the person used on the job and whether those skills could be used in a different, easier job.

In other cases, the crucial factor might be the person's age. For many people, the claim is easier to win as the claimant gets older. The Social Security Administration utilizes something called a "grid," using the factors of age, education, and work experience to make a determination. A case that may not win for a person at age 48 might be a winning case for a person at age 53 with the same

medical impairments. For most people under age 50, we must rule out all employment, including the easiest possible sedentary jobs.

This brings me to the most important factor in every case – medical information. By far, the most important factor in every case is what the medical records say and the doctor's opinion concerning the patient's capabilities.

Doctors get their information from three basic kinds of sources:

- objective information from a MRI or CT scan reports;
- office examinations and tests that involve the cooperation of the patient, (movement and strength tests, for example)
- information obtained from the patient. Doctors call this "history."

This "history" is extremely important. It is imperative that a doctor's records include the severity of pain and weakness, sleep difficulties, side effects of medication, fatigue, and the tremendous impact that the condition has on daily activities. A very important factor the social security judge will consider is whether the medical records support the complaints that the person makes at the hearing.

Another important support document can be a doctor's Medical Source Statement, which describes the patient's limitations. This will usually include factors such as sitting, standing, walking, lifting, bending, reaching, pushing, pulling, and handling. Doctors are sometimes unwilling to offer an opinion about such things, but they are more willing to do so if the patient told the doctor about these difficulties during office exams. ■

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*Marc Sussman is an attorney whose entire practice is devoted to Social Security Disability and Supplemental Security Income claims. An attorney since 1975, he practices Social Security Disability Law in Southfield, Michigan, and has represented claimants across the country. He is a partner in the law firm of Levine, Benjamin, Tushman, Bratt, Jerris and Stein, P.C. He can be reached at 1-800-559-3887 or by email at MJSuss@aol.com. We are pleased the Mr. Sussman has agreed to provide regular articles about Social Security issues and how they pertain to brachial plexus injury cases.*

## Decorated Military Man Wins Lifelong BPI Battle

*By Berta and Jesse De Loach*

**B**rachial Palsy, Brachial Plexus Injury or Erb's Palsy – no matter by which name it's called, it is a devastating shoulder injury incurred by many children at the time of their birth. In December 1955, Jay Allan De Loach incurred such an injury to his right shoulder.

Brachial Palsy, as Jay's parents, Berta and Jesse De Loach, came to know it, occurred during Jay's birth. At approximately 120 pounds and just shy of 5' 4" tall at the beginning of her second pregnancy, Berta experienced no unusual problems until it became difficult for her to fit behind the steering wheel of her car. Her doctor thought she might be having twins and ordered x-rays. The x-rays confirmed the presence of only one child – however, it was going to be a large one. Berta's first child, a girl, was also above average, weighing 8 pounds 6 oz.

Often in military hospitals, pregnant patients see a different doctor at each checkup. The attending doctor at the actual birth may not have been one of the previous doctors, which was the case with Berta.

During the delivery the child's head emerged but the shoulders were too large for the mother's pelvis to accommodate. The doctor tried unsuccessfully to pull the baby free by pulling on his head. The baby was delivered weighing 11 pounds and six ounces and with a lasting bpi injury. Berta did not make it through the delivery unscathed either and within 24 hours after being released from the hospital she was rushed to the emergency room due to severe hemorrhaging.

The only medical advice that was offered to the De Loaches about Jay's arm was to keep him on his back and pin his arm to the sheet so that his hand

would be above his head. As they spoke with Navy pediatricians and neurologists during subsequent checkups, they were given hope that the nerves would grow back and that, gradually, he would gain full use of his arm. They also were informed that a later operation might help him. According to the De Loaches, by instinct or just luck, they began to exercise Jay's arm so that it would not "freeze up" while the nerves regenerated.

Six months after Jay's birth, the family was transferred to Washington, DC for duty and began establishing medical contacts at Bethesda Naval Hospital. They continued exercising his arm. The exercises included raising his arm above his head, extending the arm forward and then across the front, or extending it to rear and as far behind the back as possible. They both could tell that Jay was feeling pain, but he never complained and would even urge them to continue.

One doctor wound an Ace bandage in a figure eight under Jay's armpits and across his back in an attempt to hold the right shoulder from dropping. Even stuffing the arm pit areas with cotton did not prevent severe chafing, so Berta constructed a harness of wide elastic bands that did the same job without the chafing. At the next doctor's visit, he suggested to Berta that she patent the device.

By the fall of 1958, they realized Jay's young life would be limited. They watched Jay's sister, Laura (only one year older), swing by herself or climb the chain link fence while Jay could only watch – he did not have the balance, coordination or strength to allow him to do such things. Otherwise, he was a happy, well-adjusted, three-year-old boy who played with his blocks and toy

soldiers and did not seem to realize he had a handicap.

A few years later, Jay had progressed to where he could move his arm up and down, flex his fingers, and demonstrate a limited range of motion. His ring and pinky fingers did not close properly, causing a loss of holding ability. He was unable to put his arm behind his back unassisted. He was unable to do pull-ups or push-ups.

At this point they were given an additional exercise, which was to have him face the wall at arms length, place his hands on the wall and do push outs while someone provided resistance at his back. Berta remembers how heart wrenching it was to hear the popping noise as his right shoulder flexed, but Jay insisted they continue in spite of the pain he felt.

During grade school, other children would tease and physically bully Jay because of the angle he carried his right arm and because of a slight speech impediment. When Jay would defend himself, the teacher would tell the De Loaches that Jay was a bully and he would amount to very little, Berta remembers.

Through speech therapy with a caring teacher and learning to hold his own in social situations, Jay began to blossom and became an excellent student. As he grew older and entered organized sports, he began shifting to his left side for strength activities. He developed a good baseball and football throw as a "lefty" and learned to kick the football left footed. He still wrote and ate with his right hand.

As a Little Leaguer, he developed into an All Star pitcher and first baseman. He was captain and quarterback of his flag football team. When he was 12 years old, he entered the Scouting program

and, showing a great deal of determination, progressed through the steps to become an Eagle Scout with Palms at age 14.

Since he was four years old building forts with his blocks and arranging his soldiers for battle, Jay knew he wanted to be a “war man” when he grew up, according to Berta. As he matured, it was evident to his parents that a military career was not in his future. Although his right arm had lengthened in concert with his left, it had not attained the muscular proportion of its mate and the shoulder was noticeably, to his parents, dropped. His parents estimated that the right arm contributed about 30 percent to any endeavor requiring two arms.

Jay continued to speak of his desire to join the military service and of his desire to seek appointment to one of the service academies. His father, who was by then a lieutenant commander in the U.S. Navy, tried to prepare Jay for the expected denial of such appointments. Jay was persistent and applied to all of the academies as well as the ROTC scholarship program. There was never any doubt about his academic qualification for such appointments, only of his physical ability. To his parent’s great surprise, Jay passed all the qualifying physical requirements and entered the U.S. Naval Academy in July 1974 to become a full-fledged “war man” in June 1978.

