

# Outreach

Winter/Spring 2009  
Issue #23

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Partial Spinal Accessory  
Nerve Transfer

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# Outreach

Winter/Spring 2009

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### On The Cover:

*Paul Fejtek of Newport Beach, CA is systematically conquering obstacles by climbing the highest mountain peak on each of the world's seven continents. Paul has successfully climbed five of these "Seven Summits" so far. Read more about Paul's adventures on page 18.*

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# President's Letter: A Fresh Perspective for UBPN

*By Rich Looby, UBPN President*

My journey in the world of brachial plexus injuries began almost 12 years ago, in June 1997. It was my wife's and my first baby. It is a story we have heard in our UBPN community over and over. The baby got stuck, the baby got pulled, fundal pressure was inappropriately applied, and my precious daughter sustained a permanent, left obstetrical brachial plexus injury at birth.

It wasn't long after that I found the Erb's Palsy Injury resource group. There were many spirited discussions then and now. It seemed like a small group of people just looking for the best treatment and answers for their children. This small group has grown tremendously with the explosion of the internet and the familiarity of most with searching for answers electronically. Soon EPIRG became incorporated as a non-profit 501c3 in 1999, the birth of UBPN.

We have a long list of people to thank for developing and forging through to bring us to what UBPN is today. In the last week of August 2008, Nancy Birk stepped aside from the role of president to become our immediate past president, and Cathy Kanter (who was one of the founding members of UBPN) stepped out of the Past Presidency role to enjoy time outside of UBPN duties. Both women need to be acknowledged for their many years of hard work in their previous positions, including their tireless efforts to receive non-profit status, the work towards past camps, the recruitment of reliable individuals, and the work needed to make UBPN one of the most respected organizations for our ever-growing community.

Today, UBPN is continuing the transition to a new group of executive leadership and renewed vision for our board of directors. We have said goodbye to many faces on our board of directors, each of who contributed greatly to bring us where we are today. Without their efforts and dedication, it would be difficult to reach the goals that have been set for UBPN.

Let me take a little time to re-introduce what UBPN offers the community. Our website is the face of UBPN. It serves the world as an introduction to how this injury occurs, obstetrically and traumatically. The pages are loaded with ideas for therapy, interventions, and methods people can incorporate into their daily routines to deal with their injury. Our medical resource directory, allows people to research the best course for medical and/or therapeutic intervention. Online brochures are available for awareness and prevention that are readily downloadable for personal distribution. We have a registry, although underutilized, which helps people find others near them for support and reassurance. Probably most importantly and most used, is our message boards. We have almost 10,000 individuals registered on our message boards. It has proven to be a great resource for many to find answers to their questions, find support and make valuable connections.

We have many other programs that can be found on our website: Medic Alert opportunity, InterAction, In Touch, Open Arms, Outreach, Prevention, Wings, and the Within Reach Program. Descriptions of these programs can be found online.



UBPN President Rich Looby



UBPN also self publishes *Outreach* magazine twice a year-free of charge to almost 4,000 addresses worldwide. Kim West is the chair of the Outreach committee and is the brains of putting together every single issue. While we have archived our past magazines on our website we know that a hard copy is more treasured. Outreach committee also publishes brochures, our new online e-newsletter, maintains our website content and a myriad of other media, both electronic and paper.

Camp UBPN, run under our InterAction program, is also well received by all who attend. We offer stimulating seminars and provide outlets to get to know one another through fun activities and interesting presentations. Karen McClune is our InterAction Committee head and is currently evaluating sites for the next camp in 2010.

Our Prevention Committee is also in the midst of finalizing efforts towards *Spotlight On*. This program will be a 5-6 minute documentary about brachial plexus injuries. It will be broadcast on PBS stations nationwide and will eventually be viewed by 4-5 million people. Lisa Muscarella, co-chair of Prevention, has submitted all the media for the show, secured medical professionals to speak, and storylines are currently being developed. It is a very exciting opportunity that we hope will be a big step towards awareness and prevention.

So what is coming in the future?

## A New Website

In early 2009, the familiar UBPN web site will have a face-lift, courtesy of the Outreach Committee. It is an exciting time for UBPN. A completely new interface will be presented. All the registrations, usernames and messages will be retained. New features will be

unveiled including thumbnail pictures, flags, and a plethora of really cool tools will be available. In addition, we are drafting new pages that will better serve our TBPI community. Our website will be more interactive, have pictures, video animations and medical quality figures.



## Spotlight-On

Our Spotlight-On program should be wrapping up in the first quarter of 2009, and soon be broadcast across the United States to millions of viewers. We believe this will have a great impact on awareness and prevention. Needless to say, this has been one of our biggest focuses for the last 18 months. We'll let you know when it is being aired and DVD copies will be available for purchase after airings are complete. Donating \$75 or more toward this project will automatically qualify you for a free DVD, send donations indicating Spotlight-On to [donations@ubpn.org](mailto:donations@ubpn.org) or by check to UBPN, 115 Fawn Lane, Blanchester, OH 45107 with Spotlight On in the memo line.

## Fundraising

Our efforts to raise funds have also increased. In addition to GoodSearch, where anyone can raise funds simply by searching the internet, we have provided other tools for family and friends to help out UBPN. We have an

Amazon store where a percentage of every purchase goes directly to UBPN. We have provided a place through FirstGiving, where online fundraisers are easy to establish. We have opened a new Cafepress storefront and had a contest for design artwork to be featured. We also still have our UBPN camp store featuring car magnets and ribbons and bracelets. We would be happy to discuss advertising in *Outreach* magazine as well for those interested, contact [kim@ubpn.org](mailto:kim@ubpn.org). In the new year you will also see new fundraisers that we hope will be supported and successful so we can continue to serve our BPI community.

## New Leadership

UBPN is currently experiencing a passing of the guard so to speak, and with that comes introspection. With the dedication of the board of directors, I feel that we will make great progress, become a stronger, better organization for our community and continue to provide access to information, support and understanding to each one of us who come here seeking it. In this issue is a snapshot of our financial health (see page 14). While UBPN has not formally asked our community to donate funds for the services we provide, nor have we ever asked for a subscription fee for *Outreach*, nor do we have a membership fee for using the great resources on our website, we do need your support.

If you have benefited from the resources offered by UBPN, through the magazine, camp, website or message boards, please consider supporting UBPN through a donation of your time or resources. Without the community's support, UBPN would be just another brachial plexus website, not the home it has been for so many.

Thank you for your support.

*Rich Looby*  
Rich Looby

## Shop for UBPN!

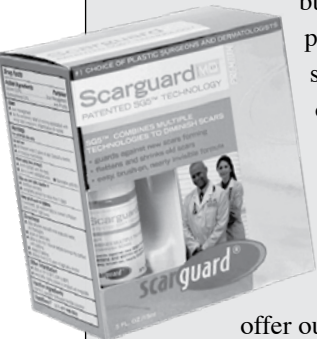
UBPN is heading to the Amazon... Amazon.com to be exact. UBPN has opened an Amazon store featuring many items that will be of interest to the UBPN community. The direct link is <http://astore.amazon.com/unitbracplexn-20>. However, there is a direct link on the UBPN web site.

It has sections that include books, toys, therapy items and utensils that will make life easier for those who struggle in a two-handed world. The books range from inspirational to medical, the toys from educational to therapeutic, and the therapy items from pain relief to strength training. The utensils are attractive and could be gifts for those family members with no injuries!

Best of all, UBPN gets a percentage of the sale on all products sold through Amazon from our affiliate site (even items not listed in our stores) because we are a 501c3 non-profit. The range starts at four percent but could go as high as 10 percent depending on the sales!

So look through our Amazon.com store site and if you were going to buy that one handed pepper grinder or salad spinner, use our site to make your purchase and support UBPN just by shopping.

We still offer our branded items (bracelets and magnets and pins) through the UBPN store.



## New UBPN Directors

UBPN is pleased to welcome two new additions to the the Board of Directors.

**Christopher Janney** is from Los Angeles, CA. He earned his membership to UBPN in 2002 via a motorcycle accident. Realizing that the UBPN community was his primary source of information and support, which enabled him to get the best available medical attention, rehabilitation, and return to an active life, he knew he had to return the favor. He remains active on the UBPN forums sharing information and helping out wherever he can.



Christopher Janney

Since conceiving a neurosurgical procedure to save his triceps, Chris hasn't stopped trying to understand and research the nature of neural regenesis and a cure for BPI. He is a firm believer in self reliance, and thoroughly enjoys helping people help themselves. Contributing to putting BPI into the history books forever, which he knows is possible, is one of his life time goals.

