Outreach

Spring 2010
Issue #24

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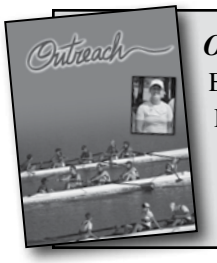

On The Cover:

Emma Preuschl of Indianapolis, Ind. is a 2008 Beijing Paralympic Silver Medalist in rowing. She rowed for Purdue University in college and is currently training for the 2012 Paralympics in London.

Read more about Emma on page 14. *UBPN would like to acknowledge that the Spring 2008 cover photo from Camp UBPN 2007 was courtesy of Ryan McClune We appreciate his contribution to Outreach.*

OUTREACH is a publication of the United Brachial Plexus Network, Inc.

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UBPN, Inc. 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. Outreach is produced on a volunteer basis.

President's Letter: A Fresh Perspective for UBPN

By Rich Looby, UBPN President


UBPN President Rich Looby

The United Brachial Plexus Network is the single best source of information and support for those who are living the injury, and for parents and family members who are looking to find the best care for a loved one. Our message boards are utilized daily. We receive email inquiries daily from individuals from around the USA and even more frequently internationally. More often than not, they are seeking support and additionally guidance to facilities where they can receive the care they need. For this reason alone, UBPN is vital for the brachial plexus community.

The hard work required for this organization to survive is done by volunteers. Unpaid volunteers who maintain a civil messageboard, run awareness programs, run prevention efforts, scan websites for accuracy, answer emails, publish documents like Outreach and pamphlets for distribution. Not only do these volunteers do a magnificent job on these tasks, they do them on a shoestring budget, frequently contributing money and resources in addition to their time. That is how much they believe in the mission of UBPN.

Club Narakas

Recently two UBPN board members traveled to Luxemborg to attend the Narakas meeting. Club A. Narakas was designed in honor of Algimantas Otonas Narakas (1927-1993), a pioneering surgeon for brachial plexus intervention. Their attendance was partially funded by UBPN, however a large portion was personal contributions. Kim West and Tanya Jennison were able to meet a large contingent of highly respected surgeons who are dedicating their practice of medicine for the care of our community. It was a rare opportunity to let these surgeons know about UBPN, and how we can work together to best help our community.

Thank You to a 10-Year Volunteer

We need more volunteers who have the passion for the UBPN mission. After ten years of service, Sabrina Randolph is moving on. Sabrina has served as UBPN treasurer since its inception. During this time, Sabrina saw UBPN become a true 501c3, maintained our books and completed our taxes year in and year out. Without this function, UBPN would not have been able to provide the services that have been so valuable to our community. UBPN is surely going to miss her valued contributions but we want to wish her the most sincere successes in her career and happiness with her growing family. We are thrilled that Julie Furrier of Massachuests has agreed to take on this vital role.

Spotlight On Continues to Progress

Our signature PBS piece, Spotlight On, is progressing well. One of the most significant opportunities to bringing prevention and awareness to the general public, Spotlight-On may very well be the point we can reference as turning the tide in favor of safe birth practices.

Fundraising is Our Priority

To be able to continue strong programs like Spotlight On and this Outreach, and to continue to provide a safe supportive environment for the communtiy through our website, we need to continuously raise monies to fund them.

In as much, we are in need of experienced volunteers with skills in fundraising. Grant writers, planners, and those with general fundraising skills would all be warmly welcomed to our team. If anyone has experience in this realm, or have ideas that you could help bring to reality, UBPN would be most grateful to discuss your skills and suggestions.

UBPN BOD Meets

The UBPN Board of Directors convened in Chicago for our annual meeting. We were able to discuss our programs and refocus our efforts on areas our community would best benefit. In part, we identified future committments, reorganized some priorities and reassigned members to different committees of preference.

Claudia Strobing has volunteered to be Camp Coordinator for UBPN Camp 2010. She and her volunteer team are busy organizing speakers and activities. You can read more about the location on page 5.

UBPN does have several board positions that will become vacant in the next year. We encourage anyone interested in serving on the board, to contact myself or another member of our board. We can provide you with additional details and what the position entails.

UBPN continues to provide quality programs and services to the BPI community. We hope that as individuals and family members you are able to appreciate the work of our board and volunteers. As always, comments, suggestions and input are always welcomed. Even more importantly, if you have any skills that you could volunteer towards UBPN's efforts we would encourage you to contact us at info@ubpn.org.

Rich Looby

Rich Looby
President UBPN

Thank You to UBPN Board Members For Service

Courtney Widzinski served on the UBPN Board of Directors for five years. She recently stepped down to take on a new challenge – motherhood.

Courtney, newborn Jeffrey, and Jeff Widzinski and their dogs, Harley and Lucy

"It was a tough decision for me to step down from the Board of Directors. Since taking on an active role with UBPN in 2004, my life has taken on many changes and all for the better! I was married in 2008, my husband and I bought a house in September 2009 and, I'm proud to announce, Jeffrey Michael Jr. was born (via c-section) December 15, 2009 weighing 7lbs 7 oz. and 100% HEALTHY! With all of these changes, I needed to take a step back and focus on my family life, not my arm!

I thought my life was OVER after my accident in 2001. My thoughts were far from the truth. After finding UBPN and joining the board, I connected with so many people who understood what I was dealing with. I was able to help others with this injury. I was able to share my experiences and make a difference. I was able to grow as a person and I made LIFE-LONG friends!

Thanks to everyone involved in taking this organization to the next level! Keep on keepin' on!"

Karen McClune served on the UBPN Board for six years. She became involved after her son, Ryan, was injured traumatically. She also served as Camp UBPN director.

Karen McClune

"Thank you to everyone who made my years on the board positive ones. It has been a joy to watch this organization grow and to see so many individuals become involved, especially the help I received organizing Camp UBPN 2003 and 2005 together. It was fun getting to know all of you. I couldn't have done it alone.

I look forward to seeing new changes and expansion of programs that will further the goals of UBPN. UBPN will always be a part of me and I hope to continue to help those that need support and encouragement.

Last but not least, I want to thank all those who supported Ryan after his accident. It was reassuring to know he had support when he couldn't reach us living so far apart."

Thank you and best wishes to Courtney and Karen.

Free Bracelets Available

Through a special grant from The MedicAlert Foundation, UBPN is able to provide sponsored (free) memberships to all children under the age of 18 referred by UBPN.

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

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

What is provided?

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

Who is Eligible:

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

How to Apply:

- Email Judy Thornberry, UBPN board member, for an application (judy@ubpn.org).
- Fill out the application.
- Include a cover letter that Judy will mail with the application.
- Send the application and the cover letter to the address given by Judy.

Camp UBPN 2010 to be Held Near St. Louis October 8-11

The UBPN Camp Committee is pleased to announce that Camp UBPN 2010 will be held at YMCA Trout Lodge in Potosi, Missouri, October 8-11. You can read more about the Lodge and surrounding area on the web at *http://www.ymcaoftheozarks.org/troutlodge/*

Activities and adventures abound here and fall leaves are sure to be starting to change while at camp. In addition, the facilities include a fitness room, television lounge and wireless internet locations.

Online registration and additional details are available at the UBPN website. In addition, registration forms are available by request from claudia@ubpn.org or by calling UBPN toll-free at 1-866-877-7004.

UBPN's New Web Presence

UBPN recently overhauled the organization's web site. In addition, to a completely fresh look, the message boards, medical directory and the prevention area were all updated.

The message boards now allow you to include an avatar, signatures and the ability to see who is online and in what country members are located. A brand new addition is a chat area to talk live with our many community members.

We hope you will visit the site and take advantage of the many resources now available.

UBPN has also become part of the Facebook Social Network with both an organizational page and a fan site. In addition to Facebook, UBPN also "tweets" with Twitter.

Both social networking tools allow us to bring you immediate information and news vital to those impacted by brachial plexus injuries. Be sure to search for UBPN the next time you are online. Links are also available on the UBPN website.

Find us on Facebook

Brachial Plexus Injury Recovery: Reinnervation

Mark A. Ferrante, MD
Professor and EMG Laboratory Director, Department of Neurology, University of Tennessee Health Science Center, EMG Laboratory Director, Neurology Service, VAMC Memphis, Tennessee

The degree of recovery associated with individual lesions of the peripheral nervous system (PNS) reflects a number of variables, including the type of lesion (e.g., traction injury), the percentage of nerve fibers involved, and the distance between the innervated endorgans (i.e., sensory receptors; muscle fibers) and the lesion, as well as the degree of connective tissue involvement. These same concepts apply to recovery from brachial plexus injury. This discussion first reviews nerve fiber anatomy, nerve fiber injury, and the various methods of reinnervation. An application of these concepts to brachial plexus injury follows. An abbreviated discussion of obstetric brachial plexopathy concludes this manuscript.