The lack of any real subsequent medical help, the failed promises that Jay could be medically helped when he was older, and the seeming lack of understanding of the injury on the part of doctors all contributed to a devastating childhood for the De Loaches little boy, according to Berta. The fact that he overcame his handicap to attain success in his adult life can in no way be attributed to the medical profession, says Berta. It can only be attributed to the determination of a little boy and young man finding ways to accommodate a brachial plexus injury. ■

**Rear Admiral  
Jay A. DeLoach  
Deputy Commander,  
Submarine Force,  
U.S. Atlantic Fleet**



Rear Admiral DeLoach was born in San Diego, California and followed in the family tradition of Naval Service following graduation from the U.S. Naval Academy in 1978. From 1978 to 1986, he entered training and service in submarines, completed ten strategic deterrent patrols, and served as the Engineer Officer on both the USS Patrick Henry (SSN 599) and USS Lewis & Clark (SSBN 644), winning three Battle Efficiency ‘E’ awards. From 1987-89, he was the Sonar Transducer Branch Chief at the Naval Sea Systems Command. Upon completing active duty, he affiliated with the Naval Reserve and served in a broad spectrum of assignments, including Naval Maritime Intelligence Center, OPNAV N87 Submarine Warfare staff, Navy Recruiting, COMSEVENTHFLT staff, and Naval Sea Systems Command Inspector General.

Rear Admiral DeLoach commanded NR COMSUBRON SIX Detachment 504, NR OPNAV Detachment SITE-R, and NR COMSEVENTHFLT Detachment 111. He stood additional duty as a Duty Captain in the Navy Command Center in the Pentagon. He served as the Reserve Force Director for 44 reserve units reporting to the Commander Submarine Force, U.S. Atlantic Fleet. He completed two extended active duty assignments with the Joint Staff J7 working on Joint Doctrine and Professional Military Education initiatives. He is currently the Deputy Commander, Submarine Force, U.S. Atlantic Fleet.

Rear Admiral DeLoach has earned three advanced degrees: a Masters of Arts in National Security and Strategic Studies from the Naval War College, a Master of Engineering in Nuclear Engineering from the University of Virginia, and a Masters of Arts in Personnel and Supervision from Central Michigan University. He served as President of the Commander, Naval Reserve Readiness Command Region NINE Policy Board, and is currently the Vice Chairman of the SECNAV Reserve Policy Board. In his civilian job, he is a Senior Staff member of the Defense Nuclear Facilities Safety Board in Washington, DC.

His personal military decorations include Legion of Merit, Defense Meritorious Service Medal, Meritorious Service Medal (2), Joint Service Commendation Medal, Navy Commendation Medal (3), Navy Achievement Medal (3), and five Gold Wreaths for Recruiting Excellence. While serving as the Chairman of the Recruiting District Assistance Council (RDAC) in the Texas Panhandle, he was recognized by Naval Recruiting District San Antonio as the “1994 RDAC Member of the Year” for the State of Texas. He was selected to *Who’s Who in Executives and Professionals* for 2002 and 2003. He is a member of several professional societies, including the Naval Reserve Association, Reserve Officer Association, U.S. Naval Institute, and Naval Submarine League. ■

## Straight Talk From Those Who Live It Each Day: Teens Answer Questions From UBPN President Nancy Birk

*Tell us something about yourself and what you like to do in your spare time.*

**Brittney:** I am a seventh grader at my middle school and I just turned 13 in February. I play soccer on a competitive team, swim team in the summer, and play the clarinet in the Honors Band. I am in gifted/accelerated classes and really like going to school (because my friends are there). I would describe myself as energetic and I am always happy (my friends nicknamed me 'Smiley')! I like to go shopping at the mall with my mom and training for races with my dad and little sister! I spend a lot of my free time hanging out with my friends doing flips on my trampoline, playing kickball, soccer, swimming, playing basketball, etc. I also love playing on the computer, GameBoy®, and Play Station 2®.

**Jameson:** My name is Jameson, I am 15 years old. I have a right OBPI but I have never let it hold me back. I enjoy hunting, paintball, and X-box. I am currently attending a local college and I love it, I had bad luck with public schools in earlier grades and enjoy a more mature environment. I have high hopes for my future. I work a summer job at a local water park and rarely find something I can't do. I have an upbeat attitude that allows me to achieve my goals. If I could give advice to other teens and younger kids with OBPI, it would be to NEVER give up if you want something even if you think your injuries will hold you back, you go for it and you don't stop working for it until it is yours.

**Amy:** I am 18 years old, and I'm finishing my senior year of high school. In my free time, I fill out scholarship forms, but when I finish those, then I love to play softball and dodgeball. If I can't do

that, then I paint little plaster figures, or I go swimming. During the summer when it gets hot out, I like to stay in and play computer games and research brachial plexus injuries. I like to write research papers on brachial plexus injuries. I like to spend my remaining time with my family.

**Joshua:** Hello, my name is Joshua. I have a right OBPI. I'm fifteen years old. I am a 9th grader, currently attending a private school. I'm taking AP classes for every subject except math. My hobbies are snowboarding, computers (hardware, software, assembly), video games, art, politics, and model-making. Yeah, I'm pretty nerdy. Anyway, my bpi arm has never limited me from doing anything I've wanted to do. I'd be more than happy to give advice for other teens that have questions.

*When did you first realize that there was something different about your arm?*

**Jameson:** I first realized that my arm was different around kindergarten, but I was always catching people stare at me in grocery stores before that. My first day of kindergarten was hard because, on top of the normal "I don't want to go" mentality, my peers asked me questions and when they found that I was different, they started teasing me. Even though my arm is injured, my mind and soul couldn't find anything wrong with me. Sure my arm was different, but my hopes and dreams are no different than other kids my age. I have horror stories about my early experience in school, just because other kids didn't like my different looking arm. It really got to bother me in years to come. I just couldn't understand why they teased me. One day I woke



Brittney

up with the realization that by me getting upset, I was falling right into the bullies' hands, so I made a goal to just laugh in the face of those teasing me. This, however, brought a whole new type of torture for me. Since teasing me didn't work anymore, they tried physical violence. After that, one too many visits to the principal's office caused my mother to home school me for two years, after which, I started attending the local college.

**Joshua:** When did I first realize that my arm was different? Wow, this is a hard one. Probably back when I was in the first grade and couldn't climb the monkey bars.

**Amy:** I guess for me I never really realized that there was anything wrong with my arm until kindergarten. I had had doctor appointments and court stuff before that, but it did not really set in until I could not write like the other kids. I wrote every thing backwards, so my teachers had to get me cards to trace so I could spell my name. Then, there was physical education and recess, where I could not do activities like the rest of my class, like jumping jacks and playing on monkey bars.

