

The Magazine for Brachial Plexus Injuries
ISSUE 25, 2011

Outreach

by the United Brachial Plexus Network, Inc.

WHAT'S INSIDE
creativity
inspiration &
perseverance

ubpn CAMP

SAVE THE DATE!
JULY 22–JULY 25, 2012

Trout Lodge, YMCA of the Ozarks

Located two hours South of St. Louis, Missouri, Trout Lodge offers swimming, zip lining and a plethora of other outdoor activities. We will also have doctors, therapists and practitioners of alternative therapies and techniques.

Registration will begin in July 2011. We will be offering an early bird registration so be on the lookout for our announcement! Payment plans and scholarships are available, and ages 17 and under are free. Space is limited so sign up early.

We are looking forward to another great ubpnCamp. *See you there!*

FOR THE LATEST INFORMATION VISIT
WWW.UBPN.ORG



Attendees of Camp UBPN 2010

Outreach

EDITOR + DESIGN

Jennifer Patankar, art@jenudi.com

MAILING ADDRESS

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

TOLL FREE + FAX

1-866-877-7004

WEBSITE

www.ubpn.org

EMAIL

info@ubpn.org

OUTREACH FOUNDER

Bridget McGinn

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.

The appearance of information in *Outreach* does not constitute nor imply endorsement by the United Brachial Plexus Network, Inc., its Board of Directors, the *Outreach* publication, nor its editorial staff. Readers should consult with trusted clinicians to determine the appropriateness of products or services for their specific needs.

2011–2012 BOARD OF DIRECTORS

Rich Looby, MA President	Karan Allrich, NY Julia Aten, WA
Kim West, OH Vice President	Anise Braggs, MO Traci Foster, PA
Tanya Jennison, NY Secretary	Christopher Janney, CA Lisa Muscarella, AZ
Nancy Birk President Emeritus	Claudia Strobing, SC Amy Johnson, MN

COPYRIGHT © 2011, UBPN, INC.

Information from *Outreach* may be duplicated for educational use; however, written consent from the author and editor must first be obtained. For more information contact art@jenudi.com.

In this issue

GREETINGS

From the Editor 2

CREATIVE CORNER

Accept Yourself 3

ENTREPRENEUR

Overcoming Adversity 4

INSPIRATION

Determination 6

Do you believe in miracles? 8

Special thanks to

Blume, Goldfaden, Berkowitz, Donnelly, Fried, & Forte, a law firm whose generosity has made this issue of *Outreach* possible. If you desire information about the legal rights of yourself or your children, or wish a referral to a law firm in your area that is experienced with brachial plexus injuries, contact John Blume or Carol Forte.

Blume, Goldfaden, Berkowitz, Donnelly, Fried, & Forte
One Main Street, Chatham, New Jersey 07928
(973) 635-5400 • www.njatty.com

Connect with us online at
FACEBOOK.COM/THEUBPN
TWITTER.COM/UBPN

From the Editor by Jennifer Patankar

My face to the sky

Dreaming about just how high

I could go and I'll know

When I finally get there

These are the opening lyrics to *Everybody Got Their Something* by Nikka Costa. It is one of my favorite songs to get me back into a good mood when my arm is frustrating me. It is upbeat and reminds me that no one is perfect.

I am a self motivated artist and designer. I really enjoy publication design and

when the opportunity to volunteer for UBPN's *Outreach* crossed my path I felt obligated to help. I have an LOBPI. Numbness runs through my entire arm and hand, it is weak and I have limited range of motion. While I do have use of my arm I used to get easily frustrated and could barely talk about it. That changed recently when I had a "eureka moment."

While studying art and design at Texas State I struggled in my drawing classes. My work was good, but I never landed on my "style." I also enjoyed graphic design so I took up both in hopes that one day I finally would cross paths with illustrations that felt like my own.

In late 2010, I was approached to illustrate a children's book. It was my first opportunity to illustrate professionally, so I took the job as a challenge. After a few trial and error drawings I had a radical idea to attempt an illustration with my "wrong" hand, which in my case was also my BPI side. I liked the result, but I was terrified to send the drawing over to the writer for critique.

In the past, I kept my injury to myself, only telling people minimum details and on a need-to-know basis.

I finally summoned the courage to send it, and the writer loved it.

I could not have been more surprised. Since then I have continued drawing wrong-handed for work beyond that first children's book.

Prior to my wrong hand drawings I did not have any good memories involving my BPI arm. The past year has been life changing for me, and I can happily say that I no longer see my arm as a burden.



About the editor

Jennifer is 27 and resides in San Francisco. She works professionally as Jenudi and can be reached via [@jenpatankar](#) on Twitter, or at [ubpn.org/forum](#) under the username Jennifer P.

"Do one thing every day that scares you."

Eleanor Roosevelt

Accept Yourself by Joyce Clemons

Accept yourself as you are.

Appreciate yourself as you.

You are not perfect.

Your body may be injured.

but do not let that be who you are.

Your attitude may not be perfect.

but you can change it.

It is your decision to

continue being your best self

or be less than your best.

It is your job now to learn

how to live a different life

than you had before.