NERVE FIBER ANATOMY

The human nervous system includes the central nervous system (CNS), which consists of the brain and spinal cord, and PNS. The PNS functions as an intermediary structure between the CNS and the environment. The PNS provides environmental information (sensation) to the CNS and enables the CNS to act on the environment (movement). Sensory neurons located between the vertebral bodies of the spinal column convey sensory information to the CNS through cytoplasmic extensions (sensory axons) that innervate sensory receptors located throughout the skin and joints of the body (Figure 1). In a similar manner, motor neurons within the substance of the spinal cord project motor axons that innervate skeletal muscle fibers (Figure 1). Once the motor axon enters the substance of the muscle, it arborizes into a large number of terminal branches, each of which innervates a single muscle fiber. Thus, each motor neuron controls a larger number of muscle fibers. The ratio of the number of muscle fibers innervated by an individual motor nerve fiber is termed the innervation ratio. This ratio reflects the complexity of the movements executed by the particular muscle. Muscles with more dexterity (e.g., finger muscles) have lower innervation ratios than those requiring little dexterity (e.g., calf muscles).

Some axons are coated with myelin. Myelin increases the speed of conduction of the electrical impulses traveling along the nerve fiber. Axons with a myelin coating are referred to as myelinated axons, whereas those without such a coating are termed unmyelinated axons. A nerve fiber consists an axon, its myelin coating (when present), and all of the other cellular wrappings surrounding it (e.g., Schwann cell; basement membrane). The sensory and motor nerve fibers constituting the PNS are grouped together as they travel toward the skin receptors and muscle fibers. These collections of nerve fibers intermingle, exchange nerve fibers, and separate as they advance peripherally (centrifugally). This nerve fiber exchange accounts for the various structures of the PNS, from proximal to distal: the roots, plexuses, and named nerves. The nerve fibers innervating skeletal muscle tissue are large-diameter, myelinated fibers, whereas those innervating sensory receptors vary with the type of sensory information conveyed. The larger-diameter sensory nerve fibers conveying proprioception (the awareness of one's body orientation in space), vibration (rhythmic stimulation), and touch (superficial, non-painful stimulation) are myelinated, whereas the smaller-diameter sensory nerve fibers conveying pain and temperature perception are lightly myelinated or unmyelinated.

Nerve fibers are surrounded by connective tissue elements. The connective tissue surrounding the individual nerve fibers is termed endoneurium. Groups of nerve fibers are grouped together into structures called fascicles. The connective tissue surrounding the individual fascicles is called perineurium. These fascicles, in turn, are surrounded by epineurium, the outer wrapping of the various PNS structures.

NERVE FIBER INJURY

Although sensory and motor nerve fibers can be injured in many ways, the clinical manifestations of such injuries are limited to loss of sensation (e.g., numbness) and loss of strength (e.g., weakness). Nerve fiber injuries can be classified according to their severity. The severity of the injury reflects the degree of nerve fiber and connective tissue disruption at the lesion site. The least severe injury involves only the

myelin coatings of the involved nerve fibers, a condition termed demyelination. Since myelin increases electrical impulse conduction velocity, myelin disruption slows it. Since slowed conduction only delays impulse arrival by a few milliseconds, mild degrees of myelin disruption are not associated with sensory loss or weakness. With greater degrees of myelin loss, however, the electrical impulses are unable to traverse the lesion site, and sensory loss or weakness results. This is termed neurapraxia, and, according to the Sunderland classification, is termed a first degree lesion. Second degree lesions also involve the axon. Because the axon is an extension of the cell body, the portion distal to the site of disruption decays via a mechanism termed Wallerian degeneration (named after Waller for his early work in the middle of the 19th century). With even more severe lesions, the connective tissue elements are disrupted. Third degree lesions involve the endoneurium, fourth degree lesions, the perineurium, and fifth degree lesions, the epineurium. With fifth degree lesions, the nerve fiber and all of its supporting structures are physically separated at the lesion site. In this setting, the two ends retract, leaving a substantial gap between them.

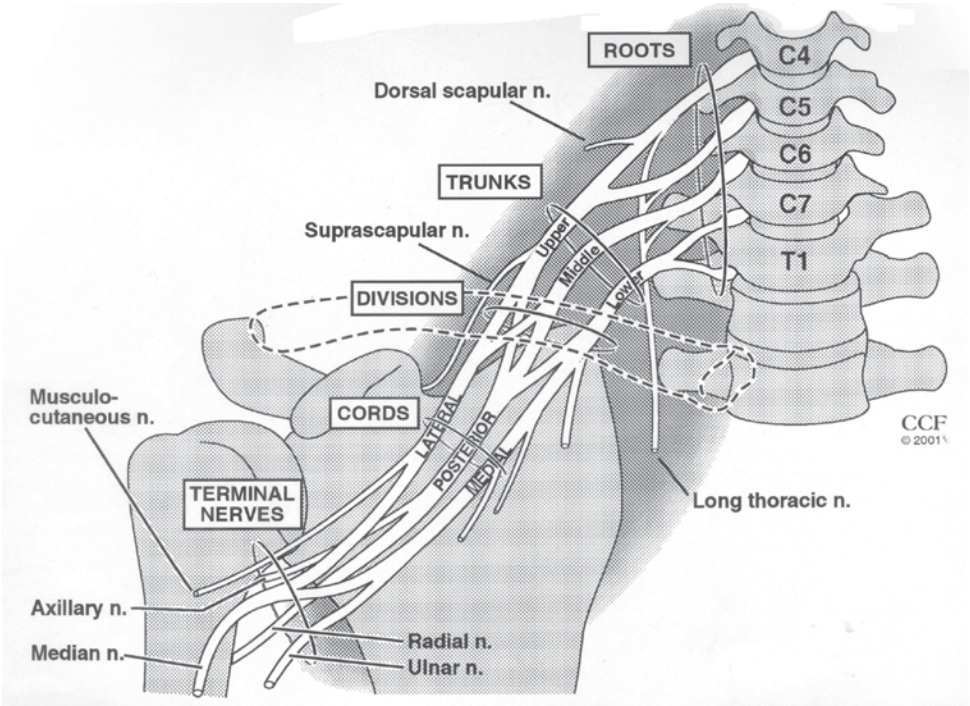

Figure 1. The anatomical relationship between the spinal column and the proximal elements of the brachial plexus. (From Ferrante MA. Brachial plexopathies: classification, causes, and consequences. Muscle and Nerve 30:547-568, 2004, with permission.)

METHODS OF RECOVERY

As previously stated, nerve fibers can be disrupted to varying degrees. Those lesions limited to demyelination have an excellent prognosis because remyelination usually occurs within a few weeks to a few months. Because the new myelin segments are shorter in length and thinner in depth, nerve conduction velocity is slowed over the remyelinated region. However, conduction velocity slowing usually has no clinical correlate (i.e., patients are asymptomatic).

Following axon disruption, however, recovery occurs via reinnervation by one of two processes: 1) proximal axon regrowth and 2) distal axon sprouting. Both of these reparative processes have limitations. With proximal axon regrowth, the disrupted axon grows distally (at a rate of about one inch per month) from the site of axon disruption, attempting to reach its original endorgan. The primary limitations for this type of reinnervation are the degree of connective tissue involvement and the distance to the endorgan. The integrity of the connective tissue elements -- the endoneurium, perineurium, and epineurium -- at the lesion site determines the ease with which regenerating axons can traverse it, the necessary first step in their peripheral advancement. When these structures are intact, all the regenerating axons can readily progress distally. With substantial damage to the endoneurium and perineurium, even with sparing of the epineurium, there may be so much internal scarring that axon regrowth is impossible. When the distance between the lesion site and the denervated muscle fibers exceeds 20-24 inches, reinnervation by axon regrowth usually is unsuccessful because the muscle fibers degenerate after being in the denervated state for more than 20-24 months (i.e., by the time the axons arrive, the muscle fibers have already degenerated). Thus, any time the regeneration distance is greater than 20-24 inches, muscle reinnervation by axon regrowth is unlikely to be satisfactory. Since denervated sensory receptors do not undergo degeneration, there is no time limit for successful reinnervation.

The second mechanism of reinnervation, collateral sprouting, occurs when the terminal portions of unaffected motor nerve fibers send out branches that adopt (reinnervate) the denervated muscle fibers; the adopted muscle fibers are thereafter controlled by the adopting motor neuron. The requirement for reinnervation by collateral sprouting is that the lesion be incomplete. If all of the nerve fibers are affected at the lesion site, then all of them undergo Wallerian degeneration. Thus, there are no distal elements from which to sprout. Recovery through collateral sprouting typically is much faster than axon regrowth. When collateral sprouting is extensive, the adopting motor neurons innervate far more than their customary number of muscle fibers. In this setting, muscles may fatigue relatively easy with sustained use.

In summary, in the setting of axon disruption, the worst prognosis is associated with complete lesions located more than 24 inches from the denervated muscle fibers, whereas the best outcomes follow incomplete lesions located within 20-24 inches of the denervated muscle fibers. When the connective tissue coverings are spared, recovery usually is excellent because axon regrowth is unimpeded. With third degree lesions, the prognosis depends on the degree of connective tissue proliferation (scarring), which blocks the path of the advancing axons. With fourth degree lesions, there is marked internal disorganization of the connective tissue elements and the prognosis for recovery by axon regrowth is poor. In general, fourth and fifth degree lesions require surgical intervention for maximal improvement.