Christopher studied philosophy at University of New Hampshire, drama at Yale, and is currently studying directing at UCLA.

**Tanya Jennison** is from West Winfield, New York. She has a unique perspective regarding brachial plexus injuries. Her first exposure to BPI came as a labor/delivery (L&D) nurse when she heard a neonatologist say that a newborn's injury "would go away soon." Her second exposure came with her own daughter's permanent injury in 2002. BPI had not been discussed in her nursing textbooks or curriculum, and injuries were "rare" since she hadn't heard of it but once before. The learning curve began, and UBPN came into her life.

Tanya is married with two children. Casey was born after a shoulder dystocia with no injury, but he did require a difficult resuscitation and transfer to another hospital. Amber arrived almost eight years later – another shoulder dystocia and a BPI.



Tanya Jennison and her daughter, Amber

Currently, Tanya works as an L&D nurse, but enjoys some educational pieces as well. She strives to educate the staff (nurses, midwives, and doctors) concerning BPI and shoulder dystocia. She is considered a resource when there is an injury to a newborn. Prevention and awareness are her passion, and the reason that she has come to the Board of Directors of UBPN. She is truly honored and grateful for the opportunity to serve on the Board of Directors and wishes to thank all who have supported her thus far. Tanya is also currently serving as UBPN Secretary.

# Shoulder Function Following Partial Spinal Accessory Nerve Transfer for Brachial Plexus Birth Injury

*John A.I. Grossman, Patricia Di Tarantola, Daniel Alfonsob, Lorna E. Ramosa, Andrew E. Price*

**Summary** Over a 5-year-period, 26 infants underwent a partial transfer of the spinal accessory nerve into the suprascapular nerve using a nerve graft, as part of the repair of a brachial plexus birth injury. At a minimum follow-up of 2.5 years, all children had shoulder function of Grade 4 or better using a modified Gilbert Scale. Average lateral rotation was measured at 538.

## Introduction

Although the transfer of the spinal accessory nerve into the suprascapular nerve has been well described for adult brachial plexus injuries, there is little available information on the use of this technique for infants with brachial plexus birth injuries.

## Methods and materials

Over a 5-year period (1997–2001) 26 infants underwent a partial spinal accessory nerve into suprascapular nerve transfer as part of the primary reconstruction for a brachial plexus birth injury.

All patients were available for a minimum of two and a half years of follow-up. The average follow-up time was 4.3 years. There were 13 male and 13 female infants. The right upper limb was involved in 16 and the left in 10. The injury pattern is summarised in Table 1.

**Table 1** Injury pattern (N=26)

C5/C6/C7	7
C5/C6	9
Global	10

## Technique

All procedures were performed using the operating microscope and a reversed nerve graft (sural or cervical plexus sensory) with a modified end-to-side technique at the proximal end. The spinal accessory nerve was entered using a diamond knife under high magnification after the take-off of 1–2 motor branches to the upper/middle trapezius and the graft placed within deep neurotomy. The suprascapular nerve was opened after its take-off from the upper trunk, well outside of the zone of injury for a direct coaptation. In all cases the upper trunk divisions were reconstructed using available spinal

nerve donors C5 and/or C6 and sural nerve grafts.

All repairs were done using fibrin sealant, without sutures. The average follow-up time was 4 years. Shoulder function was evaluated using the modified Gilbert system1 (Table 2).

Active external rotation was measured at the most recent followup. This was done with the child in the standing or sitting position and observing their multiple attempts to remove a sticker from behind the ear. Data was confirmed by a review of videos taken at each evaluation.

## Results

No operative complications occurred. No infant has exhibited any evidence of trapezius atrophy. Out of 26 patients, only two infants with poor recovery of external rotation of less than or equal to 108 have required a subsequent muscle transfer to maximize shoulder function.

**Table 2** Modified Gilbert shoulder evaluation scale

Grade 0	Completely paralysed shoulder or fixed deformity	
Grade 1	Abduction = 45°	No active external rotation
Grade 2	Abduction < 90°	Bi active external rotation
Grade 3	Abduction = 90°	Active external rotation < 30°
Grade 4	Abduction < 120°	Active external rotation 10°–30°
Grade 5	Abduction > 120°	Active external rotation 30°–60°
Grade 6	Abduction > 150°	Active external rotation > 60°

Grossman JAI, Price AE, Tidwell MA, Ramos LE, Alfonso I, Yaylali I. Outcome after late combined brachial plexus and shoulder surgery after birth trauma. J Bone Joint Surg [Br], 2003;85:1166–8.

**Table 3** Pre- and postoperative shoulder evaluation (modified Gilbert)

Stage	Preoperative	Postoperative
0	19	0
I	4	0
II	2	0
III	1	0
IV	0	10
V	0	7
VI	0	9

Both advanced to Gilbert Grade 5 with active shoulder external of 458. Shoulder function at the most recent follow-up for the series is summarised in Table 3. The average active shoulder external rotation in the group was calculated at 538 (range 108–908).

## Discussion

In 1994, Kawabata<sup>2</sup> reported the use of a spinal accessory transfer for 13 infants with brachial plexus palsy. However, in only two of these patients was the transfer into the suprascapular nerve. Birch has reported three cases of late transfer of the spinal accessory nerve into the suprascapular nerve for repair of a brachial plexus birth injury with excellent results.<sup>3</sup> Many other reports<sup>4–8</sup> discuss the use of the spinal accessory nerve into a variety of recipients for repair of traction injuries to the brachial plexus in adults.

The results of the study suggest that this is a useful transfer in cases of brachial plexus birth trauma with intraoperative findings of limited spinal nerve donors (C5/C6) for reinnervation of the suprascapular nerve.

The decision to use an interposition graft with the end-to-side technique is undoubtedly controversial.<sup>9</sup> We undertook using this technique to minimize any potential weakening of the trapezius<sup>10</sup> because many of these children are already subject to scapular instability.<sup>11</sup> We were encouraged by our favourable clinical outcome using this type of end-to-side repair in other brachial plexus reconstructions in infants,<sup>1,12</sup> and by the growing clinical<sup>13</sup> and experimental<sup>14</sup> data supporting this technique.

Although considerably longer follow-up is necessary to confirm the value of this method, the low incidence of secondary muscle transfers for shoulder reconstruction during the study period supports its use in plexus repair in infants.

*A special thank you to Dr. John Grossman of the Brachial Plexus Program, Miami Children's Hospital, Miami, FL, and Dr. Andrew Price of the Brachial Plexus Program, Hospital for Joint Diseases, New York, NY, for allowing UBPN to reprint this study in Outreach.*

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# Tracking Incidents of Obstetrical and Traumatic Brachial Plexus Injuries

by *Richard Looby, UBPN President*

## Birth Injuries

Brachial Plexus Injuries (BPI) are listed in the National Organization of Rare Disorders (NORD) website at [www.rarediseases.org](http://www.rarediseases.org). This is surprising since this preventable injury is listed side-by-side with unpreventable genetic disorders, and other various difficult to pronounce rare diseases. Of course, until someone we knew experienced a BPI, most of us were unaware that this injury existed. According to a series of 2005 articles in *Advances in Neonatal Care* by Kathleen Benjamin, brachial plexus injuries are common birth injuries, with an incidence of 0.13 to 5.1 per 1000 live births.

As evident from the review above, statistics for obstetric BPI (OBPI) are widely varied in the United States, because there are no mandatory requirements to record its incidence, or report the injury when it happens. There even seems to be contradiction on whether it is a rare or common injury. The raging debate as to the cause of the injury continues, with articles as recent as March 2008 in the *American Journal of Obstetrics & Gynecology*: (*Permanent Brachial Plexus Injury Following Vaginal Delivery Without Physician Traction or Shoulder Dystocia*, Lerner et. Al.) allegedly falsely reporting a permanent injury

without doctor applied traction.

With that being said, there are countless examples of the OBPI rate being between 0.4 to 6 per 1000 live births. This wide range is reflective of the lack of a standardized and mandatory reporting mechanism. These rates of injury are often found quoted in literature studies and are often chosen to reinforce the authors' points of view.

This can be demonstrated through literature references. Adler and Patterson (J Bone Joint Surg Am. 1967 Sep;49(6):1052-64). reported improvement in the rate of BPI incidence in New York. In 1938 the rate was ~1.56 per 1000 live births and in 1962 the rate decreased to 0.38 per 1000 live births. They attributed this change to improved obstetrical care.