It is hard but you can do it

with a lot of hard work and determination.

It will get frustrating, annoying, and

feel like life ain't worth it.

That is normal

and fine to feel that way.

But it is not fine

to keep feeling that way.

So put your head up, smile, and say:

"I will be my best self

No matter what happens to me."

About the author

Joyce lives in Evansville, Indiana. She had surgery for Thoracic Outlet Syndrome, and the surgeon stretched her nerves resulting in a TBPI.

Overcoming Adversity by Keith Pancake

In March of 2009, life was treating me quite nicely. I had a fantastic job as an arborist and was even able to start my own company. That all changed when a large red maple which had been damaged in an ice storm suddenly broke as I was felling it. As the tree failed I began to run down an escape path;

as I neared the end of the path the trunk violently impacted my right shoulder—driving me into a snow bank. As my partner worked to free me from the debris we noticed that my right arm didn't look good. At the time, I had never even heard of the *Brachial Plexus*.

While waiting on the EMTs, I made one of the toughest phone calls in my life to my wife—telling her I was in an accident but okay. Then the pain set in. Those of us with Traumatic Brachial Plexus Injuries are all too familiar with this indescribable, unmanageable sensation. I struggled more with the endless, unanswerable questions that people concerned with my well being asked.

Then there was the emptiness I felt as I waited in pain for the requisite three months to pass so the specialists could properly assess my nerve damage by MRI. The technician told me that there was no

hope; that there was too much damage after reading the scan. My team of doctors at Dartmouth Hitchcock Medical Center solemnly echoed the technician's report with the caveat that prosthetics technology is advancing at an incredible rate, and I might be a candidate.



I initially balked at the idea of amputation. Wanting to remove all doubt, I sought out Susan Mackinnon at Barnes Jewish Washington University who elected to attempt a nerve transfer and transplant.

Due to the extent of the damage, the chance for success were low, but it was still worth the effort.

I had a procedure lasting 15 hours which unfortunately yielded no return of function to my arm. Now I am a candidate for a procedure to amputate my arm, fuse the shoulder and attempt to operate a prosthetic.

Even today, the pain remains unbearable. I've tried everything from acupuncture to Reiki and pain medications. So far, remaining active and engaged with the appropriate medications seems to sooth the best.

How was I to survive this ordeal and the ensuing pain without sinking into the depths of depression? More

importantly I needed to do my best to keep the stress levels manageable for my entire family. This injury takes copious amounts of understanding from those closest to us. The answer has been to get up and get going. Kick myself in the pants and figure out how to be innovative and creative. My wife has been instrumental in keeping my spirits high and inspiring me to remain motivated.

Before I was injured I purchased a small sailboat, and I instantly fell in love with the wind in my face as I cruised around the small lakes near my house. I was crushed when I could no longer launch my boat for a few hours after work. I was facing yet another challenge courtesy of my injury. So I began researching adversity and looking for people who I could draw inspiration from.

I had to go no further than the bookshelf in my office. I enjoyed many books about people who faced adversity that survived *and* thrived. Some of my favorites were by Dennis Conner, Sir Ernest Shackleton and Joshua Slocum. I was inspired by them to find a way to get back on the water. Almost immediately I began experimenting with ways to sail with one arm.

This project really got my creative juices flowing. I have had to find innovative solutions; for example, how to simultaneously steer and trim the sails. It is a mirror image of the types of challenges people with TBPI face constantly. I found myself looking at problems and breaking them down into manageable, solvable pieces.

With my boat nearing completion the New England winter set in, so I began to study the other aspects

of sailing. I soon realized that I would need an entire program just to get my boat to the launch and safely back to the trailer after sailing.

While taking a management class, the professor asked us to create a business model and to discuss how to make it succeed. I decided to create an organization to raise awareness of the struggles that people with TBPI face every day by retrofitting my boat and sailing it around local lakes. This was the genesis of *SailinSolo*—my way to get back on the water.

My goal is to find people willing to donate sailboats that can be modified to meet the needs of people with TBPI and other upper extremity injuries. The retrofitted boats will be given to interested disabled individuals along with the training necessary to develop a safe sailing plan. I am in the process of obtaining non-profit status to make all donations tax deductible.

SailinSolo is a large endeavor. Along with my family duties and returning to school it keeps me moving and my mind occupied which is the best medicine I've found for this injury. Hopefully *SailinSolo* will find smooth water and fair winds.



About the author

For more information about *SailinSolo*, contact Keith at sailinsolo@gmail.com or follow @sailinsolo on Twitter. Keith is currently studying Geography at Keene State, and he will be undergoing surgery mid-2011 to further attempt the management of his TBPI.

Determination

by Billy Tonis

As I grew up in a northern California suburb, athletics were the primary focus in the Tonis household. From my parents to my two sisters, we were brought up with a discipline that taught us to achieve our goals. From this, I believe it laid the foundational strength, admiration and appreciation that I rely on today. Although my attitude comes off as easy-going with a joking personality, my inner ambitions are strong driven and almost compulsive.