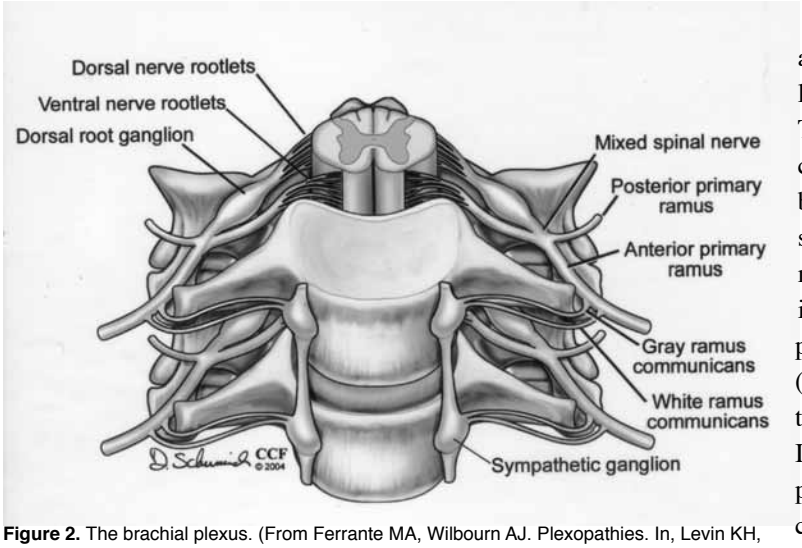

Figure 2. The brachial plexus. (From Ferrante MA, Wilbourn AJ. Plexopathies. In, Levin KH, Luders, HO (eds): Comprehensive Clinical Neurophysiology. Philadelphia, W.B. Saunders Co, 2000, pp 201-214, with permission.)

BRACHIAL PLEXUS ANATOMY, INJURY CLASSIFICATION, AND RECOVERY

The brachial plexus is a triangular-shaped structure that extends from the spinal column to the axilla. It supplies sensation and strength to most of the upper extremity (arm, forearm, and hand) and shoulder and is the most complex structure of the PNS. Its susceptibility to trauma reflects its large size, superficiality, and position between two highly mobile structures (the neck and arm). Like other elements of the PNS, the nerve fibers constituting the brachial plexus derive from sensory and motor neurons. As these fibers travel distally, they intermingle to form the various elements of the brachial plexus: 5 roots, 3 trunks, 6 divisions, 3 cords, and 5 terminal nerves (Figure 2). The roots are named for the vertebral body that lies adjacent to their site of exit from the spinal column. (Note: Because there is not a C8 vertebral body, the C5 through C7 nerve root pass above their respective vertebral bodies, the C8 nerve root passes below the C7 vertebral body, and the T1 nerve root passes below the T1 vertebral body.) The C5 (fifth cervical) and C6 roots combine to form the upper trunk, the C7 root continues as the middle trunk, and the C8 and T1 (first thoracic) nerve roots unite to form the lower trunk. Each trunk divides into two divisions, one anterior and one posterior. The 3 posterior divisions merge to form the posterior cord, the anterior divisions of the upper trunk and middle trunk join to form the lateral cord, and the anterior division of the lower trunk continues as the medial cord. From the cords, several named nerves, referred to as the terminal nerves of the brachial plexus, are derived: the median, ulnar, radial, musculocutaneous, and axillary terminal nerves. In addition to these 5 terminal nerves, other named nerves derive from the brachial plexus along its course.

Brachial plexus injuries can be classified in several ways. Of these, the most clinically relevant approach, which is also the simplest, is based on anatomy. Since the divisions are located behind the clavicle (the collar bone), the brachial plexus can be divided into three smaller plexuses: the supraclavicular plexus (the roots and trunks, which are located above the clavicle), the retroclavicular plexus (the divisions, which are located behind the clavicle) and the infraclavicular plexus (the cords and terminal nerves, which are located below the clavicle). This classification scheme has considerable clinical utility, both diagnostically (e.g., supraclavicular elements are more often affected by traction injuries, such as obstetric palsies) and prognostically (e.g., infraclavicular lesions tend to have better outcomes). In general, supraclavicular plexopathies are more common, more frequently follow traction injury (which can produce lengthy lesions), are more severe (since greater force is required to produce them), and tend to be associated with a worse outcome. For clinical reasons, the supraclavicular plexus is further divided into an upper plexus (upper trunk and C5 and C6 roots), a middle plexus (middle trunk and C7 root), and a lower plexus (lower trunk and C8 and T1 roots). The infraclavicular plexus is not further divided because its lesions do not show significant diagnostic or prognostic variation based on location.

The recovery potential for brachial plexus lesions reflects the same factors discussed above: distance, completeness, and degree of connective tissue involvement. Most symptomatic brachial plexus lesions involve axon disruption (i.e., second through fifth degree lesions) and, thus, their recovery requires reinnervation via axon regrowth or collateral sprouting. As discussed above, the best outcomes follow incomplete lesions (collateral sprouting can occur) located within 20-24 inches of the denervated muscle fibers (axon regrowth can occur) without connective tissue involvement. Regardless of the degree of connective tissue involvement, distant and complete lesions do not recover. This explains why, when there is no connective tissue impediment to axon advancement, shoulder muscles show good recovery and hand muscles show negligible recovery following lesions of the supraclavicular plexus.

When traction injuries cause fifth degree lesions, the term rupture is applied when the brachial plexus element pulls apart at a site distal to the spinal cord, whereas the term avulsion is used when the root of the brachial plexus is plucked from the spinal cord. Avulsion injuries are the most devastating type of brachial plexus injury, not only because they are fifth degree lesions, but also because they essentially are irreparable. Thus, the clinical deficits associated with them essentially are permanent. The nerve fibers of the C5 and C6 roots elements of the brachial plexus are tightly anchored to the vertebral body, whereas those of the C8 and T1 roots are not. Thus, in the setting of traction injury, fibers of the upper plexus are more likely to rupture at the site of connective tissue tethering (better prognosis, since may be amenable to surgical repair), whereas lower plexus fibers are more likely to be avulsed from the spinal cord (much worse prognosis). Regarding infraclavicular plexus lesions, surgical outcomes are better for lateral and posterior cord repairs than for medial cord repairs.

OBSTETRIC BRACHIAL PLEXOPATHY

Obstetric brachial plexopathy (OBP) follows a type of traction injury that typically occurs when vaginal delivery of the shoulder is impeded, thereby prompting excessive lateral deviation of the head and neck in order to free it. OBP may also follow a breech delivery. When this occurs, the risk of root avulsion and bilateral involvement is greater. In addition, OBP has been reported following delivery by cesarean section. Thus, OBP is not always related to a poorly performed vaginal delivery. Risk factors for OBP include large infants (common in the setting of maternal diabetes), small mothers, low or midforceps delivery, vacuum extraction, second stage labor exceeding 60 minutes, passive head rotation with the shoulders fixed, multiparity, ethnic background, and delivery of a previous infant with an OBP. Conversely, small infant size (e.g., fetal growth restriction; prematurity) is protective. The incidence of this type of plexopathy ranges from 0.5-2.6 per 1,000 full-term live births and reportedly is declining. Based on the brachial plexus roots involved, five patterns of injury have been described: (1) C5 and C6 (Erb palsy), accounts for about 50% of the cases; (2) C5, C6, and C7 (Erb-plus palsy), represents about 35% of the cases; (3) C5 through T1 with partial sparing of hand function; (4) C5 through T1 without partial hand sparing; and (5) C8 and T1 (Klumpke palsy), which is almost never seen. Since traction injuries involving the C5 and C6 nerve root fibers are more likely to rupture than those involving the C8 and T1 nerve root fibers, the prognosis for Erb palsy is better than for Klumpke palsy. The distance-time factor associated with proximal axon regrowth also favors the former over the latter.

The management of OBP remains controversial. Overall, these lesions tend to be less severe than traction injuries occurring among adults. Although many reviews suggest that the number of infants showing at least some spontaneous recovery exceeds 90%, the natural history of OBP is unclear. Two Swedish studies reported that 20% to 25% of these individuals are significantly impaired in later life. Unfortunately, there are no clinical or laboratory methods to unequivocally identify this group. Consequently, physical therapy and watchful waiting for evidence of recovery usually is employed. The duration of such a waiting period is controversial. Surgical repair produces the best results when performed within the first year. Thus, the observation period usually ranges from 3 to 9 months.

REFERENCES

Ferrante MA. Brachial plexopathies: classification, causes, and consequences. Muscle and Nerve 30:547-568, 2004.

Ferrante MA, Wilbourn AJ. Plexopathies. In, Levin KH, Luders, HO (eds): Comprehensive Clinical Neurophysiology. Philadelphia, W.B. Saunders Co, 2000, pp 201-214.

In Memoriam: Jennifer Engelhardt

Jennifer Rae Engelhardt, a founder of the Chicago BPI Support Group, lost her courageous battle with cancer in 2009 at age 36. She is survived by her daughter, Peyton Nicole; fiancé Declan Doyle; and her parents Ronald and Joann Ehardt. In addition to her role in the Chicago BPI support group, she was also active with the American Cancer Society. The United Brachial Plexus Network community extends our deepest condolences and sympathy to Jennifer's family and friends. She will be deeply missed by many.

Obstetric Brachial Plexus Palsy Interventions and Outcomes: A Survey of Physical Therapists in Southeast Michigan

Lindsay Harrington, Kris Thompson, PT, PhD.