The change in incidence has all but been refuted by current literature as today's obstetricians claim there has been no change in the rate of incidence. Graham et al (J Matern Fetal Med. 1997 Jan-Feb;6(1):1-5) claim the incidence of Erb's Palsy in their population is similar to that of other reported studies and has remained unchanged over the past 30 years at ~1/1000, even as our cesarean rate has risen from five to 20 percent. This idea supports that the injury is not a mechanism of obstetrical care – but as a result of maternal forces.

Camus et al cited an incidence of 1.09 per 1000 live births in France (J Gynecol Obstet Biol Reprod (Paris). 1985;14(8):1033-43). They believed

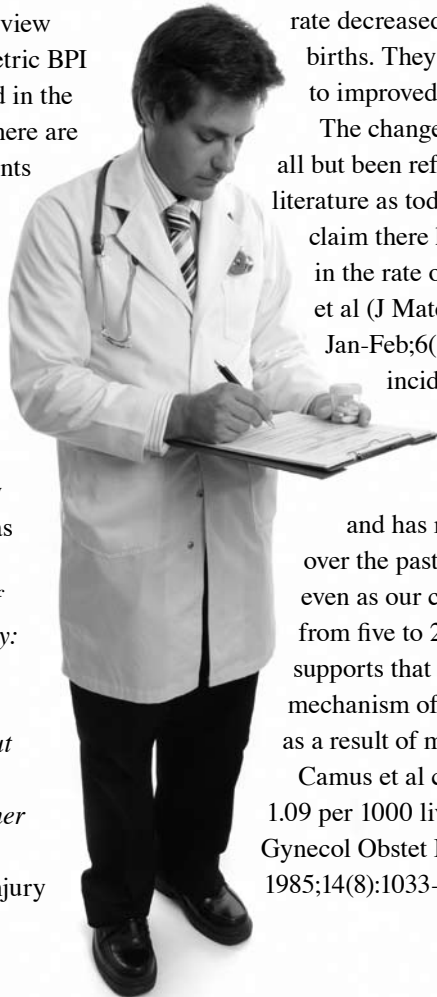
that vigilant monitoring and increased obstetrical training might prove preventative in many injuries.

Fletcher reported incidence of brachial plexus injury ranges from fewer than one case to four cases per 1,000 term births in the United States. (Physical diagnosis in neonatology. Philadelphia: Lippincott-Raven, 1998:441-504)

An unbiased review of their own hospital discharge records at Johns Hopkins hospital in Maryland, found an incidence of 5.8/1000 over an 11.5 year span (American Journal of Obstetrics and Gynecology Volume 194, Issue 2, February 2006, Pages 486-49). This hospital has an aggressive stance towards reduction of this preventable injury and have published numerous articles in regards to proper delivery techniques, delivery forces, and maneuvers to help relieve shoulder dystocias. *This may be the best reflection of the true incidence of the injury at birth.*

Another possible source of injury rate is the hospital discharge records using code 767.6 (the ICD code for OBPI).

UBPN did a review of available outpatient databases using ICD code 767.6 as a search criteria and found that in 2004, there were 10,320 records with this classification in the top seven discharge codes. With ~4 million live births, that is ~2.5/1000 of all births. Approximately 25 percent of those live births however are c-section, meaning the rate of injury increases to 3.4/1000 for live vaginal births. UBPN believes that this number is lower than the real rate of injury since the injury is often not included in the medical records, and there is an unfounded belief that the





injury spontaneously recovers in more than 90 percent of the babies suffering the injury, thus is neglected to be reported.

There are no reliable published data that support the rate of recovery and in fact there are papers that challenge the spontaneous recovery rate (Developmental Medicine & Child Neurology 2004, 46: 138–144).

This Danish group estimated that more than 30 percent of children who suffer the injury have a permanent disability.

There are many online sources that quote the rate of injury. EMedicine quotes the injury rate as 0.5–4.4/1000. Given today's births, that equates to 2,000 to 16,000 injuries every year. If John's Hopkins rate is more accurate, that would be 24,000 injuries per year!

Obviously, a more accurate method of recording and tracking the injury is necessary. Only then will the truth be known about the impact this injury is having on families. Only then will the public and responsible agencies demand an investigation to identify the real source for these injuries and how to prevent them. Only then will the medical community take the responsibility to truly train the obstetrical caregivers towards safe delivery techniques without applied traction. Only then will we see a decrease in the rate of this preventable injury.

## Traumatic Injuries

Traumatic Brachial Plexus Injuries (TBPI) can occur from a myriad of circumstances and it would be difficult to list all the mechanisms that could result in a non-obstetrical brachial plexus injury. A large portion however are usually the result of a high impact blunt

Table I ICD9 codes for peripheral nerve injuries

ICD9 code	Description
781.4	Traumatic transient paralysis -arm
353.0	Brachial plexus lesions
723.4	Brachial neuritis
344.9	Complete paralysis arm
953.4	Injury to brachial plexus

force where the patient is impacted, largely due to sudden displacement of head, neck, and shoulder. The most common mechanism (70 percent) is from motor vehicle accidents (Pain Physician 2008; 11:81–85), with motorcycles contributing largely to this population. In fact, in a Polish study, 51 percent of all the analyzed brachial plexus injuries were due to motorcycle accidents (Nawrocki et al, 2004). These injuries are usually secondary to other trauma, such as head trauma and/or broken bones.

Narakas developed his rule of “seven seventies” in his experience over 18 years with 1068 patients:

- Approximately 70 percent were motor vehicle accidents (MVAs).
- Of the MVAs, 70 percent were motorcycles or bicycles.
- Of the cycle riders, 70 percent had multiple injuries.
- Of the multiple injuries in cycle riders, 70 percent were supraclavicular injuries.
- Of the supraclavicular injuries, 70 percent had at least one root avulsed.
- Of the avulsed roots, 70 percent were lower C7, C8, T1.
- Of the 70 percent avulsed roots, 70 percent of those were associated with chronic pain.

Other non-obstetrical brachial plexus injuries can occur due to sports injuries, gunshot or stab wounds and from

falls, or being stuck by a falling object. Additionally, mal-positioning of the limb for lengthy periods of time (such as in anesthetized surgery)

or prolonged chronic exposure to additional weight on the shoulders (like a backpack) can lead to permanent paralysis. These injuries may also occur without blunt force due to viral or bacterial infection, diabetes, radiation treatment, tumors and medical error.

The plethora of circumstances that can lead to a brachial plexus injury, makes it more difficult to track. There are numerous codes that could be used to describe a brachial plexus injury on outpatient discharge records, depending on the source of the injury. There is no way to determine whether the injury is reliably tracked, although due to the complexity of the circumstances that lead to these injuries it is believed that they are under-reported. Looking at the International Classification of Diseases 9 (ICD-9) codes we find many listings for non-obstetrical brachial plexus injuries (Table I).

Of these codes, 953.4 seems to be the more universally used for traumatic brachial plexus injury. If we look at inpatient coding using this ICD9, we see that in the U.S., the rate of TBPI is approximately 2,000 new injuries every year (Table II). Goldie and Coates suggested that 450–500 closed supraclavicular injuries occur each year in the United Kingdom.

Brachial plexus injuries due to other causes are more difficult to analyze, however there are some published studies which have evaluated other causes. According to Chang et.al, in the annals of Vascular Surgery (Volume 21, issue 5), the incidence of a permanent brachial plexus injury following thoracic outlet syndrome surgery is 0.6 percent over a five-year period.

Unlike obstetrical brachial plexus injuries, the traumatic injury is more often profound, resulting in complete paralysis almost 35 percent of the time (Yoon and Lee, 1982) with males being four times more likely to be injured.