**Brittney:** I don't remember ever suddenly realizing that my arm was different. I just always knew it was.

***Tell us a funny story about living with this injury.***

**Brittney:** I have an arm injury? Everybody knows but me?

There are lots of funny things about having an arm injury. I make jokes and laugh about it all the time! Here is one of my favorite stories about my injury. There was the time I was in third grade and I fell at recess, so I went to the nurse. (I wasn't really hurt I just liked going to the nurse.) There was a substitute nurse there who didn't know me. She freaked out! She called my mom and told her I was hurt and couldn't straighten my arm or lift it very high. My



Jameson

mom knew I was fine and asked what arm it was. She told her it was my left. My mom tried to explain that I was fine but the nurse was foreign and didn't understand. My mom had to drive up to the school, look at me, and then tell her I was fine again!

There was also the time a kid came up and asked

me what happened to my arm. I was sick of telling people so I replied, 'plane crash.' He stared at me in shock. Then I said, 'just kidding' and told him what really happened. It's really amusing so I do it to people who ask sometimes for a few laughs. They laugh too when I tell them I'm kidding, but the looks on their faces are so funny!

**Jameson:** When I was younger, I would use my right hand to hold things and I used to forget that they were there because I couldn't feel that I was holding anything in my hand. I would walk around the house in circles trying to find what I had lost. My whole family would join in and when we had turned everything inside out, I would look at my hand and there it was. I was holding it the whole time! I've done this with just about everything – the remote, pens, toys, cookies – everything.

**Amy:** This year I started using e-stim on the muscles in my lower arm and to get the correct placement of my electrodes, I have circles drawn on in the correct places. Every day I do range of motion in the nurses office at school, and it seems like a million people kept asking "why do you have circles on your arm?" For a while, I tried to explain it to every one that they were for a type of therapy that I do. That got old in a hurry. So to be funny, I told anyone that asked that they were crop circles, my source of alien communication. Some of the younger kids (like 4th graders) actually believed it, and would ask me about the aliens when they saw me in the hallway. The nurse and I would lead them on for weeks at a time, then, tell them the truth.

Now it's just a joke between the nurse and I, and I have decided to tell the little kids that I like to draw.

**Joshua:** I really don't have any funny stories about my arm. Yeah, I know, I'm boring.

***What bothers you the most about your arm?***

**Amy:** The thing that bothers me the most about living with this injury is most definitely that people that don't know me think that I can't do every day things. I hate it when people don't let me do the stuff that everyone else is doing because they think I can't handle it. I was turned down for a job as a cashier because the guy thought that I would not be able to handle it. I mean how hard could it be? Teachers also treat me differently. When a job that requires lifting needs to be done, I will always be told to hold the door even if I volunteer to do the other job. Being set apart from the other kids is what bothers me the most.

**Brittney:** I've never really thought about what I don't like about my arm. I always try to stay positive but there are a few things that really do bother me. I don't like the way it hangs when I'm standing still or walking. Sometimes I'll see a reflection of myself and cross my arms, but other times I just think, "I don't really care about what other people think. If they have a problem with my arm that's their problem not mine!" I also don't like the way I look when I run sometimes. I hold my arm funny when I swing it. I used to be really self-conscious about it. I'm not any more though because I realized that I am the fastest runner in my PE class! So if anybody's going to say something about it they'll be saying it in my smoke! It also used to bother me that at dances, when you dance with a boy you have to put your arm on his shoulder. At my first dance I was scared that if somebody asked me to dance I wouldn't be able to get my arm up there! This really bothered me. When a really cute guy came up and asked me, I suddenly turned confident! I put my arm on his shoulder easily. Now when

I go to dances I'm not worried about being asked; but instead, I look forward to it! I have danced with many boys and surprisingly, it's one of the only times I can get my arm that high!

**Jameson:** I guess the thing that bothers me the most is sometimes when there is high humidity, my arm hurts, and it feels like my bones itch – but you can't scratch it. Other than that I really can't say that anything really bothers me.

**Joshua:** To be perfectly honest, nothing really bothers me about my arm. I've come to accept it as a part of who I am.

**What have you been able to do that you didn't think you would be able to do?**

**Brittney:** One of the only times I didn't think I could do something was last year. We were doing volleyball in PE class. I didn't think I'd be able to serve because I couldn't supinate enough to throw the ball up. At first I couldn't do it, but then I had an idea! I put the ball on the top of my hand to throw it up. I could serve it over the net! Another way I found was to throw it up and hit it all with my right hand. Other than that time, I have always thought that I could do anything I wanted to and I have not found anything I couldn't do! (Well ok, I can't do a backbend but does that really count?)

**Jameson:** There isn't much that I've wanted to do that I couldn't because of my injury. I did, however, use it as a crutch to get out of doing the things that I didn't want to do, like various chores around the house.

**Amy:** I never thought that I would be able to do my hair, or do more than one push-up. To me, doing my own hair was only a distant dream that I never thought could become a reality. Now because of OT and e-stim, and my braces, I can do my hair all by myself! Also, I have never had enough strength in the muscles of my arm to do push-ups, now I am up to 10 at a time (I do cheat though and do them from my knees). It has taken an enormous amount of time and therapy to be able to complete these tasks, but I CAN do them!

**Joshua:** Let's see. Typing. Even though I can only use three fingers on my right arm, I have become a competent typist. Push ups. I never thought I would be able to do more than a few. Because of fourteen years of therapy, I am able to do two sets of ten, even though I cheat while doing it (Knees on the ground).

**What do your friends think about your arm?**

**Amy:** I had to cheat and ask one of my friends on this question because we really never talk about it. So I asked a friend in PE with me. She said that she did not even notice that there was anything wrong until the end of 10th grade (she came in 9th grade), when I was talking about it with someone else. Since I try to let nothing stop me from doing what I want, my friends often forget that there is even anything wrong with me at all. Some of my old friends that graduated last year thought it was really cool too that I could do so much and be so "normal" with an injury. Mostly though, we don't really talk about my arm.

**Jameson:** I have had a most interesting experience with friends. At one time my closest friends were once the people that teased me the most. In one instance,

Amy



my friend Mike used to ride my bus in 1st grade and he used to give me a hard time. Well, one day, I had had enough and I kicked his butt. By the time the bus driver stopped, I had him by the neck and was banging his head against the side of the bus. I haven't had a lot of friends, I was the "loner," but I always had a few good close friends that I could go to. Friendship didn't come easy for me, because at the time I was supposed to be making friends, I was turning anti-social, I gained a reputation at an early age of not wanting to be around others my age.

**Joshua:** Most of my friends do not even know that I have an injured arm. For my close friends that do know, they don't care. They don't give me a hard time about it.