Obstetric Brachial Plexus Palsy (OBPP) is caused by a difficult child birth when the infant's head and shoulder are stretched resulting in a disruption of all or some of these nerves. (Campbell) OBPP usually occurs as a result from the following: Shoulder Dystocia, which is a difficult vaginal delivery of the infant's shoulder, or the newborns' neck/shoulder experiences traction injuring the brachial plexus nerves. The symptoms of OBPP include: paralysis of muscles, sensory loss in the upper limb. As result from a literature review, the incidence for OBPP is about 0.19 to 2.5 per 1,000 live births (Noetzel & Whetherly, 2006). It has been stated axon regeneration proceeds at approximately 1 mm per day. Injury involvement is usually unilateral, however, 4% of cases are bilateral. The brachial plexus consists of a "ventral rami" containing five nerves (C5-T1) branching off of the vertebral column and innervating the upper limb. The rami is divided into upper (C5-C6), middle (C7) and lower (C8-T1) nerves. (Benjamin)

The risk factors for OBPP are not always a predictor for the disorder and many experts speculate prevention is the key to decreasing the incidence of this damaging disorder. Maternal factors such as gestational diabetes, a high BMI ≥29 m/s^2, weight gain ≥ 15.9 kg or parity, which is having more than one child, may have been shown to be common risk factors. Birthing risk factors involve whether the birth is performed cesarean vs. vaginal. A study by Hankins et al., stated that 331 cesarean deliveries have to be performed to avoid one OBPP case, thus the risk for OBPP is not completely avoided by C-section. Some other birthing risk factors involve a precipitous second stage of delivery and the usage of instrumentation during the delivery. Another risk factor for OBPP is Shoulder Dystocia (SD), when the infant's shoulder gets stuck on the mother's pubic bone during childbirth delivery. A study conducted by John Hopkins University found that OBPP was 75 times more likely to occur after a SD delivery. Fetal risk factors for OBPP incidence are the following: weight ≥ 4,000 grams, a high APGAR score, and whether he was born breech vs. cephalic. In addition, the OB/GYN or midwife years of practice is a risk factor for possibly preventing the disorder.

Four types of Obstetric Brachial Plexus Palsy are classified as the following: Erb-Duchenne/ Erb's (Upper C5-C6), which occurs at 73-86% frequency and results in paralysis of the shoulder muscles, elbow flexors and forearm supinators. If C7 is involved, wrist and finger extensors are paralyzed. Next, Klumpke's (Lower C8-T1), which occurs at 0.6-2% frequency and results in weakness of the triceps, forearm pronators and wrist flexors, "claw-like" hand. Then, the type Erb-Klumpke (Total C5-T1), which occurs at 20% frequency and results in total sensory and motor deficits of the entire upper extremity, also known as "flail arm". Finally, Horner's Syndrome, which occurs at 0.1% frequency and may be associated with either Klumpke or Erb-Klumpke Palsy. This type results in total arm involvement usually is a result of an avulsion at T1. Symptoms include deficit sweating, recession of the eyeball, abnormal pupillary contraction, ptosis and irises of different colors. (Saunders)

Diagnostic testing for Obstetric Brachial Plexus Palsy is done by several methods. The first and most important step is the Observation. This is done by typically the nurses or doctor because they are the first to witness a disturbance of normal upper limb movement or reflexes. APGAR testing is performed on the newborn and is needed to determine normal skin appearance, pulse, grimace, activity and respiration. Electromyography (EMG) determines the type of injury and identifies the innervation status of the involved muscles. Computerized Tomography (CT) Myelography displays images which are produced that clearly show both the bony structures of the spine

and the nerves. Many negative results, however, are seen with this scan with pre-operative evaluations for OBPP. The Mallet Scale (see Figure 1 at right) is a scale used to measure range of motion for the shoulder and elbow and is graded from 0-5. The vigorimeter is a bulb dynamometer to measure grip strength. The Gilbert and Tassin Test is a muscle grading system from 0-3 for observed contractions.

Surgery timing and recovery is controversial since recovery may be spontaneous and surgery may or may not interfere with normal development. By the age of 3 months an "Early Recovery" is classified when a patient may recover with satisfactory muscle activity without surgery. By 3-6 months, failure of recovery of elbow flexion and shoulder abduction are good indications for surgical interventions. (Zafeiriou). In addition, by 6-9 months a "Late Recovery" is classified when a patient may recover with satisfactory muscle activity without surgery. Poor or no activity, however, may need surgery at this time. Some surgeons will try to prolong surgery to the first year to allow nerve regeneration, however, some studies agree surgery should be performed within the first 6 months, thus, results differ per case. In the case of a total plexus palsy, surgery is needed in most cases as soon as 3 months. Furthermore, surgery at an older age could sacrifice fine motor skills, which are harder to get back to normal. If OBPP is left untreated there is a higher risk of residual deficits. These deficits include: bone deformities, muscular imbalances ("winged scapulae" or "trumpet sign") apraxia (limb neglect), limb length disparities and behavioral, social and developmental problems.

Physical Therapy goals address physical therapy to be maintained until one to two years old and follow-up as needed. Home Physical Therapy is very important in OBPP rehabilitation. Protocol for Home Physical Therapy includes: educating the guardian such as proper feeding, carrying and bathing for infant, passive range of motion (may begin 4 weeks after birth), abduction and external rotation of the shoulder while stabilizing the contralateral limb and wrist and forearm range of motion. It is important to be cautious for dislocations or subluxations of elbow and shoulder joints. In physical therapy, an important emphasis on range of motion, strengthening, facilitation of active movement and promotion of sensory awareness have shown to be more effective for treatment of these cases. The Collaborative Perinatal Study found that 92% of infants born with OBPP recovered complete function with physical therapy alone, with only 5% requiring further physical therapy to achieve a better level of recovery.

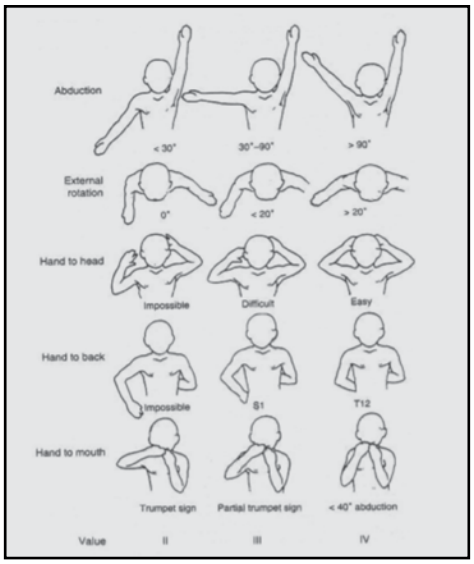

Figure 1: The Mallet Scale

(DHEW) Physical Therapy Interventions include Occupational therapy, surgery, Botox injections, Electrical Stimulation, Casting/ S.P.I.C.A, Taping (Kinesio or TheraTogs, which aid scapular stability and assist weak muscular contractions) and Home Physical Therapy. Other interventions include: constraint induced therapy, dynamic orthoses and passive and active assisted range of motion.

PURPOSE

The objective of this research survey study was to describe the physical therapy interventions and protocols for treating Obstetric Brachial Plexus Palsy (OBPP). We had sought to describe the functional outcomes for the following cases based on a survey of physical therapists throughout Southeast Michigan. In addition, it was intended to promote understanding for OBPP among public and health professionals, physical therapists and families affected by the damaging disorder.

METHODS

A survey tool was developed to examine the numbers and types of patients with OBPP seen by physical therapists and to describe the types of interventions and the outcomes. IRB approval was obtained for the study through Oakland University. Subjects were a convenience sample of physical therapists working at physical therapy facilities in Southeast Michigan that treat pediatric patients. Thirty-five facilities were sent three to ten survey packets depending on the number of physical therapists at each site resulting in a total disbursement of two hundred surveys. The clinical coordinators and physical therapy faculty were notified about a survey packet including an introductory

letter, informed consent form and survey. After receiving the survey packet, they were asked to distribute packets to the physical therapists who treat pediatric patients. Subjects who agreed to participate in the study were asked to complete and return a written survey. The survey took 7-10 minutes to complete. An analysis for successful interventions and functional outcomes of this incidence was compared from the results of the survey and reviewed scholarly researched articles. Also, the statistics program SPSS was used to organize data. Oakland University library scholarly databases used: Medline, Health Source: Nursing/ Academic Edition and CINAHL: EBSCO. Key words searched were as followed: "brachial plexus injuries", "obstetric brachial plexus injuries", "management and brachial plexus injuries".

RESULTS

Thirty-five surveys were returned. The Subject description included: 49% had a Bachelor Degree in physical therapy, 31% had a Masters Degree in physical therapy, 20% had a Doctoral Degree in physical therapy, and other specialization were (NDT (11%), PCS(9%), MSPT (20%), DPT(3%)). Of the sample surveyed, 17% had other specializations including: Masters of Education, Masters of Health Sciences, Serial Casting, CranioSacral Therapy, Feldenkrais Practitioner. From the results, 94% had treated less than seven patients with OBPP in the past five years. Intervention results were as follows: 60% had treated less than one quarter of the four types of OBPP, 53% had stated occupational therapy as being used with more than three-quarters of OBPP patients treated and over 40% had stated casting and botox injections as interventions for OBPP in less than one quarter of patients. Outcome results were as follows: 44% of the physical therapists claimed that only less than one quarter of patients return to full recovery, 44% of physical therapists claimed that less than half still experience residual complications, nearly 39% of physical therapists claimed that 51-75% of OBPP patients could perform bilateral play movements after physical therapy and as a result from physical therapy, 47% of the physical therapists indicated three-quarters of OBPP patients reached satisfactory and 25% reached unsatisfactory level outcomes.