Table II Rate of injury to the brachial plexus (ICD9 953.4)

Year	Age 0-17	All other ages
1997	237	1860
2000	210	1850
2003	240	1781

*continued on page 23*

# Hyphenated History: Erb-Duchenne Brachial Plexus Palsy

*Carrie Schmitt, BA, Charles T. Mehlman, DO, MPH, and A. Ludwig Meiss, MD*

## Abstract

*Throughout history, the discoveries of their predecessors have led physicians to revolutionary advances in the understanding and practice of medicine. The result is a plethora of hyphenated eponyms paying tribute to individuals connected through time by a common interest. The history of Guillaume Duchenne de Boulogne, the “father of electrotherapy and electrodiagnosis,” and Wilhelm Heinrich Erb, the “father of neurology,” offers insight into the personal and professional lives of these astute clinicians and their collaborative medical breakthrough in the area of neurologic paralysis affecting the upper limbs.*

French physician Guillaume Benjamin Armand Duchenne lived from 1806 to 1875. Born in the coastal town of Boulogne, France, to a sea captain who received the Croix de la Legion d’Honneur from Napoleon in 1804 for his leadership during wartime, Duchenne was expected to continue the family’s nautical legacy.<sup>1,4</sup> However, his interest in medicine led him to Paris to study under many respected physicians, including Baron Guillaume Duputryn (1777–1853) and Francois Magendie (1783– 1855).<sup>2,5</sup> After having mediocre success as a student of Parisian medicine, Duchenne returned to Boulogne to practice as a family doctor.<sup>1,3,5,6</sup> After the 1834 death of Barbe Boutroy, his first wife, and his 1839 marriage to Honorine Larde, he became less interested in his practice and more fascinated with the diagnostic and therapeutic potential of electrical stimulation.<sup>1,3</sup>

Unlike the invasive electropuncture method recently developed by Magendie and Jean-Baptiste Sarlandiere (1781– 1838), Duchenne invented a portable machine that used surface electrodes to minimize the spread of electric current,

resulting in less pain and tissue damage to the patient.<sup>2,3,5</sup> Duchenne referred to his process as local faradization, giving credit to Michael Faraday (1791–1867), the scientist who invented the induction coil in 1831.<sup>3,4</sup> In 1842, Duchenne moved to Paris to explore the uncharted territories this field offered.

Known as Duchenne de Boulogne in Paris, he was considered an eccentric by his peers for his provincial mannerisms until many years later, when his work and expertise earned him international attention.<sup>2,6</sup> Without any official position with a hospital or university, Duchenne made his rounds by following his patients from hospital to hospital for years.<sup>2,5,6</sup> Through these extensive clinical studies and observations, he was able to identify many neuromuscular diseases, including atrophic paralysis of childhood, progressive locomotor ataxy, glossolabiolaryngeal paralysis, and facioscapulohumeral muscular dystrophy (now known as Landouzy-Dejerine syndrome). He has several eponymic namesakes, including Aran-Duchenne spinal muscular atrophy (chronic progressive wasting of muscles leading to weakness and paralysis), Duchenne syndrome (nuclear

amyotrophy in chronic bulbar paralysis), Duchenne trocar (a Duchenne-designed harpoon-like biopsy needle that required no anesthesia for patients), Duchenne-Griesinger disease (pseudohypertrophy of affected muscles), and the “Duchenne smile” (a sincere smile that Duchenne claimed uses muscles of the mouth and eyes).<sup>3,5</sup> Duchenne is considered a pioneer in electrotherapy, electrodiagnosis, neurology, and medical photography.

Famous for his photographs of electrical stimulation performed on “Old Man”—appearing in a primary work, *Mecanisme de la Physionomie Humaine* (The Mechanism of Human Facial Expression,) in 1862—he also presented a detailed atlas of the human brainstem with the first photographic illustrations of brain neurons and nuclei.<sup>3</sup> Duchenne had a profound effect on later innovative medical explorers, including Jean Martin-Charcot (1825– 1893), Robert Remak (1815–1865), and Hugo von Ziemssen (1829–1902), and was held in high esteem by Charles Darwin (1809– 1882).<sup>2,7</sup> An avid admirer of the arts, Duchenne used his scientific findings to participate in the dialogue of the aesthetic world. He criticized such works as the Laocoon in the Vatican Museum for displaying



Guillaume Benjamin Armand Duchenne, also known as Duchenne de Boulogne (1806– 1875).

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anatomically impossible lateral forehead lines of the frontalis muscle. Still today, Duchenne's extensive studies of facial muscles have relevance in the fields of plastic surgery and computerized facial expression.<sup>3</sup>

Duchenne died September 17, 1875, of a cerebral hemorrhage in Paris.<sup>1,4</sup> His view of his work as both art and medical documentation is evident in his donating his photographs to the Ecole Nationale Supérieure des Beaux-Arts of Paris instead of the Faculté de Médecine.

His life was quietly appreciated with a bas-relief that was placed on the wall of la Salpêtrière's Hospital and now rests at the amphitheater's entrance to the Myology Institute at the Pitié-Salpêtrière Hospital.<sup>3</sup>

## Erb

Wilhelm Heinrich Erb was a German physician who lived from 1840 to 1921. He was born in a small village in the Bavarian Pfalz to a family of woodcutters in the Black Forest.<sup>8</sup> Bertha Karoline Hermann, his first wife, died and left him a son in 1873. He married Anna Gass in 1873 and had three more sons.<sup>1</sup>

Erb studied at Heidelberg and Erlangen and received his doctorate from Munich in 1864. After working as a Privat-Dozent (assistant professor) in the



Wilhelm Heinrich Erb  
(1840–1921).

Medizinische Klinik (medicine clinic) for Nikolaus Friedrich (1825–1882) at Heidelberg, he left to become professor and director of the medical polyclinic in Leipzig.<sup>1</sup> He returned to Heidelberg in 1883 to take Friedrich's place as director of the medical clinic, where he stayed for the remainder of his career.<sup>4,8</sup>

Erb's greatest contribution to medicine is his role in establishing neurology as a specialized field separate from psychiatry.<sup>4</sup> He successfully argued for the inclusion of neurology in the medical school curriculum: "Total devotion of a man and the consecration of all his powers [are] required in order to attain even approximate mastery of this huge field."<sup>4</sup> It is this belief that drove him to found *Deutsche Zeitschrift für Nervenheilkunde* (*German Journal of Neurology*) in 1891.<sup>4,9,10</sup> In 1907, he and Herman Oppenheim (1858–1919) founded the Gesellschaft deutscher Nervenärzte (Society of German Neurologists), with Erb serving as its first president.<sup>1,8,10</sup> Many aspects of his clinical examination of the nervous system are still practiced today.<sup>11</sup>

Although the cause of Erb's death in 1921 is unclear, he is said to have died after listening to Beethoven's *Eroica*, one of his favorite pieces of music.<sup>1,8</sup> Erb is also remembered for his prolific writing; he published more than 237

papers and several books on such topics as electrotherapy, spinal cord diseases, and peripheral nerve diseases.<sup>11</sup> While bowling with friends, Erb discovered the patellar reflex when he observed a colleague hitting himself with a heavy key under the patella, causing the involuntary knee jerk.<sup>1</sup>

The honors bestowed on Erb include a bronze statue, now located in "Erb's Department" at Krehl Medical Hospital, and many eponyms, including Erb dystrophy (a slow-progressing juvenile form of muscular dystrophy), the Erb point (the point on the side of the neck 2 to 3 cm above the clavicle and in front of the transverse process of the sixth cervical vertebra), the Erb reflex (biceps femoris reflex), Erb-Charcot paralysis (a rare syndrome consisting of spinal syphilis with various side effects), Erb-Goldflam syndrome (characterized by ptosis, strabismus, and general muscular exhaustion), the Erb-Westphal symptom (loss of knee jerk reaction, the most important reflex anomaly seen in tabes dorsalis), the Erb test (a test of degeneration), and the Erb phenomenon (increased irritability of motor nerves in tetany).<sup>4</sup>

## Erb-Duchenne Brachial Plexus Palsy

Although Smellie in 1768, Danyau in 1851, and Gueniot in 1868 described a shoulder injury at birth that resulted in paralysis of the arm, Duchenne clearly stated the etiology as neurogenic paralysis and established the term *paralysie obstetricale* (obstetrical palsy).<sup>2,4</sup> In *De L'Electrisation Localisée* (1872), he presented the history of reported clinical cases to explore the causation and treatment for infantile obstetrical paralysis. Whereas previously the injury had been categorized as untreatable and had been ignored with an attitude of helpless passivity by physicians, Duchenne was aggressive in his approach to treating the injury with intent observation and experimentation.

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*continued on page 22*

# The Child With A Long-Term Illness

*This article is the first in a series dedicated to the mental health of children and adults with brachial plexus injuries. Although the following article is generalized, it is a good overview of mental challenges facing OBPI and TBPI children and their parents.*

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The child with a serious medical illness is at greater risk for developing emotional problems. Unlike a child with a temporary sickness such as the flu, the child with a chronic illness must cope with knowing that the disease is here to stay and may even get worse. Almost all these children initially refuse to believe they are ill, and later feel guilt and anger.

The young child, unable to understand why the sickness has occurred, may assume it is a punishment for being "bad." He or she may become angry with parents and doctors for not being able to cure the illness. The youngster may react strongly against pampering, teasing, or other attention. Uncomfortable treatments, and restrictions in diet and activity may make the child bitter and withdrawn. To help your child deal with and understand the disease you need to give them honest, accurate, and age appropriate information.