**Brittney:** My friends don't care that my arm is injured. It is no big deal and they don't treat me differently than anyone else. They're there for me when I need them. Once in PE, my partner and I were lifting weights and I couldn't lift up the left side of the weight. When it was our turn she held up the left side for me, while I did it with my right side! I make jokes and laugh about it with my closer friends. Sometimes I tease that I can get out of running in PE if there's a sub. (I never have tried though.) I tease that if I get pushed over in a soccer game, I can get a free kick if the ref didn't realize my arm was already like that (again I have never done that but it's fun to tease about)! Once, one of my guy friends told me that my arm was cool and he wanted a cool arm like mine! Ironical huh? My arm is no big deal to any of my friends!

**Have you ever had surgery? If not, would you consider it someday in the future?**

**Brittney:** No, I have never had a surgery. I don't think that I will have a surgery in the future. I haven't heard of any surgeries that sounded good for me yet. I'm happy with the movement I have right now. Some surgeries may take away my other movements and I don't want that! That would mess me up because I'm used to doing everything

with these functions and if I suddenly got new ones in place of my old ones I'd have to relearn how to do everything a different way!

**Amy:** Yes, I had three surgeries, before I was 12 years old. My first surgery has helped me the most. It allowed me to open my hand without assistance. The second one still has potential. I just need to target the muscles and work on them more. I was not in formal therapy of any kind after this surgery. They sent exercises home for me to do, but what 10 year old wants to do therapy every day? And the third surgery, they tightened some loose tendons to help my finger movement.

If I could go back I would probably choose the surgeries again anyway because at least then, I had some hope of gaining function. I am actually considering having another surgery, a tendon transfer, to make it possible to open and close my hand all the way without the assistance of my braces. If I think it will help me even a little bit, then I am going to try it.

**Jameson:** I have had three surgeries: two radial head removals and when I was ten, I had a kind of shoulder reconstruction surgery, but I don't really remember what they did exactly but I know that they did some muscle transfers and that kind of thing. I have a policy about surgery and that is "if I can survive with things being the way they are, I would rather not mess with things." Surgery isn't exactly a fun event and I am in no hurry to have more. I have adapted well and surgery would just make me have to adapt to a new set of circumstances. The nature of my injury is that most surgeries that are done at my age are trade-offs, trading one set of movements for



Joshua

another. In one of my radial head surgeries, I sacrificed pronation for supination. The longer you wait to do necessary surgery, the harder it is to get all the proposed benefits, so in my case, most of the optional surgeries that have proven to be very helpful in younger patients are now useless for me.

**Joshua:** Oh man, I have had quite a few surgeries. To be perfectly honest, I cannot name the specifics on all of them. The last one I had was on June 24<sup>th</sup>, 2004. I had to have a ulnar nerve transposition. I am having another surgery on April 15<sup>th</sup> to correct a deviation in my wrist.

*What about therapy? What kinds of therapy have you done and what do you now do? What's your favorite way to 'work out' with your arm?*

**Brittney:** I remember going to lots of therapy sessions when I was little. I went twice a week. I tried the e-stim, but I hated it. I also slept wearing a cast to try to keep my arm straight. I hated that too because it was very uncomfortable. When I was seven, we moved. I never restarted physical therapy. Now to work out my arm, I swim, jump on the trampoline, do PE, play catch, run, go to soccer practice, and play lots of games with our neighbors. In other words I'm very active so my arm is always getting a workout!

**Jameson:** I don't really like to do therapy, but I do lift weights a little and I make sure that I don't lose any of my range of motion by stretching. I should probably care a little more than I do but I find it hard to get motivated, progress is hard to see sometimes so I get a little down.

**Joshua:** I have been in therapy all of my life. I have tried e-stim, but I hated it

with a passion. I stretched, did weight training, and swimming. I am partial to swimming, it's just plain fun, in my opinion. I am currently using a TES unit. It helps with sensory awareness, nerve growth and muscle development.

**Amy:** For therapy I am currently using e-stim, strengthening, and ROM. In the past, I only did ROM. I have found that using e-stim with strengthening is really effective. I have gained so much function in the past 8 months from this. I can do push-ups, put my hair up, and other small stuff now. Without all my therapy together, I probably would not be gaining very much. My favorite way to work out with my arm is to play softball. The arm doesn't seem to do a lot, but by the end of practice it usually feels like jello, so it must be working. I don't really like to just sit and do therapy. I like to be doing other stuff, so I don't get bored.

*Are there certain things in school, like band or sports or cheerleading that you think are harder for you? Have you ever not participated in something because of your bpi arm?*

**Jameson:** I would say that my arm hasn't stopped me from doing anything I wanted to do. I have really never had any true desire to do anything like band or PE at school. One thing I did enjoy when I was younger was soccer.

**Joshua:** For the most part, my arm has not limited me in what I can do, band/sports wise. My arm limited me in what selection of instruments I could play. I was stuck with the French Horn and Baritone Horn. Not that I mind, since I really like playing the French Horn. The only sport that I cannot do is wrestling, in fear of further injuring my arm.

**Amy:** Often times, many things are harder for me until I find my own way, then they are a piece of cake. There are certain sports I just don't play because they are too hard for me, like volleyball, and basketball. But I am always willing to try because sitting out is never fun. I may not be the best, but I am the best I can be. Really, the only thing that did not work out well was dancing for a

*“And to all you parents out there, don’t worry so much.*

*We will be just fine, if we have a problem we can’t solve on our own, you are the ones we will come to.”*

*– Amy*

musical play I was in last year. I chose not to participate in the dancing parts because the choreography had a lot of overhead movements and I did not want to be the only one not doing the same as every one else. Also, coordination is not always on my side so that makes it kinda difficult to dance.

**Brittney:** I have never let my arm injury stop me from doing things I want to do, like participating in sports or band. My private clarinet teacher told me that I would fall behind when the music got harder because of my arm. Nobody tells me I can’t do something! I told her I could do it! I did. I went straight from the 6<sup>th</sup> grade band to the 8<sup>th</sup> grade band! My band directors never cared that my elbow sticks out when I play, just that I sound good.

As far as cheerleading and school sports I was never really interested in them. I’m more of a soccer player not a pom-pom waver. I know that if I ever did want to try out for a sport, I wouldn’t let my arm stop me! I wouldn’t care if I can’t do the cheerleading dances right or don’t serve a volleyball the same way as everyone else. All that matters is having fun! It doesn’t matter what other people think. It’s my life, not theirs!

**What message or words of advice would you give to younger kids with this injury?**

**Joshua:** Do not let your injury limit the things you want to do. Stay strong and don’t let anything get in your way of your dreams.

**Jameson:** Stay strong and go for your dreams. Never let your injury stand in the way of something you want to do. Get a good education and help educate others about your injury.

**Brittney:** Here are some pointers for kids with an arm injury. The most important thing to remember when you have an injury is to never let it get you down. Only bad things can come from being negative. You can do anything if you put your mind to it! If you can’t do something one way, try it a different way. You’ll be able to do it!