Discussion

It appears from the low number of cases treated by physical therapy , the incidence of obstetric brachial plexus palsy may de decreasing. It may be true, however, a majority of the cases today are treated by occupational physical therapists. According to the survey results, no type of obpp stood out as more prominent. Home physical therapy programs showed to be very important in the treatment for patients with obpp. The most popular treatment methods for obpp from the survey tool are electrical stimulation and casting since both of these interventions were discussed in the literature as proper protocol for older patients with obpp (more than 6-9 months). The ages most seen by the physical therapists were indeed older, ages 9 months to more than one year. Yet, the type and timing of surgery were not statistically significant from the results. A wide majority of the patients with obpp who had been treated by a physical therapist did not receive surgery. The treatment for obpp is determined widely on the location and severity of the nerve root injury. Obpp continues to affect infants caused from a difficult childbirth, however, with proper

Lindsay Harrington *is a graduate from Oakland University with a Bachelor in Science and a focus in physical therapy. With the opportunity from an undergraduate scholarship in the summer of 2007 named, Undergraduate Physical Therapy Research Educational Experience (UP TREE), she began as a junior researcher in the focus of Obstetric Brachial Plexus Palsy (OBPP). After completing a literature review on OBPP and observing various experiences related to the disorder, she was very interested on continuing the research primarily focusing on physical therapy interventions and outcomes. With the help from the Honor's College and Oakland University, she completed her senior thesis as a research survey. Special thanks was contributed by her faculty mentor and director of the physical therapy program at Oakland University, Dr. Kristine Thompson. In addition, support was offered throughout the faculty from the physical therapy program. Lindsay has started a Doctorate of Physical Therapy program at Oakland University and while the future is still open for what direction her practice will follow, the impact received by the important need for education and research in the area of brachial plexus injuries and children has been an eye-opening experience with only hope for the future.*

awareness, education and therapy there is hope for reduced incidences and more treatable cases.

Limitations for study

The sample size was small and included only about a ten percent return rate for the survey. The sample of convenience was a limitation for the location of the physical therapists who treat pediatric patients were from those located in southeast michigan only. Many patients are treated by occupational therapists and this study did not include occupational therapists so results on interventions and outcomes may be incomplete.

Conclusion

According to the survey tool results, the awareness of obstetric brachial plexus palsy among physical therapists that treat pediatric patients is not as common as with occupational therapists. Many of the physical therapists who had treated less than three patients within the past five years had not treated the child at an early age. The use of additional modalities such as electrical stimulation and taping were a common technique for the physical therapists, in addition, some recent information about orthoses to treat obpp. Overall, the outcomes for obpp patients seen by physical therapists who treat pediatric patients were 75-100% satisfactory. The success of home therapy programs shows the importance of a thorough and persistent home-based protocol given by the physical therapists. The knowledge and awareness of this disorder can best be treated by prevention. Furthermore, early intervention with surgery or physical therapy may prevent future, irreversible complications for the patient.

Acknowledgements

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Figure 1. Diagram of Mallet Scale.

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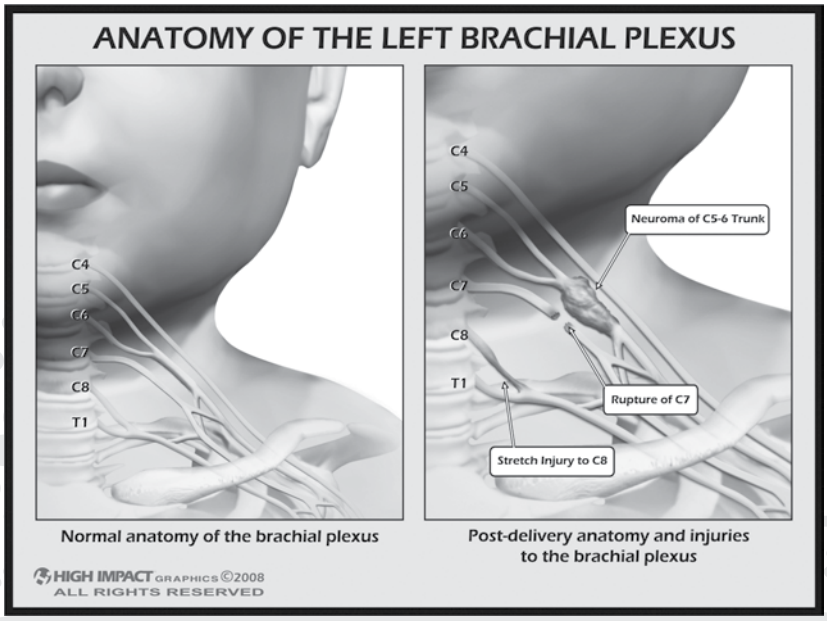

EMBRACE: Rower Brings Home Silver From 2008 Paralympic Games in China

Emma Preuschl, Silver Medal Paralympian

"You have a shot at silver, keep pressing away Great Britain! Catch, drive, send. You've taken a seat-20 strokes left-push them away." My heart was racing. As the legs, trunk and arms mixed 4+ crossed the finish line at the 2008 Paralympic Regatta in Beijing, China I embraced a dream that became my reality. As a young girl I could have never imagined becoming an elite athlete especially since I have a limp arm.

My injury is called Erb's Palsy of the Brachial Plexus. Cranial nerves C5 and C6 were torn during birth. I have no feeling in my index finger and thumb. My elbow is permanently contracted. As an infant I had limited use of my left arm. It wasn't until age two that I could use my arm at any capacity. I skipped crawling and went immediately into walking because I couldn't use both arms to crawl. I do not remember a time in my childhood that I was not doing daily physical therapy. I have vague memories of being tortured by my exercises; in fact the only way I agreed to go to physical therapy was if I got to go during school hours and miss class. The exercises were quite painful and the level of concentration and patience was taxing, especially since I was only 7 years old. However, with my mother's persistence, I am able to live an active lifestyle.

As I got older, I desperately tried to hide the fact that I had anything wrong with my arm. I stopped doing the physical therapy stretches at home; I was ashamed of my weird arm. There was a time in eighth grade when a boy made fun of me for having "retarded" arms. You can imagine what that does to a teenage girl's self esteem. No one wants to be called names, particularly for something they cannot fix. Despite the name-calling, I was active in sports. I took it upon myself to use sports as my physical therapy. I figured sports were similar to physical therapy. My parents worked very hard to not focus on my injury; I was never treated special; household chores like dishes, vacuuming and dusting the house were on my weekly kaper chart. I saw myself as a normal kid. I played as many sports as my parents would let me: volleyball, basketball, softball, and kickball. I never told my coaches I had any kind of problem and I was adamant that my parents not say anything to the coaches either. I just simply adapted to the sport; serving the volleyball with one arm, using both hands to catch the softball and dribbling the basketball with my right arm. In fact, when I tried out for the seventh grade cheerleading squad they asked me why my arms weren't straight and I didn't tell them. I didn't make the team either. Playing sports continued to be a part of my life throughout high school. I ran junior varsity cross country and junior varsity softball at Cathedral High School in Indianapolis. Staying physically fit and active helped maintain the mobilty in my left arm that I gained through physical therapy. I have found that if I do not exercise my left arm has less functional skills.

2008 Silver Medal U.S. Paralympic Rowing Team takes home the silver. Emma is in the second boat from the bottom, far right.

In college I had to find a sport to keep my arm mobile so I took the swim test to join the Purdue Crew Club. Joining the rowing team was one of the best decisions I have ever made. Athletically I started out at the bottom of the totem pole. Slowly I worked my way up into the varsity boat for one season.

Three years into rowing I experienced seizures in my shoulder and finally decided to tell my coach about the Erb's Palsy in my left arm. He was astounded that I had never disclosed my injury to him before. He was more than willing to work with me to make adaptations. As a senior on the Purdue Crew team, at the Dad Vail National Championship Regatta in Philadelphia, I won my first Dad Vail medal. Finishing third in the Women's Open Weight Junior Varsity event. It was a proud moment for me.

I served as a volunteer coach for the Purdue Novice women's crew to stay involved with rowing in my last year of school – at this point rowing had become my greatest passion. To stay active, I trained for my first marathon. During disability awareness month, I was approached to participate in a newspaper article. I stressed to the reporter that I did not want to be labeled as disabled

anywhere within the article. The article was published and suddenly my life was turned upside down. My very private, very personal secret was exposed to the Purdue University community. My own teammates were shocked to read this news about my arm. My coach was so proud of me he had it posted on www.row2k.com for the rowing community to read.

Not a month later, the national adaptive team coach, Karen Lewis, recruited me. She wanted me to submit times to try out for the 2008 Paralympic rowing team. My first reaction was, "I am not disabled. No, I don't want to try out."

Now, you're probably thinking why would someone who says they are a self-confident leader deny the basic facts about themselves – the fact that they are disabled. I still have not found an answer for that question but I think many of us do it subconsciously.

After some consideration, I decided to submit times. Luckily, I had been training for my marathon and was in fairly good shape. I submitted times fast enough to get an invitation to attend the selection camp. After five days of rigorous training and practices, I was selected for the U.S Paralympic rowing team. The 2008 Paralympics was the first time in history the Paralympic Games featured a rowing competition.