A teenager with a long-term illness may feel pulled in opposite directions. On the one hand, he or she must take care of the physical problem, requiring dependence on parents and doctors. On the other hand, the adolescent wants to become independent and join his or her friends in various activities. When a teenager with a long-term illness tries to decrease or stop taking the prescribed treatment without consulting with the physician, this often shows a normal adolescent desire

to take charge of one's own body.

Chronic illness may cause school problems, including avoidance or refusal to attend school. This can increase the child's loneliness and feeling of being different from other youngsters. It is important for parents to help a child maintain as normal a routine as possible. They should respond not only to the child's illness, but to the child's strengths. Child and adolescent psychiatrists know that if isolated or overprotected, the child may not learn to socialize or may have difficulty separating from parents when it is time to be involved in school or other activities outside the home. It is often helpful for the child to be in contact with others who have successfully adjusted to living with a chronic illness.

In their prolonged periods of hospitalization and/or rest at home, children may develop excellence in a hobby or a special talent such as art, model airplanes, or a foreign language. They may also try to learn as much about their illness as possible. Such activities are emotionally healthy and should be encouraged.

Children with long-term illnesses are often treated by a team of medical specialists. This team often includes a child and adolescent psychiatrist, who can help the child and family overcome problems and develop emotionally healthy ways of living with the disease and its effects.



## The Child And Adolescent Psychiatrist

The child and adolescent psychiatrist is a physician who specializes in the diagnosis and the treatment of disorders of thinking, feeling and/or behavior affecting children, adolescents, and their families.

The child and adolescent psychiatrist uses a knowledge of biological, psychological, and social factors in working with patients. Initially, a comprehensive diagnostic examination is performed to evaluate the current problem with attention to its physical, genetic, developmental, emotional, cognitive, educational, family, peer, and social components. The child and adolescent psychiatrist arrives at a diagnosis and diagnostic formulation which are shared with the patient and family. The child and adolescent psychiatrist then designs a treatment plan which considers all the components and discusses these recommendations with the child or adolescent and family.

An integrated approach may involve individual, group or family psychotherapy; medication; and/or consultation with other physicians or professionals from schools, juvenile courts, social agencies or other community organizations. In addition, the child psychiatrist is prepared and expected to act as an advocate for the best interests of the child.

Child and adolescent psychiatrists can be found through local medical and psychiatric societies, local mental health associations, local hospitals or medical centers, departments of psychiatry in medical schools, and national organizations like the American Academy of Child and Adolescent Psychiatry and the American Psychiatric Association. In addition, pediatricians, family physicians and school counselors can be helpful in identifying child and adolescent psychiatrists.



# Looking to the Future in BPI Illustration

*If you have been receiving UBPN's Outreach magazine, you've probably noticed our quaint black and white illustration we've used for years, illustrating the brachial plexus, its injuries and repairs. One of UBPN's dreams has been to upgrade our illustrations for the magazine and for our web site. We have been blessed with a generous donation of both from High Impact medical illustrators. You can see two of the illustrations below.*

*What makes this story even more compelling is how one of the owners became personally motivated to assist with birth injury litigation support.*

It has taken High Impact and its co-founders Brice Karsh and Doug Arnest, childhood friends for over 20 years, the last 10 years to become one of the dominant players in the litigation support industry. But like many journeys, the road to success was paved with hurdles and much blood, sweat and tears have been spilled along the way.

After spending a few years carefully growing High Impact's parent company Forensic Medical Reviewers, Inc., a medical-malpractice expert witness referral company, Brice thought he could offer his existing clientele additional products and services. Thus, with the help of his good friend Doug, High Impact began in a garage in Vail, Colorado as the two set out to take make their mark in the litigation support industry.

Their "big break" came sometime in their fifth year when they were asked

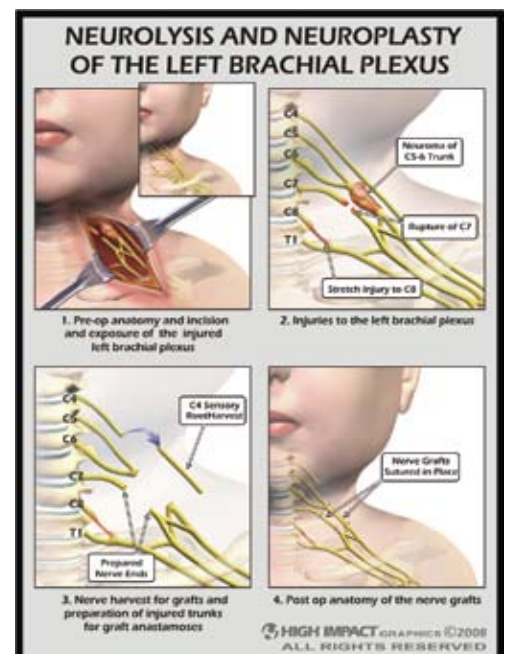
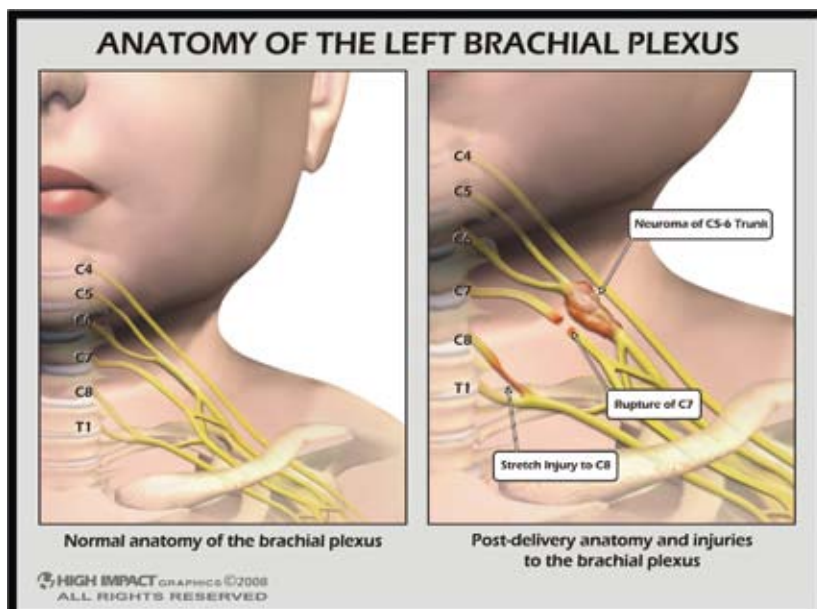
to think about how to create a ground breaking digital presentation interface to show fetal heart tracings for hypoxic brain injury cases. With an almost limitless budget and several months before having to meet the deadline, the High Impact DigiStrip digital fetal monitor presentation system was born. The first case the system was ever used on resulted in a record \$27 million jury award and the rest as they say is history. From that point, the High Impact Team became known as the visual experts for "baby cases" all over the country and with that distinction came continual access to the premier experts in the field of OB/GYN. As a result, other types of injured infant cases were sent to High Impact for ideas on how to best present them visually.

This natural progression included the Shoulder Dystocia/Brachial Plexus cases, which happen to hold a special

place in Brice's heart as his own son suffers from a permanent Erb's Palsy injury from birth. Now almost 15 years old, Brice's son Brandon has had a better recovery than many but still suffers the emotional and physical effects of not being able to properly use his right arm.

"Brachial Plexus injury cases are the most emotional cases I work on because I deal with the injury on a personal level everyday with my son and the often unspoken truth is that the vast majority of these injuries are 100% avoidable," Brice states. "Every animation we create is a step forward in educating the public on the true mechanics of these injuries as well as helping obtain justice for these children who should never have to live with such a handicap."

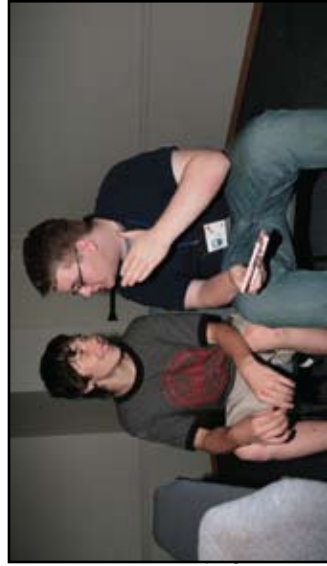
Please visit [www.highimpact.com](http://www.highimpact.com) for more information regarding forensic and birth trauma animation.