Never feel sorry for yourself or others will feel sorry for you too (who wants that?) Just because you have an arm injury, people won’t treat you different (they only will if you act different!) You can have all the things you want in life with an injury. For example, I have lots, and lots of friends, and a boyfriend, I play soccer, I play the clarinet ... the list goes on! Your arm is only an obstacle if you turn it into one. Your life should not revolve around your arm. On the list of things that are important in your life, your injured arm should not be in the top five (mine’s not even in the top ten).

**Amy:** To all the younger people—don’t be afraid to try new things. You may not get it on the first try, but if you keep at it you can do any thing that you choose to. My new thing is going to be rock climbing. I don’t know if I can do it, but I can’t wait to try. You will never know your limits if you don’t push them, so press on!

**What about your parents? Anything you’d like to tell them?**

**Amy:** And to all you parents out there, don’t worry so much. We will be just fine, if we have a problem we can’t solve on our own, you are the ones we will come to. Often we can see when you are worried and in turn we begin to worry and second guess every thing. Don’t be afraid to let us try new things, like different sports, we know what we can and can not handle. And one more thing, our injury is not your fault, so don’t blame yourselves.

**Brittney:** As far as my parents, there’s not too much I’d want to say to them that they wouldn’t already know! I’d tell them thanks for always being there for me when I need them. I’d also tell them thanks for not ever babying me because of my injury. Since I have never been babied, I am now very determined and confident.

**Jameson:** I would like to thank my parents for being there and helping me realize there isn’t anything that I can’t do. We know our limits; you won’t help us grow to be strong individuals by putting us in a “bubble”. I don’t blame my parents for who I am, it’s safe to say that had I not suffered this injury I wouldn’t be the same person; so in a way I am thankful for my situation. Thanks to my parents for helping me become a responsible, confident and adjusted person.

**Joshua:** Like Brittney, there is not much that I would want to say to them that they already do not know. But, I’d like to say this. I cannot express myself on how grateful I am for having such wonderful parents.

**Nancy Birk:** Thanks very much to our Teen Panel for sharing so openly from their hearts. Your answers have brought a few tears and lots of smiles to all of us. ■

To submit questions or if you have suggestions for future “Straight Talk” panels, contact UBPN at [info@ubpn.org](mailto:info@ubpn.org).

# A Letter of Thanks to Tom & Trish Cirino

■ by *Lisa Smith-Proffitt, Brachial Plexus Palsy Foundation*

For the last 6 years, our family has been fortunate enough to attend the Brachial Plexus Palsy Foundation's Annual BPI event sponsored by Tom & Trish Cirino near Plymouth Meeting, Pennsylvania. This is a place where BPI families can come for emotional support as we confront and share daily challenges. The BPI event helps us to stay encouraged and provides tools to help move us along in our healing journey.

It is because of the Cirino's relentless commitment to bringing awareness to brachial plexus birth injuries that a well-deserved, heartfelt THANKS is long overdue. From their well-coordinated efforts at providing children with spirited, therapeutic entertainment to catering delicious picnic luncheons, the Cirino's always give unselfishly. Each year, the Cirino's take on the arduous task of arranging appointments for children and their parents to meet with the Texas Children's Hospital Brachial Plexus Team. These evaluations and informative sessions mean so much for families who are unable to travel to Houston.

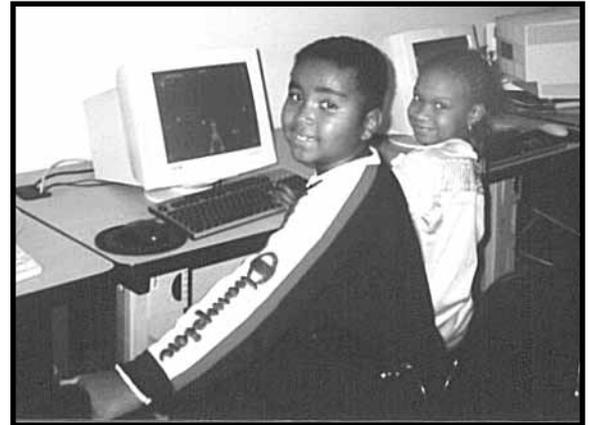
Trish and Tom



A special thanks is also long overdue to Dr. Saleh Shenaq and Lisa Thompson, RN, for their years of dedication and commitment to enhancing the lives of children with brachial plexus injuries. My 7-year-old son, Teco, has significantly benefited from Dr. Shenaq's expertise through surgical intervention and prudent treatment plans. My family and I will forever be thankful to Dr. Shenaq and Lisa for giving Teco a greater quality of life. We look forward to seeing Dr. Shenaq and Lisa each year at the BPI event in Pennsylvania.

This annual BPI event also allows us an opportunity to see old friends and meet new ones. We share experiences, offer suggestions and explore ways to help our children cope with having a BPI. We attempt to reduce the anxiety, stress and feelings of isolation that our children may experience at daycare, elementary, middle and high schools.

My son, Teco, looks forward to each BPI event because he gets to see and play with his 7-year-old friend, Chanel



Teco and Chanel

Leonard, who he first met at 11 months of age. Through the years, they've been roommates at Texas Children's Hospital, and together have worked through difficult times with their respective birth injuries. We are so proud of them both. Now that they are older and a bit more competitive, they always enjoy a friendly game of basketball at each BPI event.

Each year that my family and I attend the BPI event in Pennsylvania, we leave with reaffirmation of a greater commitment to continue to bring awareness to brachial plexus birth injuries within our communities in the state of Maryland.

Thanks Tom and Trish!

## **The Brachial Plexus Palsy Foundation**

**210 Spring Haven Circle, Royersford, PA 19468** <http://membrane.com/bpp/>

*The Brachial Plexus Palsy Foundation is a 501(c)3 non-profit organization designed to provide funds for the research and education of Brachial Plexus Palsy in infants and children. Tom & Trish Cirino began the Foundation in 1995 after the birth of their son, Andrew, who suffered a severe brachial plexus injury to his right arm. Their desire was to find ways to help with education and treatment of this injury.*

*One of the major goals of the Brachial Plexus Palsy Foundation is to contribute to hospitals both regionally and nationally that are currently treating brachial plexus injuries and conducting ongoing research for better methods of treatment.*

*The Foundation has also contributed funds to support other brachial plexus groups across the country in their efforts, including the United Brachial Plexus Network.*

## Realizing a Dream: Running the New York Marathon

■ *By Michael Schumacher, The Netherlands*

About a year ago, a special Netherlands's foundation was established to help people with Cystic Fibrosis lung diseases and mental handicaps. The main goal of the foundation was to raise money and to finish the NY marathon with a group of about 80 runners.

The New York Marathon would be my fifth marathon. My best time ever was in Berlin at 3 hours 56 minutes, so I set my pace time for New York at 3 hours and 50 minutes.

On Thursday, November 4, our group flew from Brussels to JFK airport. It was raining as we came into the Big Apple. It was about 4 p.m. and it was nearly dark. Our hotel was the Millennium Broadway only 150 metres (164 yards) from Times Square. This was really amazing. My room was on the 30 floor. For me, as a man from the flat and quiet country, this was quite a shock.