It all seems like small coincidences that fit nicely together, but I know deep down in my heart that this was always God's plan for me. God has big plans for me. I have a favorite passage from Pvbs.3:5-6; "Trust in the Lord with all your heart, in all your ways acknowledge him and he shall direct your paths." At the times in my life when I feel defeated, confused and even joyous I am reminded that each good and bad thing that crosses my path serves an important purpose in my life's journey.

The Paralympics was another opportunity for me to participate in a leadership role. This time however, I would be representing the United States of America. Me, the girl who can

2008 Silver Medal U.S. Paralympic Rowing Team (top row left to right) National Adaptive Team Coach: Karen Lewis Biller, Emma Preuschl, Jesse Karmazin, Tracy Lee, Jamie Dean, Simona Chin Campbell (front row left to right) Angela Madsen, Scott Brown, Ron Harvey, Laura Schwanger

barely do 25 push-ups, would serve as an athlete on the first US Paralympic rowing team in history. I had the chance to win the first gold medal ever given to adaptive rowers at an elite level. It was truly a privilege and honor that is hard to express in words.

I spent the next four months training for the trip to China. Being the novice of the boat, I simply followed the lead of my teammates. A true leader knows when to lead and when to follow and at this juncture of my life it was important for me to listen to the advice of others. Training wasn't easy. A typical day in August for me included rising at 4:15 a.m. to ride my bike three miles to practice; finishing two breakfasts by 10:30 a.m., by 12 noon I would head off to the gym to lift weights. As 5:30 p.m. rolled around, I was back at the boathouse for another two-hour practice on the water. August was a long month for me but it was worth it in the end. The United States boats were not slated to medal at the games.

I raced in the legs, trunk and arms four with coxswain division and won a silver medal; sweeping past Great Britain in the last 100 meters of the race.

Some highlights of my trip to China include wearing a USA uniform, standing on the medal dock with a silver medal, walking in the opening ceremonies, getting VIP treatment in the Olympic Village, and taking my wheelchair teammates to the top of the Great Wall of China.

Being involved in the paralympic movement has opened my heart and my eyes to another world of service opportunities, leadership, integrity and character. I was one of 220 US Paralympic athletes representing over 18 different sports. More than 4,000 athletes and coaches from more than 32 countries attended the 2008 Paralympic Games. I plan to continue competing in hopes of attending the London 2012 summer games.

As leaders, parents and disabled persons, I challenge you to embrace diversity. Embrace the diversity of disability, embrace the diversity of sport and embrace the challenges people of disability face. It is too easy to hide-out in today's society in the shadow of a community or a family. Take the higher road and push the limits because you never know what path lies before you. Accept the challenges and break the barriers.

Northeast BPI Group Meets in Boston

The Northeast BPI group organized a gathering at the Museum of Science in Boston, MA on October 31, 2009. Special thanks is acknowledged for the speakers who travelled to present at this event, including Dr. Scott Kozin of Shriner's, Pennsylvania; Dr. Waters, Dr. Bae and Susan Morehouse, PT, MS of Boston Children's; and James Baron, Esq. who discussed IEP and 504 rights of children with disabilities.

Much thanks is given to Levine and Associates for sponsoring this event. Without their contributions financially and logistically, we would not have been able to provide such a successsful program.

The gathering was a smashing success. The location at the museum was beautiful, the food was great, and because two rooms were available the younger kids were entertained by volunteers while the adults had a chance to listen to the speakers. The medical presentations covered all aspects of surgical and therapeutic intervention, and the rights of children in the schools was highlighted-pointing out the differences of IEP and 504 (the powerpoint presentation can be found on UBPN's website). Presenters and participants provided some great feedback. The content was perfect for the newly initiated as well as the "seasoned" families. Having the opportunity to meet the experts in this field is invaluable for our community and we hope that we can continue to hold these events in the future for others!

The Halloween costume judging was great with Wally the Green Monster winning the grand prize.

After the presentations, everyone was given entrance to the museum of science and enjoyed the rest of the day.

Dr. Waters of Boston Children's

Dr. Kozin of Philadelphia Shriner's Hospital

Views from Attendees:

"Life changing, that's how a felt as I try to sort out my emotions of the day. Thank you for your effort in bringing a voice to this situation that is just handed to us as b.p. parents. My child is four and this was my first look at other kids and how this has effected their lives. I came away with so much, thank you for giving us parents the gift of knowledge, and the effort it takes to succeed. This injury starts at day 1 and knowing what to expect at age 5 is a gift. To see the degree of this injury is stunning. My effort for this cause is in high gear, I want to do more. I'm happy to be a part of the group."

"We had a great time on Sat. and appreciate you organizing the event. We would love to come to future events and think the idea of a motivational speaker would be wonderful. The doctors' presentations were wonderful.

My child is old enough to understand much of what was said and I feel she now understands her own injury better. She too has patchy sensation in her effected arm so that was interesting to all of us.

Thanks again and if you were to plan another, we would definitely make every effort to attend."

To have your local BPI news or events published in Outreach, send details to *kim@ubpn.org*. Let everyone know what you are doing to raise awareness or support our community.

BPI

A burden in unwelcome form
Poses hardest to conform
A world of which they can't relate
Makes it hard to appreciate
The forms and functions, they don't know
Have come for us painfully slow
Things can only work so much
Sometimes even sense of touch
They don't know how it may feel
To be alone through this ordeal
In our dreams we can play
When we wake, it's back to gray
We should avoid being blue
Over things that we can't do
Just cant seem to get it out
An easy fix we always doubt
Can they understand this pain
We are different, we're not plain
Sometimes it feels like we are small
We can't seem to reach it all
It's just hard to educate
The ridicule does not abate
Try to lead a normal life
Leave behind the constant strife
I use words to show the truth
Of what has happened through my youth…

– By Mellissa Lawing

My name is Mellissa Lawing, of Alton, Rhode Island. I have a left Brachial Plexis injury. I graduated in 2008 from Western New England College with a Bachelors degree in Biology. My hobbies include writing poetry and treasure hunting (also known to some as geocaching). I've never let my arm stop me from doing anything. I went white water rafting twice by the time I was 12 and got my black belt in karate at the age of 14.

Me and My Arm Named Earl.

Ellie Moore

The birth of a child is typically a moment full of joy, excitement, and magic. Mine was filled to the brim with chaos. I was a large baby, positioned strangely and losing air. The doctor panicked and pulled. My mother and I survived, which is why I can accept the fact that this traumatic birth left my left arm all but paralyzed. The condition is called Erb's Palsy. It is a brachial plexus injury resulting from torn and stretched nerves. At the age of two I underwent an operation performed by Dr. Peter Waters, intended to improve my condition. This operation truly changed my life for the better.

While I regained a great deal of movement, my range of motion remains relatively limited. Although this is a frustrating reality, I attribute many of my best qualities to it.

I define success as following through, trying your hardest at whatever you do and chasing your dreams. A successful person is never afraid to try and fail, and they don't take "no" for an answer. A truly successful individual has few regrets, but many loving relationships and never takes himself to seriously. I believe that my experiences with my disability have helped to train me for success. Living with Erb's Palsy has taught me perseverance, responsibility, and that anything can be laughed at. It has set me up for success in all walks of life, including my experience at the University of Colorado at Boulder.

My operation granted me higher range of motion. That doesn't mean I get to keep it though. It is a constant struggle to maintain the range that I was lucky enough to get. I have been attending physical therapy with Kathleen Richards for as long as I can remember. Every night of my childhood was spent with my amazing mother stretching my arm, and pushing me to do exercises that Kathleen taught us to strengthen my weak muscles.

Even before we met Kathleen my mother was coming up with innovative ways to help me. When I was a toddler she would put a piece of candy in front of me and hold back my right arm. She'd put lotion on my right arm and make me rub it in with my left. She'd

Ellie Moore rapelling at Pure Tek Canyon in Costa Rica.

have me turn the knobs on the oven and put on hats with my left hand. This may seem like torture seeing as it was prior to my operation, and I was still virtually paralyzed, but in actuality it was brilliant. I needed to work in order to be functional.

With practice, I was able to improve beyond what the surgery had granted in some aspects of life. As a kid I couldn't touch my stomach, which meant up until high school I had to lean against a wall to button my pants. With practice and exercise that's now a thing of the past. Other movements, however, are a struggle to just maintain never mind improve. My overhead motion has always been extremely limited. If I lose any more degrees, I will lose the ability to wash my hair with two hands, and the ability to tie it back on my own.

This risk of losing part of my independence is the impetus behind my desire to work. My disability has taught me that there is no room to slack. I need to earn what I have. I can't give up, for if I do, not only will I let myself down, I will let my family, and all the doctors and therapists that have worked so hard for me down too. It has taught me responsibility and routine. Things don't always come easily, but if you stay on top of them, they won't be so hard.

Growing up with a partially paralyzed arm, what I had the ability to do was always in question. I learned quickly, however, that if I didn't try, I wouldn't be able to do anything. I strived to do all of the same activities that my friends were doing. As a child I took gymnastics and ballet. I would be out in the yard playing baseball with my family wearing a lefty glove, catching with my right hand and quickly taking the glove off to throw with it too. I started playing lacrosse in third grade. At first I couldn't play lefty at all, and there was question whether I could ever become a great player. I practiced extra hard, and I was invited to join a very competitive club team, and later made the junior varsity team as a freshmen, along with only four or five other girls in my class. In the meantime, I signed up for the crew team. I awkwardly managed the period of sculling (rowing using two oars), but found my place as a starboard sweep rower (using two arms to pull one oar). I never cared if someone said I couldn't do something; I would simply set out to prove him or her wrong.