# UBPN Annual Report

*Fiscal Year July 1, 2007 - June 30, 2008*

	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Total</u>
<b>Revenues and other support</b>			
General Donations	7,594		7,594
CAMP			
Wristbands/Magnets/Tree		947	947
Endowment		1,200	1,200
Registration		14,653	14,653
General Donations		1,055	1,055
CAMP Total		17,855	17,855
Outreach		0	0
<b>Total Revenue</b>	<b>7,594</b>	<b>17,855</b>	<b>25,449</b>
<b>Expenses</b>			
General Office			
Supplies	(1,192)		(1,192)
Phone services	(616)		(616)
D&O Insurance	(1,405)		(1,405)
BOD Travel	(2,486)		(2,486)
Bank Charges	(228)		(228)
<u>Subtotal</u>	<u>(5,927)</u>	<u>0</u>	<u>(5,927)</u>
Outreach			
Outreach Printing/Mailing		0	0
Outreach Mailing		(185)	(185)
Subtotal	0	(185)	(185)
CAMP Expenditures			
Camp Facilities		(25,719)	(25,719)
Camp Sponsorships		(540)	(540)
Camp Supplies/Crafts		(1,511)	(1,511)
Camp Mailings		(191)	(191)
Camp Events		(977)	(977)
Subtotal	0	(28,938)	(28,938)
<b>Total Expenditures</b>	<b>(5,927)</b>	<b>(29,124)</b>	<b>(35,051)</b>
<b>Change in Net Assets</b>	<b>1,667</b>	<b>(11,269)</b>	<b>(9,602)</b>
Net assets at beginning of year	17,399	10,687	28,086
Net assets at end of year	19,066	(582)	18,484



## United Brachial Plexus Network's Awareness Goals and Direction

- To increase awareness of brachial plexus injuries among the general public.
- To increase the participation and involvement of the medical community for awareness.
- To increase the participation and involvement of the brachial plexus communities to reach out to neighboring communities.
- To make a sincere and conscious effort to reach new families/individuals affected by brachial plexus injuries.
- To enhance our community involvement and sense of personal belonging.

# Obstetrical Brachial Plexus Injuries:

## *Information for Parents*



**United Brachial  
Plexus Network, Inc.**

1610 Kent Street  
Kent, OH 44240

Toll Free or Fax: 1-866-877-7004

Web Site: <http://www.ubpn.org>





## Future Treatment

It is never too late to seek a second opinion. You may have options available to you whether they are surgical or therapeutic. Seeking treatment could improve your quality of life. The UBPN web site provides a medical resources page, which can assist you find a local provider.

Along with the physical symptoms, many people also carry emotional symptoms. The United Brachial Plexus Network has message boards available for support. You can meet and exchange information with others with injuries, provided a common bond and finding others who can relate to your daily challenges.



### People with obstetrical brachial plexus injuries can do anything that they set their minds to...

An obstetrical brachial plexus injury is not a limitation, it is a creativity instigator. Having an injury does not mean that you can not participate in the same activities as your peers; it simply means that you must be creative enough to find a different way to perform the same activity.

Many people with brachial plexus injuries find themselves hiding their injuries and feeling down. You should never have to do this! Brachial plexus injuries are nothing that we asked for so why be ashamed of it? We can use our injuries for good if we do not hide them...

Educate friends and family and even random strangers so we can stop this preventable birth injury!

One challenge you may find is that eventually you might begin to see overuse symptoms in an unaffected or less affected arm. Along with the symptoms of overuse (pain is the big one) come secondary injuries.

Secondary injuries can include but are not limited to: Osteoarthritis, chronic pain, Scoliosis, spinal rotation, Horner's Syndrome, Spinal Stenosis, Carpel Tunnel Syndrome, nerve damage to "good arm," medial and lateral epicondylitis (tennis elbow and golf elbow), cubital tunnel syndrome, tendonitis, and a loss of range of motion.

Not everybody will have these secondary injuries. However, seek treatment when possible if you do begin to see signs of these injuries to prevent further damage and possibly gain relief from symptoms.



# Two Little Monkeys Raises Awareness and Funds for Brachial Plexus Injuries

By *Andrea Metzler*

Our daughter Allison loves the Wonder Pets or Wonder Peps, as she calls them. She's very fond of the letter P, beginning and ending many of her words with it. If you ask her to count to 10, it will sound something like this, "one, pooh, pee, pour, pive, six, peven, eight, nine, pen!" She also claims that her best friend is Sportacus (from the show Lazy Town) and cheers for herself while climbing around at the park, "Go, Ally, Go! Go, Ally, Go!" Ally enthusiastically embraces swimming, running, jumping, soccer, her friends, family and kitty cats – she's your typical crazy little two year old. Allison also suffers from an obstetrical brachial plexus injury affecting her right shoulder and arm.

An MRI at six months of age indicated the malformation of Allison's glenohumeral joint and the consequent need for immediate surgical intervention. We had seen six teams of doctors from all over the country but now we had to make a major decision. It was time to choose the team we felt most comfortable with and whose surgical strategy we thought appropriate for our daughter. We chose Dr. Scott Kozin and his team at The Philadelphia Shriners

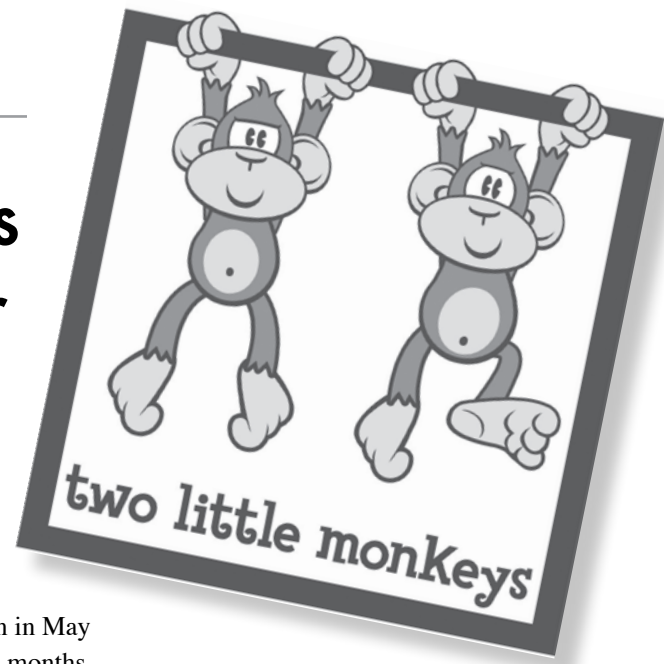
Hospital for Children. Dr. Kozin performed an anterior capsule release (ACR) on Allison in May of 2007, she was just shy of nine months old.

Shriners Hospitals provide specialized pediatric care free of charge to children under the age of 18. Their number one priority is improving the lives of children affected by orthopedic conditions, burns, spinal cord injuries and cleft lip and palate. They rely solely on donations to fund their mission. As we became more familiar with Shriners and the incredible impact they have on

the children they treat, we knew that we wanted to give back to them. Just as critical though, we wanted to find some way to make an impact in the BPI community – for the families currently struggling with the injury, for the families with injured newborns, and to hopefully raise awareness in the general public about

this injury. Thus, we began thinking of ways to accomplish our goals.

Two Little Monkeys "went live" in February of 2008. We had our first fundraising event in March, 2008, in which we raised a little over \$10,000 for the Brachial Plexus Team at the



Philadelphia Shriners Hospital. We have been going strong since then, having sold over 500 shirts and initiating our Monkey of the Month feature on the Two Little Monkeys website. This section of the site highlights a new child and his/her family every other month. We hope that this section will not only allow contributing families an outlet in which to help others affected by OBPI, but also assist families who continue to struggle with this injury in their quest for information and support through the experiences of others.

We are planning to add two new features to [twolittlemonkeys.org](http://twolittlemonkeys.org) in the upcoming months. These include several new T-shirt designs and the formation of the Team Monkey running/walking club. Team Monkey will raise money for Shriners and awareness about OBPIs through participation in races, walks and events.

Please visit [twolittlemonkeys.org](http://twolittlemonkeys.org) and read more about our organization, Shriners Hospitals and the children participating in Monkey of the Month. Also, consider buying a T-shirt for yourself, your family, or as a gift. Help us raise money for Shriners Hospital and raise awareness about Obstetrical Brachial Plexus Injuries. Working together, we can make a difference... as Ally and the Wonder Pets would say, "What's gonna work? Team Work!"



Allison models a two little monkeys t-shirt.