On Friday, we went to pick up our running numbers. My number was 24040. This was quite a happening – so many people, yet perfect organization. The rest of our day was free to sight-see. I visited Ground Zero and Liberty Island. I especially found Ground Zero to be impressive.

The Friendship Run was scheduled for Saturday morning. This is a 5-mile run only for the foreign runners. It was a nice opportunity to get familiar with the course and the finish area in Central Park. The race coordinators had everything under control, all was perfect. Later that day, we had a city bus tour with a Dutch guide who has lived in NY for more than 50 years.

Sunday, November 7, was Marathon day. We woke up early to catch the bus to Staten Island – the starting area. Once there we had to wait for several hours.

Around 10 a.m., the crowd started to move toward the starting line. It was never so good to hear Frank Sinatra sing “New York, the city that never sleeps....” I was so full of emotion as the starting shot went off.

We came to the first bridge, the longest one, the Verrazano Narrows Bridge. This was so amazing to run there with 38,000 runners from all over the world. All those runners from so many different countries. All the runners with their own background, their own goal ...

The crowd, more than two million, was enthusiastic all the way. Crossing all those bridges was really difficult. The temperature was very high for a marathon, 22 C. (72 F.) The days before were not warmer than 12 C.(54 F.) There was

a lot of music on the way. We passed all the boroughs of New York, even the Bronx. I found the hardest part of the race was 5<sup>th</sup> Avenue. It was hot, 5 miles long, with lots of people and going uphill. Unfortunately, I got cramps in both legs at the 20 mile mark. Cramps, when running a marathon, are caused by heat and dehydration.

Another runner helped me to the side of the road, a friendly American. I had to let go of my goal of a 3 hour and 50 minute pace. Up until 20 miles, I was perfectly on schedule. After that, I had to recover from the cramps. This takes time, so I had to go slower.

I was happy to see the finish line in Central Park with a time of 4 hours and 6 minutes. Happy to reach the finish line again. Again I had the experience of never giving up and adjusting your goals. Reaching these goals is so important to me. It helps my struggle with pain much easier. It makes me mentally stronger resulting in a higher output in my work. The feeling of “I know I can do it.”

I think anyone who puts their mind to it can run a marathon. You have to invest time, lots of time – but you get so much in return. Try it, I promise you can do more than you think ....

2005 will be my new marathon year. In April, I'll run the Rotterdam Marathon and in September the Berlin Marathon. The last one will be a 3 hour and 50 minutes one!

For anyone with BPI who wants info or to contact me, feel free to do so: [m.schumacher@zonnet.nl](mailto:m.schumacher@zonnet.nl) ■

*Michael suffered a brachial plexus injury in 1986 as a result of a motorcycle accident.*



## Why Isn't My Arm Straight?

*By Caroline Reilly, Age 9*



*Why isn't my arm straight?*

*Why couldn't it be like most peoples arms?*

*Why couldn't it have been different?*

*Maybe I could have been a boy*

*Maybe I wouldn't have been born*

*Maybe I could have had a straight arm*

*Why did I have to be me?*

**IT'S HARD**

*Why couldn't it be someone else?*

*I know why my arm isn't straight*

*Because God wanted me to be special*

## Consider a Donation to UBPN, Inc.

The United Brachial Plexus Network, Inc. (UBPN) is a national organization with international interests, which strives to inform, support and unite families and those concerned with brachial plexus injuries and their prevention worldwide. We have an outstanding track record of success and we are prepared to accomplish even greater things in the future.

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.

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.***

Name: _____	<i>I would like to make a donation to UBPN, Inc. of the following amount:</i>
Address: _____	<input type="checkbox"/> \$15 <input type="checkbox"/> \$25 <input type="checkbox"/> \$50 <input type="checkbox"/> \$100 <input type="checkbox"/> Other:\$ _____
City: _____	<input type="checkbox"/> Please contact me about estate and planned giving.
State: _____      Zip: _____	Please make my donation in honor of:
Phone: _____	_____
E-mail: _____	<i>Thank You! You will receive confirmation of your donation by mail.</i>
	<b>UBPN, Inc., 1610 Kent Street, Kent, OH 44240</b>

# Mayo Clinic's Brachial Plexus Team ...

continued from page 7

brachial plexus or from a number of other sites to be used for recovery of both motor and sensory functions. Surgeons may direct nerve fibers to a specific motor or sensory "target," improving chances for recovery of function.

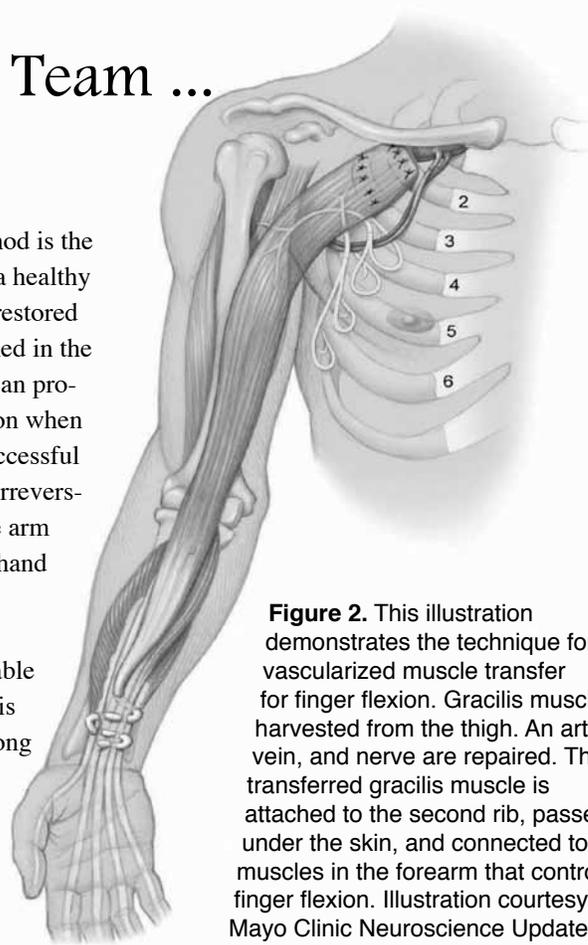
Potential nerve transfers include the spinal accessory nerve, intercostal motor and sensory nerves, and the phrenic nerve. In addition, the Mayo Clinic team also uses the contralateral C7 transfer from the opposite (uninjured) side (Figure 1 on page 7). Transferring a part of the uninjured C7 nerve root, usually combined with a vascularized nerve graft, provides the possibility of restoring grasp function in patients with total plexus avulsion.

In a patient with an upper trunk injury, other innovative techniques that are done closer to the target muscle may be used to improve function. For example, a fascicle of the ulnar nerve or the median nerve may be used to reinnervate the biceps muscle; in addition, one of the nerve branches supplying (a part of) the triceps may be used to reinnervate the deltoid muscle.