One of the most important skills my arm has taught me is the ability to accept the things that I can't change, take them in stride, and learn to find the humor in them. On only two occasions have I broken down and cried about my disability. In only two moments of weakness have I asked, "Why me?" forgetting for a moment that I'm lucky to have my life, my mother, an arm that isn't in a sling. Things could be so much worse.

A few years ago I jokingly named my left arm Earl, and it stuck. Everyone who knows me, and Earl, refers to him by name. My friends and I will laugh as we compare me to the man from "Scary Movie", and as I help someone up I'll lend them Earl and say, "Here, grab my good arm." While Earl has taught me how to be resourceful, adapting to work with what I do have, he has also taught me to accept the realities that I just can't change and not let them ruin my life. My arm will never be perfect, and I'm okay with that. It's just an arm. I have another one.

I feel that my experiences with Erb's Palsy have prepared me for anything I may encounter. I will take initiative, be responsible, and try my hardest. I won't be afraid to try new things and meet new people, which I think is, besides receiving an education, one of the main points of college. I won't cry over a failed quiz. Instead, I'll study harder for the next one and I will never take myself too seriously. For this, I thank Earl.

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.

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

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Please make my donation in honor of:

_____

Thank You! You will receive confirmation of your donation by mail.

UBPN, Inc., 32 William Road, Reading, MA 01867

Climbing Back in the Saddle and Speeding Forward

Chris Mitchell

Mad Sunday 3rd of June 2001 10.15 a.m.

There I was, waiting to go through a CAT scan, my mum, wife and best pal at my bedside. The doctor was saying things like, "do you understand what this means, you have probably lost the use of your left arm permanently." I was slipping in and out of a morphine-induced coma, to be honest I thought the doc was talking to somebody else.

Thirty minutes prior, I had been out riding with a bunch of mates on the Isle of Man where I live. It was the Sunday in the middle of the fortnight, famously known as Mad Sunday. This is the day motor sport enthusiasts take to the Mountain circuit and ride/drive their vehicles around the circuit. I had booked the week off work, and had been looking forward to it all year. I have always been into bikes, for as long as I could remember, and a true fan of the Tourist Trophy (TT) races.

That Sunday morning I had joined my friends in Douglas, and we set off on our bikes past the grandstand, the atmosphere was amazing, just over half way around the 37.75 mile circuit we stopped in the town of Ramsey for a coffee, and more importantly to wait for the Mountain Road to close and to re-open to one way traffic. We had stopped in Ramsey square, just off the TT course, I had a coffee and tasty bacon roll for breakfast, I had been up early and already completed two laps that morning on my own, it was biking heaven.

Eventually the road was re-opened and it was time for us to re-join the TT Course and make our way over the Mountain section to complete our first lap out together, as we made our way around the hairpin and onwards through Tower Bends, I was in the lead of our group, sweeping around The Gooseneck. I looked back and downwards to see the following bikes taking the same route. It was the 26th milestone that I was to lose control of my bike. My memory is very hazy and I don't remember exactly what happened, all I know is that it was high speed and the next thing I knew, I was being placed into an ambulance.

As well as receiving internal injuries and taking a general beating, I had received a Brachial Plexus injury to my left arm. I had both avulsed and ruptured the main nerves, pulling them out of the spinal cord, resulting in total loss of use of the left arm, this was to be the beginning of a complete new chapter in my life, one that I wasn't expecting.

A Life Change

Up to this point I had been working for the local dairy, within the production department, it was a fairly physical hands on job, and I wouldn't be able to continue in this role in my condition. It became clear fairly quickly that I wasn't likely to regain the use of my left arm again, despite going through nerve graft surgery and intensive physiotherapy and even a spell in the local hyperbaric chamber. So it was time to adapt.

I was lucky enough to be offered an office job with the company I was working for, and I enrolled at the local college and started night school, working towards a professional qualification.

The first couple of years were going to be all about discovery, finding out about what was and wasn't going to be possible, and more importantly, would I ever ride again. I wasn't prepared to hang up my leathers for good, no way!

The first two years after my accident were tough. Adapting to getting by with one working arm wasn't so bad, but dealing with the constant nerve pain was a different story. I was taking a lot of medication. Our medical cabinet went from a small box with a couple of plasters and some paracetamol, to half of Lloyds pharmacy's stock room stacked up high. After a couple of years of doctors appointments and trips to the nearest pain clinic looking for that magic potion that would take away the crushing pain, I began to take a different mindset.

I began to accept the fact that this pain wasn't going to be going away. It's all about good days and bad days, this helped me move on. I decided to try and reduce some of the medication I had been taking. I began to feel much more alert and felt ready to make some changes.

By now our daughter Ellie was three, and the two bedroom house that was just fine for my wife, Trudy and myself had soon begun to feel too small, we really had outgrown the place, so we started looking for something a little bigger. We soon found a lovely bungalow, out in the country, a small village called Ballaugh on the West of the Island, and I started to look at making another change, my job.

The office job in the dairy had been very good for me, allowing me to learn new skills while not being too demanding when I wasn't at my best. I am very thankful to the place for looking after me at that time. However I knew that I wasn't going to go much further there, particularly now that I knew I wanted a career in accounting.

Back in the Saddle

After these changes, I still had an overwhelming urge to ride again. I

contacted the National Association of Bikers With Disabilities (NABD) and received lots of good, positive advice.

After speaking with the licensing department on the Isle of Man, they said I would need to have the doctor agree I was fit. I would also need to get an occupational therapist to give me the all clear. Although they thought me mad, they both gave me the all clear to ride. The licencing department issued my full motorcycle license – Yes!!

I decided to go for a twist and get a 100cc scooter. The adaption would be a simple one, hard wiring the lights to always on and using the light switch to operate the indicators. The idea behind the scooter was that it would give me a taste of two wheels without being expensive. If I didn't take to it, I could easily put the scooter back to standard and move on, plus it wasn't going to scare the pants off me. I went on to use that scooter every day to commute to work, through wind, hail, snow, and rain. I've still got the little Peugeot and it's still going strong!

It didn't take me long to realize that my biking days weren't over yet. Riding two wheels again was possible, and after seeing how I coped on the scooter, friends and family accepted the fact that I still wanted to move onto a "real" bike.

Picking Up Speed

The next spring I moved on to a used Yamaha R6. She was in need of a good clean, with several spiders living within the fairings, but the important things like service history, tyres, bodywork, etc were all in good shape, and it was fitted with a steering damper and race can.

Now she needed adapting. I met Pete Moran, an engineer, and explained my situation and my needs. Pete had plenty of ideas – linking the brakes, using the foot pedal to operate them, even a leg or foot operated clutch, but to be honest I didn't want the brake to move from its conventional spot. I could imagine grabbing what I thought was the brake and having some sort of near-death experience. Also, I didn't want the bike to stand out as being too heavily adapted. I knew that putting another leaver on the right hand side to use as the clutch would work – somehow.

Pete soon crafted the hardware out of alloy and had the lever fitted to the bike ready for testing. I can remember wheeling the bike out from the yard and onto the road, putting my helmet on and feeling very nervous, this was a big step from my little scooter but hey, what's the worst that could happen?

It was a case of re-programming the brain again – pull in clutch while trying to hold steady revs, select gear and then gently release the clutch. I won't lie, it

was a shaky start, and as the bike got rolling and the revs steadily climbed I found myself thinking, 'what do I do now?' It all came back to me and it wasn't long before the test drive was over and a complete success. I could hardly speak as I took off my helmet.

We made a couple of minor alterations but fairly soon I was good to go. I would spend the next year getting used to riding the bike and then I was back out riding on the TT course. It was brilliant.

I would go out riding with a group of friends with bikes, usually on a Sunday morning, stopping at the café for breakfast and usually finishing with a pint on our return home – perfect.

I was growing more confident on the bike all the time. In 2007, I was on my way home on the little scooter, a car pulled out in front of me and to miss the car I had to run up on a curb. I was thrown fromt he scooter and my left elbow was smashed. So I was to spend the next six weeks unable to get my leathers on.

I was now attending the Club Racing meetings as a spectator at the local Jurby circuit. I became more and more keen to join the club and apply for my ACU license. This would be the first hurdle if I were to have a crack at racing. To apply for my race license, I had to attend a class on safety. Once you have your certificate from the class room course you can then apply for your novice license.

I sent in my license with all my medical history. I got a letter back asking me to take a medical, and asking for my doctor to sign a form that said I was fit to enter for my competition license. I still believed that somehow I was going to get turned away, I wouldn't get my race license, but my doctor signed me fit to race! By that evening I had sent all my forms back to the ACU.

The ACU decided that I would attend the race school which was run on the same day as one of the race meetings, I would be assessed during the track sessions and if I was considered a competent rider and satisfied the officials, then I would be issued my license.