# Scaling the Mountains of Adversity

*All of us have obstacles to overcome; some are just bigger and more obvious than others. Paul Fejtek of Newport Beach, CA is systematically conquering obstacles by climbing the highest mountain peak on each of the world's seven continents. Paul has successfully climbed five of these "Seven Summits" so far. The completion of the remaining two would place him amongst only 230 of the most amazingly fit and determined people in the world who have actually climbed all of the Seven Summits. What makes this daunting feat even more awesome for Paul is the fact that he was born with a brachial plexus injury, greatly affecting the strength and mobility of his right shoulder and arm.*

*Recently back from his latest expedition to the top of 16,000-foot Carstensz Pyramid on the Oceania continent, Paul writes about his quest and some of the challenges he faced both on the mountain and growing up with an OBPI:*

Carstensz Pyramid has always been one of those mountains that intimidated me. Not because of the altitude or weather conditions, I've been to almost 23,000 feet in the Andes and endured 40-below-zero temperatures and hurricane-force winds on Denali. What concerned me about this mountain located in Papua, Indonesia is the fact that it is by far the most technically difficult of the Seven Summits. Even more so than the formidable Mt. Everest! And here I am contemplating climbing it with one good arm.

I grew up with a deeply instilled notion that anything is possible, and from a very early age my mom reinforced this concept and helped prove it to me. She enrolled me on the swim team, signed me up for drum lessons, taught me how to water ski, you name it. Didn't anybody tell this lady my arm doesn't work like all the other kids?! Nonetheless, I managed to get through the challenges my BPI posed and with the constant encouragement and support from my mother, these experiences built my confidence and "can-do" attitude that positively affects every aspect of my life today.

The same bullheaded determination and creativity that helped me figure

out a clever way to hold onto the water ski rope at seven years old, is also what helped me get to the summit of Carstensz Pyramid at thirty-seven. Because of the lack of dexterity and gripping strength of my right hand, I needed to figure out a way to get myself up the near vertical rock faces I would

be encountering. All of my painstaking efforts to get to the top of certain pitches at the indoor rock climbing gym failed miserably. Until I came up with an idea for a device that I now call "The Claw."

Quite simply this is a dual-pronged coat hook from Home Depot attached to the metal plate of a simple wrist brace. After assembling this makeshift piece of equipment in my garage, I enthusiastically returned to the climbing gym. Amazingly, The Claw held my weight as I hooked it onto one handhold after another and the next thing I knew, I was at the top of the same pitch that previously seemed impossible for me to climb.

After some field testing on real rock walls, and a few modifications to The Claw, I was ready to fly halfway



around the world to successfully tackle Carstensz Pyramid! For more details, photos, and video about this adventure please visit: [www.fejteksevensummits.blogspot.com](http://www.fejteksevensummits.blogspot.com).

Shortly after returning from a big mountain quest such as this, and long before I have a chance to bask in the glory of my recent accomplishment, I'm usually asked a familiar question: "So what's next?" Although I haven't set a date for the remaining two mountains; Vinson Massif in Antarctica and the 29,000-foot big daddy Mt. Everest, I am staying in shape just in case. I'm currently training to race in an Ironman triathlon (2.4 mile swim, followed by 112-mile bike, and a full 26.2-mile marathon.) I've completed 15 lesser-distance triathlons over the years which I view as good aerobic endurance training that serves me well in the thin air environment of high-altitude mountaineering.

Don't let anybody (yourself included) tell you that can't do these or other things better suited for people with two good arms! Refuse to accept a life with limitations, and remember that



anything is possible! Allow me to cite the recent Pacific Coast Triathlon as a final example.

A certain individual with an OBPI (me) participated in this event along with 96 very fit and fully functional men in

my age group. I'm sure that 71 percent of these competitive men would be a bit surprised to learn that they crossed the finish line after the guy with the short arm that doesn't work like all the other kids!

*When Paul Fejteks isn't scaling mountains or training, he can be found at Hunter Wise Financial Group in Irvine, CA (<http://www.hunterwise.com>) where he is a Managing Director of this specialized investment bank that provides corporate financing, merger, acquisition, divestiture and advisory services. Paul and his wife, Denise, are actively involved with the Challenged Athletes Foundation which provides grants for specialized equipment and prosthetic limbs for those with physical challenges. Denise is not only a loving and supportive wife, but also Paul's climbing partner who has been by his side in good weather or bad, to the summit of all of their big mountain adventures.*

## Consider a Donation to UBPN, Inc.

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

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 would like to make a donation to UBPN, Inc. of the following amount:
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City: _____	<input type="checkbox"/> \$15 <input type="checkbox"/> \$25 <input type="checkbox"/> \$50 <input type="checkbox"/> \$100 <input type="checkbox"/> Other: \$ _____
State: _____ Zip: _____	<input type="checkbox"/> Please contact me about estate and planned giving.
Phone: _____	Please make my donation in honor of:
E-mail: _____	Thank You! You will receive confirmation of your donation by mail.
I would like my donation to go toward: _____	<b>UBPN, Inc., 115 Fawn Lane, Blanchester, OH 45107</b>



# First Support Event Held for Cameron's Smile Group

The 1st annual Missouri Brachial Plexus Family and Friends picnic was held on October 11, 2008. It was a great success. About 60

people including 11 injured attended the event at Creve Coeur Park in St. Louis, Missouri for an afternoon of food, information, games and support. Most of the families had children that had never met "anyone else like them."

Dr. Gregory Borschel, MD, a plastic surgeon and brachial plexus

palsy specialist at St. Louis Children's Hospital was one of the key speakers. His knowledge and expertise with these injuries provided many families with valuable information presented in a concise and informative way.

Mercy's Child band graced the audience with their live performance and Juli Darlington with First Steps Missouri provided information about their therapy program and crafts for the kids.

Ms. Emma Preuschl, 2008 US Paralympic Silver Medalist in Rowing



Guest speaker, Emma Preuschl, and OBPI Zoe.

attended the picnic with her mother, Mrs. Lynn Preuschl. Emma sustained a brachial plexus injury to her left arm at

birth. This was her first time meeting any other family affected by this injury. Tears flowed as she told her story. Emma's mother spoke about her journey with a daughter with a brachial plexus injury. Every mother of a child with a bpi understood and held on to each word. Their life stories provided the families with hope for the future.

After the speakers came the fun! Once Upon A Bash, a St. Louis-based company that provides designer children's parties and character visits, had activities for the kids while the parents listened to the speakers. Elmo and Dora made a surprise appearance for the kids and all the kids at heart!

Family and friends gave generously to help make this event a success. Two Little Monkeys, a company that donates proceeds from its t-shirt sales to benefit the Shriners Brachial Plexus Palsy Team in Philadelphia (see page 17), donated t-shirts to every attendee with a brachial plexus injury!

The picnic was a kickoff to Cameron's Smile Brachial Plexus Palsy Support Group which meets bi-monthly in St. Louis. The group will have two events yearly, a benefit dinner in the spring and an annual BPI picnic in the fall. For more information about the support group, please email Anise Bragg at [stilbpi@yahoo.com](mailto:stilbpi@yahoo.com).



Elmo and Dora were visitors to the Cameron's Smile Support Group event, held in October, 2008.

## Lemonade Stand Benefits BPI

*More than \$200 was raised for UBPN by Sema, Evan and Collette Mendelman.*

When we first started announcing that Evan was going to have a lemonade stand, people asked him if he was going to buy a toy with the money. He would excitedly respond "Noooo. We are going to donate it to help others!" He kept his enthusiasm throughout the summer. We made signs announcing that all the proceeds from the lemonade stand was to benefit a nonprofit. We also had previous issues of *Outreach* magazine and prevention brochures on display to increase awareness.

As cars drove by Evan and Collette would scream "Fresh lemonade! Lemonade!" while waving their arms in the air with excitement.

Evan told each of his customers that there was a secret ingredient in the lemonade. He asked what they thought it was as he poured the lemonade and put a sprig of mint in the cup! It took most of his customers several tries to guess mint but it put a smile on all of their faces. There was much excitement about donations, too, and many "Mommy! Mommy! He made a donation!!!!!!" exclamations were flying around.

It was a fun and rewarding experience for all of us.