## Muscle Transfers

Another advanced method is the microsurgical transfer of a healthy muscle. With circulation restored and nerve repairs performed in the arm, the muscle transfer can provide needed motor function when delay in or previous unsuccessful treatment has resulted in irreversible muscle atrophy in the arm or when improvement of hand function is desired.

To do this, the surgical team transfers an expendable muscle, such as the gracilis muscle from the thigh, along with its nerve and blood supply, to animate the elbow, wrist, and hand (Figure 2). Collectively, these methods often restore shoulder stability, limited but useful shoulder abduction, full elbow flexion, and, in some patients, hand function and protective sensation. ■



**Figure 2.** This illustration demonstrates the technique for free vascularized muscle transfer for finger flexion. Gracilis muscle is harvested from the thigh. An artery, vein, and nerve are repaired. The transferred gracilis muscle is attached to the second rib, passed under the skin, and connected to muscles in the forearm that control finger flexion. Illustration courtesy of Mayo Clinic Neuroscience Update.

For information about the Brachial Plexus Clinic, contact 507-538-1988.

New techniques and strategies for state-of-the art management of patients with brachial plexus injury are featured in *Hand Clinics*, Feb. 2005. The web address is [www.hand.theclinics.com](http://www.hand.theclinics.com).

## In the Next Issue:

- A Camp Scrapbook
- Kinesio Taping for the Older Child
- More on Social Security Disability
- Photos from our National Rally on Capitol Hill
- Straight Talk from OBPI Moms

*Don't Forget!*  
Additional copies  
of *Outreach* are  
available by  
calling UBPN  
toll free at  
1-866-877-7004.  
Limited copies of  
past issues are also  
available.

# The Mayo Experience...

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at Mayo. Dr. Allen Bishop and Dr. Alex Shin are orthopaedic surgeons, specializing in hand surgery and microvascular surgery. Dr. Bishop is also chair of Mayo's Division of Hand Surgery. Dr. Robert Spinner is a neurosurgeon and an orthopaedic surgeon. We were pleased with their background and experience and we felt we were getting our three opinions right there.

We were always seen on time for the various appointments, with John's chart somehow arriving ahead of us as we went to different buildings for back-to-back tests. Test results and interpretations were returned quickly and by the second day, we were meeting back with the bpi team to assess options. Given that John had full avulsion of all five nerves, the doctors' primary goal was to restore elbow bending and shoulder stability. The secondary goal was to give him elbow extension and some hand function.

The doctors felt John would be a good candidate for the Mayo team's

first phrenic nerve transfer. They also recommended a hemi-contralateral C7 transfer, gracilis muscle/tendon transfer, intercostals nerve transfer, and using the sural nerves for grafting. We had brought a notebook where we kept diagrams, notes and questions and it helped us keep everything straight. There was an opening for surgery two days out, and it didn't take us long to conclude we were where we needed to be – we cancelled our other appointments. Thus, two days became two weeks.

John had two major surgeries, seven weeks apart. He had the second gracilis transfer (known as a Double Doi) and four intercostals motor nerves to power the gracilis as well as the triceps. The sensory portions of the intercostals nerves were used to restore sensation in some of the fingers. Each surgery involved all three primary doctors and lasted more than ten hours. The chart on page 38 summarizes John's procedures.

There have been no problems with the donor sites. John has a partially col-

lapsed lung from the phrenic transfer (which we knew would happen from the doctors' discussions) but still races his bike. For a while he had some slight weakness in his good arm from the C7 but it is back to normal. The gracilis muscle is used for squeezing the legs together for activities such as riding a horse, but since John never really used that muscle to a great extent before, he doesn't seem to miss it.

John was in the ICU for two days. We didn't expect the elevated temperatures of the ICU room. The temperature is kept fairly high in order to increase blood flow to the transplanted muscle. We quickly learned to keep the ice chips and cool washcloths handy.

For the next month at home, we had to be creative with clothing and showers. John's arm was very securely attached with Velcro to thick padding between his arm and chest, since it was critical that there be minimal movement while the nerve transfers healed.

When we returned to Mayo for our first checkup, the doctors stressed the importance of daily physical therapy and electrical stimulation (e-stim). The e-stim sends a small current to the target muscle, which causes it to contract and stay viable until the nerve can make contact. Biofeedback was also added after the second surgery, which helped John train his brain to isolate and send the correct signals to strengthen the pathway to the muscle. The biofeedback unit was the only therapy item not covered by our insurance.

## Recovery

We were able to see the first signs of movement close to six months after each surgery. John was in a swimming pool and realized he could bend his arm in the water. Then a few months later, he was able to twitch his fingers – most noticeable when his hand was on a paper towel and we'd see the paper towel crinkle. Each of these movements was small at first, but with continued therapy John gained more strength and control.

*continued*



John's surgical team at the Mayo Clinic, from left: Alexander Y. Shin, MD; Allen T. Bishop, MD; and Robert J. Spinner, MD.

*Photo courtesy of Mayo Clinic Neuroscience Update.*

Early on, he was in therapy four times a week – twice in Physical Therapy (PT) (one session was aquatherapy) and twice in Occupational Therapy (OT). He still continues with PT twice a week. In addition, John used e-stim and did range of motion exercises daily to further strengthen his muscles. With all muscles now firing, he has discontinued e-stim but continues biofeedback to help isolate and strengthen some of the brain signals.

The main goal in the early recovery period was to not let the arm straighten beyond 30 degrees and to keep it safe from trauma since that would stretch the transferred nerves. John wore a sling constantly for a few months, then transitioned to only wearing it at school for protection. He currently only wears a sling when exercising.

### Arm Movement

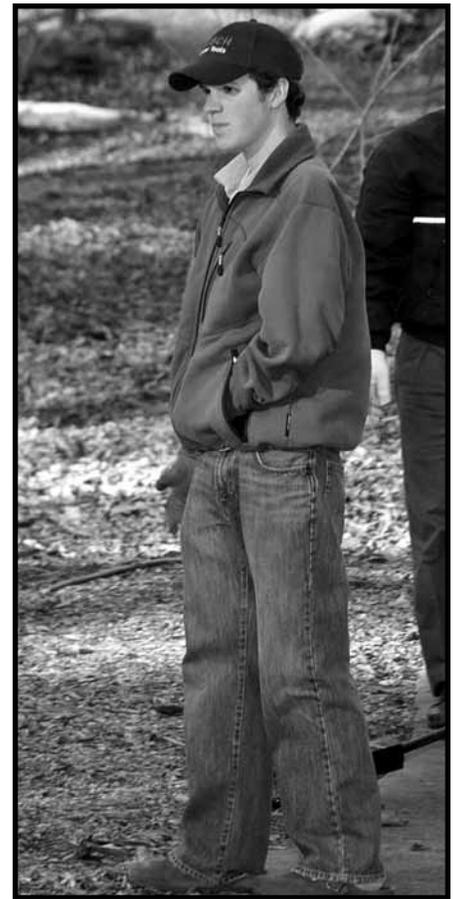
All target muscles have now been innervated. The most recent (bicep and deltoid) were due to the length of nerve growth required from the phrenic and contralateral C7. These muscles will gain strength with continued daily therapy. At this point, John’s stronger muscles allow him to bend his arm and carry things looped over it, as well as grip an item against the side of his chest. We’re pleased to see him begin to gain some functionality with an arm that had been completely paralyzed.