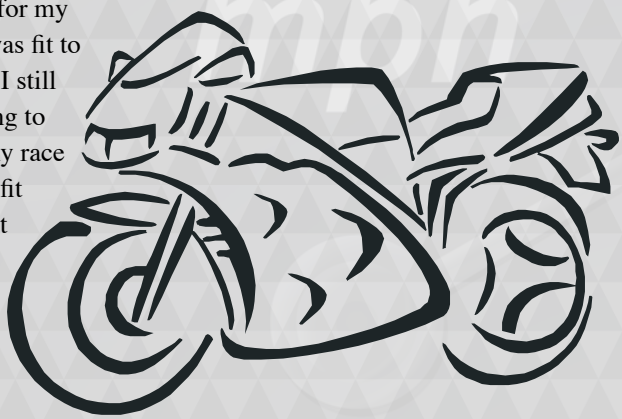
I was to put my bike through scrutiny, there was a few raised eyebrows as the officials checked over my bike, they put a blue bib on me so I could be easily identifiable on track. Within a couple of days I received my ACU license. I was an official road racer and I felt a real sense of achievement!

By this time a friend of mine who helped me line up a racing bike. I would need to test the bike before going straight into my first race. I didn't have long to get the race bike sorted, a quick call to Pete and the bike was sent down to his workshop. He would build me a functional clutch to go on the right hand side, nothing too pretty but since I'd already adapted my riding style, it worked. I was ready to test!

I could now start thinking about entering for my first race. I would need to apply to the race club for my own racing number, decide on what races I could enter, get the forms filled in and my entry fees paid. My race entry was accepted.

It was soon the evening before my first race meeting. I have to admit to a slight feeling of nerves tinged with excitement! That night was a fairly sleepless one.

I got to the circuit early. When the officials checked my bike, one of them noticed that the left hand bar had no clutch lever on it."How are you going to race with one arm?" he asked. To which I replied, "We're just about to find out!" He slapped the passed sticker onto the front fairing and sent me on my way.



The first two qualifying sessions went well. In my first race, I got to the end of the back straight and hit the brakes to find nothing there! The pin had fallen out and so did the brake pads, unknown to me until I needed to slam on the stoppers. Somehow I managed to scrub enough speed off with the rear brake before taking to the grass. So my first race ended without a finish and lift back in the recovery vehicle, luckily I didn't fall off.

The rest of the day went well, thanks to the loan of my missing brake calliper parts from a road bike in the paddock. I completed all races left in the day and gradually got quicker and quicker. It was nice to know I wasn't the slowest out there, but had plenty of room for improvement. With the exception of the first race, I did pretty well. I rounded off the day with an 18th place in my final event and a fastest lap of over 70mph average.

The next meeting was a longer distance and a slower average speed lap, to say technically challenging would be an understatement, I can't say I'm mega happy with my finishing positions, but looking at it on a whole my lap times improved during every outing.

Things are going well at work as well. I started a new job and I am continuing with my accounting qualification studies.

Last year I signed on to marshal for the Manx Grand Prix. Something I've always been interested in doing but wasn't sure if my disability would cause a problem. I declared my injury while signing up as I didn't want to jeopardise the safety of others in the event of an incident. I was reassured that there were plenty of roles to take in marshalling, not all requiring the full use of both arms! I am now a Marshal aswel, So I have been lucky enough to see both behind the scenes and out on track of the racing world.

Greeting Royalty

Charmaine Winter writes, "We are so proud of our daughter Karrie, 10 years old, who presented flowers to Duchess Camilla and Prince Charles at the opening ceremonies for their Royal Visit to Canada on November 2, 2009 in St. John's, Newfoundland, Canada.

She was chosen to present these flowers on behalf of the Easter Seals organization – the Easter Seals Newfoundland and Labrador is a charitable organization which is dedicated to maximizing the abilities and enhancing the lives of children and youth with physical disabilities through recreational, social and other therapeutic programs, direct assistance, education and advocacy.

Karrie has a left obstetrical brachial plexus injury. In February, 2000, she was operated on by Dr. Howard Clarke of Toronto Sick Kids Hospital in Toronto, Ontario."

Congratulations to Karrie, her mom, Charmaine; father, Greg; and younger brother Jordan and thank you for sharing this thrill with the UBPN community!

Karrie Winter shakes the hand of Prince Charles of Great Britain.

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 occassion. (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. 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.

Awareness Items Order Form

UBPN Gund Stuffed Puppy Dog

Quantity _____ x $20 = _____

Ribbon Car Magnet

Quantity _____ x $5 = _____

Reaching Out 4 BPI Bracelet

Quantity _____ x $4 = _____

_____ Adult _____ Youth __

UBPN Jewelry Ribbon Pin

Quantity _____ x $5 = _____

UBPN Ribbon Pins (Each bag includes 20 pins)

Quantity _____ x $10 = _____

Zipper Pulls

Stop Quantity _____ x $1 = _____

Ribbon Quantity _____ x $1 = _____

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

Name: _____

Address: _____

_____

Phone: _____

Please send check or money order payable to:
UBPN, Inc. at 32 William Road, Reading, MA 01867
Online orders may also be placed via
the UBPN Web Store at www.ubpn.org.

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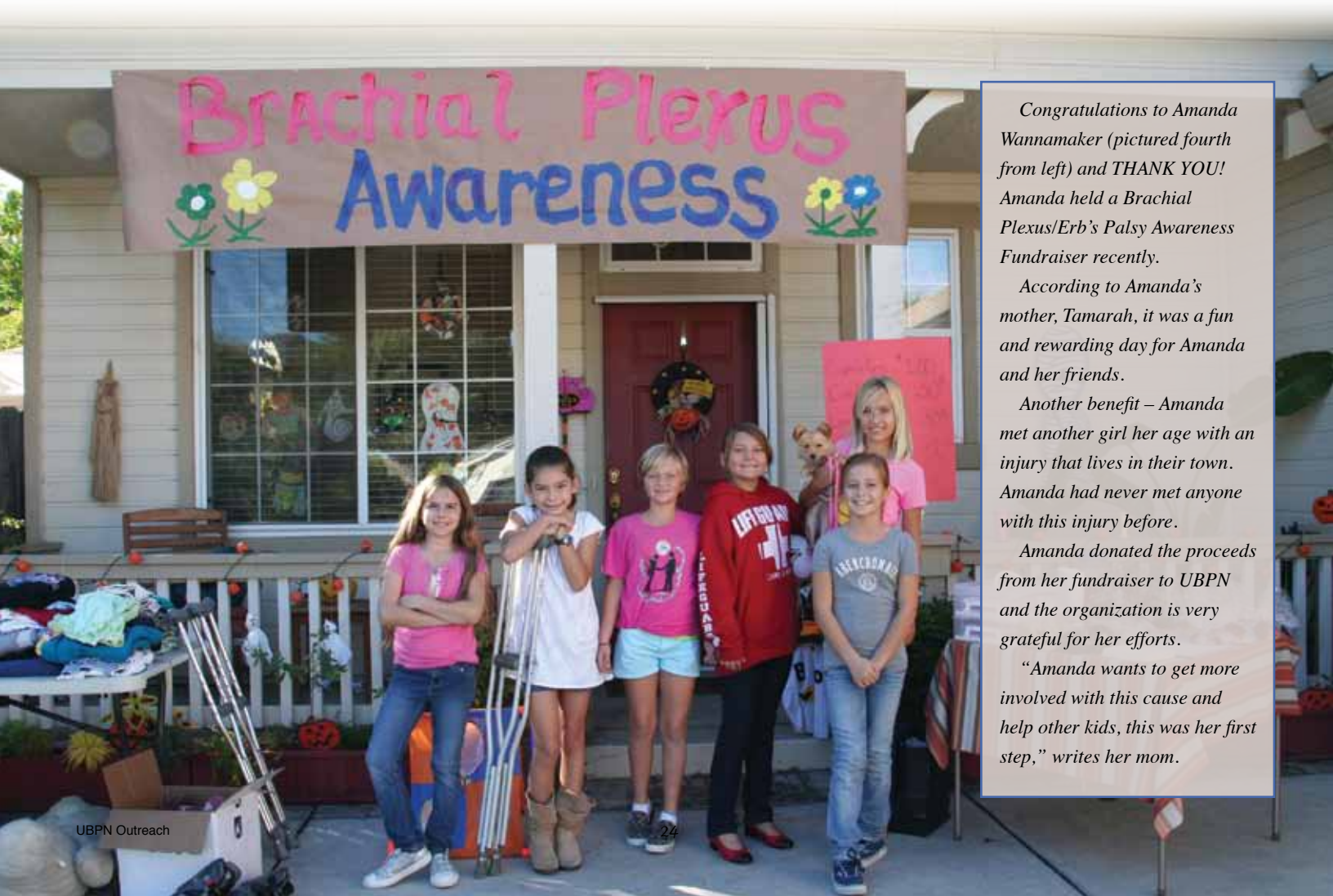

Congratulations to Amanda Wannamaker (pictured fourth from left) and THANK YOU! Amanda held a Brachial Plexus/Erb's Palsy Awareness Fundraiser recently.

According to Amanda's mother, Tamarah, it was a fun and rewarding day for Amanda and her friends.

Another benefit – Amanda met another girl her age with an injury that lives in their town. Amanda had never met anyone with this injury before.

Amanda donated the proceeds from her fundraiser to UBPN and the organization is very grateful for her efforts.

"Amanda wants to get more involved with this cause and help other kids, this was her first step," writes her mom.