# In Memoriam: Liz Black Finney

*By Courtney B. Widzinski*

*"I was walking along a street in London, on my way to start a new job, and I had to walk past a building site to get to where I was going. As I started to pass by, a slab of concrete fell over, off the site, and hit me full in the chest, pushing me to the pavement... I have to admit that now, 9 years down the line, I do not miss my old life at all. Luckily, I was in a position to be able to travel, and this is what I did for the next few months." Lizzyb (2002)*

*Liz Black-Finney, passed away on October 16, 2008, leaving all of us who knew her totally grief stricken. Lizzyb as many knew her on the message boards was a bit of a pioneer for BPI.*

*Liz was well known to a great number of people through the message boards at UBPN as well as her own message boards in the UK. Liz formed the charity TBPI UK about six years ago for support in the UK. Her work supporting those with the injury went worldwide. Liz, along with her husband Neil and fellow charity trustees, has worked tirelessly helping people with a TBPI for many years. She helped to raise the awareness of the injury and treatments available. Liz improved and saved the lives of many people with her help and advice. She had a true "can do" attitude with everyone and everything she came in contact with despite her injury.*



*"Liz saw me through the DARKEST times in my life and told me to 'get on with it' and I did! She had so much knowledge and was always willing to share it! She has been an inspiration to more people that she could ever imagine!"*

*— Liz's Yankee daughter,  
Courtney (MI)*

*"I could tell immediately she was something special. Her outlook, her humor, her caring attitude towards those of us that were new to this but also the kick up the arse attitude that refused to let the injury get the better of her or others."*

*—Marc (UK)*

*"Liz was a friend, an inspiration, a support, a dynamo in a small package, and a bloody good laugh. The world is suddenly and emptier place."*

*—Jacko (UK)*

*"Her warmth and sense of humor were evident from the start - it was impossible NOT to like Liz, she was funny, witty, warm and good company. She was inspirational and dynamic - in a very laid back sort of way!"*

*—Kazza, Gazza, Mike and Gav (UK)*

*"She was like a sister to me and we helped each other through the worst of times. I think we both managed to take sadness and depression and turn it into something inspiring for others."*

*—Mike (Canada)*



*"People of Liz's caliber are rare. She was someone, to whom, life should have dealt better cards... but in her time she achieved more in the years since her accident than those who are in a position to make a difference, ever have."*

*—Yeti (UK)*

*Liz was like FAMILY to me in fact better, when I was badly depressed and needed to talk to someone, I didn't talk to my family because they didn't want to hear my problems. How kind is that?*

*—Daveo (Spain)*

*She was a true inspiration to others, by just being Liz. I know the TBPI foundation will go on without her, it had bloody well better or she'll kick yer arses. But there will never again be anyone with her sheer force to inspire trauma or birth injured.*

# Hyphenated History.... continued from page 11

He theorized that this injury is not the result of forceps use and shifted blame to an obstetric technique in which the physician places his fingers under the armpits of the infant to extract it from the birth canal.<sup>12-15</sup> He cited four cases of birth palsies involving the upper roots of the brachial plexus as the basis for his etiologic finding: “In this kind of paralysis of the upper limb from obstetrical manipulations, the arm falls motionless along the side of the body, and is rotated inwards; the forearm remains extended, but the movements of the hand are preserved.”<sup>15</sup> In this commentary, he precisely described the most common form of brachial plexus birth injury, which now shares his name.

Duchenne used electrodiagnosis to understand the severity of the paralysis—a precursor to using electromyograms in patients with brachial plexus injuries to determine the extent of nerve damage. Offering a chance of recovery to patients who had no chance before, Duchenne advocated electrotherapy as treatment and reported success in some cases. Although Duchenne’s interest in infantile obstetrical paralysis was prognostic and therapeutic, he recognized the importance of an anatomical understanding of the injury: “I leave to others the study of the anatomical cause, and to say why in these cases the same muscles (deltoid, infraspinatus, biceps, and brachialis) are paralyzed.” That someone was Erb.

Erb’s medical breakthrough in understanding brachial plexus injuries resulted in his detailed study of the

anatomical structure, as Duchenne had suggested, which proved crucial for treatment purposes. In “Über Eine Eigentümliche von Lahmungen im Plexus Brachialis” (“Concerning an Unusual Localisation of Brachial Plexus Paralysis”) (1877), Erb described four adult cases of upper extremity palsy in which the same muscles—the deltoid, biceps, brachialis, and sometime infraspinatus—were paralyzed. From his observations, he concluded that the lesion site could not be where the four nerve branches (axillary,



Duchenne’s photograph of a 6-year-old boy with typical shoulder and elbow presentation caused by obstetrical palsy, now known as Erb-Duchenne brachial plexus palsy. Originally appeared in Duchenne’s *Album de photographies pathologiques complémentaires du livre intitulé de l’électrisation localisée*. Paris, France: Baillière; 1862.

musculocutaneous, radial, medial) that control these muscles have already separated from the brachial plexus. Examining the supraclavicular region, he determined from experimentation with electrical stimulation which nerve roots controlled the muscles consistently injured in the common birth palsy previously described by Duchenne. Erb localized the lesion site at C5 and C6, now known as Erb’s point. Erb’s insightfulness

proved crucial in understanding palsies associated with brachial plexus roots, an area previously ignored.<sup>16</sup>

Because Erb discovered the specific roots associated with brachial plexus palsy, he disagreed with Duchenne’s theory that the cause is the physician’s insertion of fingers into the infant’s armpit. Given that the lesion was in the upper region of the brachial plexus, Erb suggested that the Prague maneuver was the most likely cause, which involved the physician’s grasping the infant’s neck in an act of forcible extraction during childbirth, putting pressure on the fifth and sixth nerve roots of the

brachial plexus. Erb noted paralysis of the infraspinatus as an important clue in determining damage to the brachial plexus injury in newborns and advised that this mechanism be considered in further attempts to understand the injury.

Duchenne’s etiologic finding combined with Erb’s anatomical detective work introduced the world to neonatal brachial plexus injury, an area nearly ignored before their time. While Duchenne demonstrated adherence to a pioneer spirit in practicing medicine, Erb modeled the successful convergence of anatomical expertise and experimentation. Their combined efforts led to identification of the most common form of brachial plexus palsy, known today as Erb-Duchenne palsy, which was then presented to the medical community.

Despite advances in diagnosis and treatment, this clinical entity persists to the present day. Erb-Duchenne brachial plexus palsy occurs in up to 2 of every 1000 live births. Known risk factors include shoulder dystocia, large gestational size, maternal diabetes, prolonged labor, and difficult instrumental delivery. Electrical stimulation is still used to diagnose and treat the injury. However, treatment options, such as nerve grafts and transfers, muscle releases and transfers, elbow and shoulder reconstructions, joint fusions, osteotomies, and use of Botox, have improved outcomes for patients in ways not possible in the eras of Duchenne and Erb. In the spirit of these astute clinicians, clinical researchers continue to challenge themselves to change the implications of the Erb-Duchenne hyphenated eponym from something that can result in lifelong functional impairment to what it should be—an interesting bit of hyphenated-history.<sup>17-19</sup>

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## Tracking Incidents... continued from page 9

This difference in injury rate for males was supported by Kline et al (Neurosurgery. 51(3):673-683, September 2002). He also indicated that the incidence of such injuries and the indications for surgery have increased during recent years.

Given the circumstances that result in a TBPI, prevention efforts are not a realistic method to work towards their reduction. Perhaps a mandatory training for individuals who participate in recreational motor vehicle hobbies such as motorcycles and snowmobiles could have an impact in the overall rate, it is likely that such efforts would not be greatly supported.

The biggest need however is that the individuals who do sustain a TBPI be given all the information about treatment options as soon as a diagnosis is made. It needs to be more universally recognized that this injury is devastating to the individual, emotionally, financially, and physically. These individuals may need information on pain management, vocational retraining, emotional support, and the methods for acquiring help with the loss of income and the ensuing life change.

It is only time when medical science will find a way to restore loss function in patients with peripheral nerve disorders such as TBPI. Until then, UBPN strives to be a resource for the TBPI community.

## Personal Fundraising Made Fun and Easy!

Thinking of hosting your own fundraiser for UBPN? For a fun and easy way to invite friends and family to donate, try Firstgiving (<http://www.firstgiving.com/>). You can e-vite your supporters and track your fundraising goal online. You'll have your own fundraising web page where you can add photos, videos and more! Funds are automatically forwarded to UBPN if you select UBPN as your fundraising beneficiary. It is a fun and easy way to let your family and friends support the cause!



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## Awareness Items For Sale!

### UBPN Gund Stuffed Puppy Dog – \$20

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



### Ribbon Car Magnet – \$5

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



### Reaching Out 4 BPI Bracelet – \$4

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



### UBPN Jewelry Ribbon Pins – \$5

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



### UBPN Ribbon Pins – \$10 for 20 pins

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



### Zipper Pulls – \$1

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