### Hand Movement

The second gracilis muscle/tendon transfer has enabled John to make a rudimentary grip. His fingers and thumb come together as one motion (not individual finger movement). Each of the intercostals nerves has a sensory portion, which was transferred to the sensory portion of the thumb, index and middle finger. When it fully reaches the hand and has grown out to the fingertips, John will know when his fingers have made contact with an object, as he will feel it in his chest area. This nerve can communicate touch, but not temperature or texture (i.e., hot, cold, soft, rough.) Last May, John had his thumb fused at the joint, as it had been collapsing from the pressure of the fingers against it. He’ll have one more surgery to further adjust his hand so the grip can be more functional. The timing of that is flexible and something tells me we’ll be working around the bike racing season!

### Pain Management

As many of you know, often the pain can be the worst part of a traumatic brachial plexus injury. John’s pain was very severe. Since he couldn’t tolerate narcotics, John was prescribed Neurontin, Amitriptyline and Topomax. The dosages were pretty high, which made it very hard for him to concentrate in school. The past two summers, John



worked hard, in stages, to reduce the meds. He is now basically off all meds and only takes one Neurontin (600 mg) as needed, usually once a week. I’m convinced that the main reason John got relief from pain was due to the arm movement he has regained through his surgeries.

### What’s in Store

John is now a junior in high school and is looking ahead to college. It’s been helpful to learn from the message boards about the variety of careers held by others with his injury. We are looking for a good vocational counselor to do interest and ability testing and provide some additional suggestions for consideration. Mixed in with college planning, however, will be hard work of an entirely different kind. John is very motivated to earn a spot on the U.S. Cycling Team and compete with them in the 2008 Paralympics. So watch out! ■

Procedure	Function	Nerve(s) Used
1 <sup>st</sup> gracilis muscle	elbow bending and wrist extension	spinal accessory nerve
2 <sup>nd</sup> gracilis muscle	finger flexion	2 intercostals motor nerves (including one for sensory)
Bicep		phrenic nerve
Tricep		2 intercostals motor nerves
Deltoid		infraspinatus, supraspinatus contralateral C7 with interposition sural nerve grafts
Portion of the median nerve	sensation to the thumb side of the hand	4 sensory intercostals nerves

## Coming to Terms...

continued from page 16

nurse then stupidly said to me “Honey you’re having a baby”. Well, tell me something I didn’t know.

The doctor had me continue to push although it was totally unproductive. He then decided to use forceps and a traction rod to help get Rain out. With every pull the situation became more intense. Finally, he gave a final pull, lost his balance, and Rain popped out.

There she was. Totally silent. 3 weeks early, weighing in 10 lbs 12 oz. Immediately I wanted to know what was wrong with her. The nurses were suddenly mute, and there was my baby looking lifeless. After a brief examination, we were told that she had a little palsey in her left arm, but she would be fine in about 3 weeks.

We were referred to a BPI specialist in Houston when Rain was 2 weeks old. We took the trip there with no idea of what to expect. Ultimately, we were told that Rain needed surgery. WOW! So many decisions to make. Talk about a whirlwind. We pondered it all and decided to go forward with the surgery. Rain was 8 weeks old when she had her first surgery. From that moment on, I became consumed with this injury. It took over my life. I became a very negative, emotionally devastated individual. How long could that go on?

I remember talking with a friend one afternoon, when I had a lightbulb moment. She said something to me that I will never forget. She said “You have to realize that this injury isn’t yours, its Rain’s. You need to take yourself out of the equation and become the solution”. It hit me like a ton of bricks. I mean I was not going to have to love Rain’s life. I wasn’t going to have to adjust to this injury and the trouble it carries. The troubles were not directly mine, but indirectly. As her mother, I was to love her, care for her, cherish her, and teach her to love herself and to be the best person that she could be.

Things happen beyond our control. The important thing is what we do after a tragedy strikes. The road to emotional recovery is long, and I don’t know that I’ll ever reach the end, but I’m heading in the right direction. I still reflect on how this journey began, but they are fewer and farther between.

Five years and counting. ■

# A Tribute to Dr. Rita Lee and Dr. John Laurent

Dr. Rita Lee, pediatric neurologist and Dr. John Laurent, pediatric neurosurgeon, were two founding members of the Brachial Plexus Clinic at Texas Childrens Hospital. Sadly, Dr. Lee passed away on September 15, 2004 after a long illness and Dr. Laurent passed away unexpectedly on November 1, 2004. The brachial plexus community has lost two outstanding physicians who gave their lives to their profession.



Dr. Rita Lee

Dr. Lee received her medical degree from Baylor College of Medicine. She has spent the last 38 years committed to her profession and 28 of those years were spent as a Pediatric Neurologist at Texas Childrens Hospital. She was the Chief of the Brachial Plexus Clinic, a position she was extremely proud of. She was and will remain an inspiration to us all. We all learned a great deal from this wonderful lady and my thoughts of her will be frequent and with great admiration for everything she gave to the medical community and to me as a friend.

Dr. Laurent was a world renowned pediatric neurosurgeon, receiving his medical degree in 1972 from the University of Pennsylvania School of Medicine. He devoted so much of his time and talent to the Brachial Plexus Clinic at Texas Childrens Hospital where he served as the Section Chief of Pediatric Neurosurgery. His patients admired and loved him. He had a wonderful sense of humor and his enthusiasm for life was contagious. Dr. Laurent loved to teach and those of us who were lucky enough to work with him will never forget what we learned from this fine gentleman. His dedication and devotion to children was endless as seen in his surgeries, teaching endeavors, and research projects. Personally, I knew John Laurent as a wonderful father, husband, and friend to all.



Dr. John Laurent

These two wonderful individuals will be missed by all who knew them. Professionally, their contributions to their fields of medicine have been outstanding. We will never forget them.

Saleh M. Shenaq, M.D.  
*Professor, Baylor College of Medicine  
Houston, Texas*

**Awareness Items Order Form**

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The payment e-mail address for UBPN products  
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**Awareness Items For Sale!**

**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 it will say, [ubpn.org](http://ubpn.org). A blue bracelet will be 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 and we are offering it again for 2005. 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! What a great visible adornment to wear during the National Proclamation Rally in September.



**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 during the National Rally. Buy several to present to your Congressman and Senator and their staffs.