I had an athletic college career (turning down an academic scholarship to Kansas) catching for Ohlone College and San Francisco State University baseball teams and also competed with the Chabot College golf team. While catching for San Francisco State, I had a moment that few ball players get to have, where I hit a walk-off home run to win the game. Although it was a proud moment for me, I would later learn that it would be the last highlight of my college career.

The next day, playing America's favorite pastime would be just that, as my dreams of athletic achievement (or so I thought) came to an end with a motorcycle accident. After 5 days in the ICU and several weeks in the hospital, I found myself with a broken femur and brachial plexus injury with five avulsion nerves (Cervical 5 to Thoracic 1), leaving my right arm completely paralyzed. In a 24 hour period I went from one of my highest to one of my lowest moments, struggling mentally and physically going from a top athlete to learning the basics of walking and writing.



© WCW

Obviously, the world I knew was gone, and I was left spinning trying to find a direction in life. Things that had come so easy were now a major challenge. I found frustration as things as simple as tying shoes, cutting a T-bone steak and signing a credit card slip became daunting tasks. In addition, coping with phantom pains would be a part of my daily life. In 2000, I challenged my disability and rekindled my passion for competition as I started wakeboarding. It was a sport that made me proud and determined. Since then, I have competed and placed in top level wakeboarding competitions like the Extremity Games, INT, WWA and many others.

As I looked for more involvement in the wake industry, CIE Wakeboarding Co. was created in 2001 to promote the sport. The company has grown in the water-sports industry and created a following in the market. CIE hosts the biggest wakeboarding event on the west coast called the "CIE Spring Ride" capturing all lifestyles of the sport for all to enjoy.

Currently, I am employed with AC Transit District in the Bay Area and look towards business opportunities as I learn more about the political roles throughout the agency. As I continue my wakeboarding passion, many loyal sponsors support me along the way. So much appreciation goes to CWB Board Company, Malibu Boats/ Boat Country, Cire Boardshorts, and Wake Roots Ride Shop for all the help they have shown over the years. I continue to support the Athlete's with Disabilities Network that promote a better quality of life and create opportunities for people with physical disabilities. Although I never planned it, I found myself leading with determination and compassion to motivate others with disabilities.

The day of my accident changed my life forever; however I find myself debating whether it was a change for the good or the bad. Although I face everyday physical challenges, they are outweighed with the love at home from my beautiful wife Allison, daughter Lyla and dog Jade.

If I was given the choice again, I would put myself back on that hospital bed as my struggles will never erase those smiles. The accident has made me a stronger, more determined person that puts perseverance on a different level. The injury has taught me to keep an open mind as my lessons learned shed new light. I believe this seemingly horrific experience will help me teach others the appreciation of life, and compete to a level I never saw before. Thank you BPI, as I am grateful for my family and friends that you have brought to me today and the untold stories of tomorrow.



About the author

Billy's motto: *How you handle challenges is what defines you as a person.* You can follow @billytonis on Twitter.

THE UNITED BRACHIAL PLEXUS NETWORK

is a registered 501(c)3 non-profit organization, which strives to inform, support, and unite families and those concerned with brachial plexus injuries and their prevention worldwide.

Our vision is...

- ...to **create awareness** of brachial plexus injuries.
- ...to **provide support** for affected individuals and families.
- ...to **educate** medical and legal professionals, politicians and the general public on the issues surrounding this disability.
- ...to **maintain a network** that will unite all those concerned with brachial plexus injuries.

UBPN is maintained entirely by volunteers. We encourage anyone interested in bringing awareness to brachial plexus injuries to contact info@ubpn.org. We also encourage donations to assist UBPNs continued efforts to fulfill its vision. All donations are tax-deductible.

FOR MORE INFORMATION VISIT
WWW.UBPN.ORG

Do you believe in miracles?

by Elizabeth Beaulieu

I do because I am a miracle. Did you know that 1 in 1,000 births suffer Down syndrome; 2 to 3 in 1,000 births suffer Cerebral Palsy; 1 in 3,500 boys suffer Muscular Dystrophy and 3 in 1,000 births suffer Brachial Plexus Palsy. Brachial plexus injuries are common, but you never hear about them—as if to say it is not a serious injury, or it isn't as important as other injuries or disorders, but it is.

I believe in miracles because when I was born, I weighed over 10 pounds and my doctor knew that I was stuck, and that I wasn't breathing, so he panicked. He broke my left arm, and pulled five major nerves out of my spinal chord, causing partial paralysis on my right side. In order for a brachial plexus injury to occur, you need to apply at least 60 pounds of force for anything to tear. When I finally came out, I was dead.

The doctors have an APGAR Score test that they used on me and I was a zero. I was transferred three hours south in an ambulance. Doctors had said that I wasn't going to live, but guess what? I'm here! I may not be normal, but what is normal anyway?

This injury I have can be painful and can sometimes be a burden, but it is good in a way because it has made me a stronger person and I have been to a lot of places and met so many people. Some are mean and some are nice. It makes you appreciate what you have in life, and that you have it easy.

I matured at a young age and I learned that no one is perfect and that making fun of people gets you nowhere in life. You hear it everywhere you go. People making some rude comment on how someone looks or how they're dressed. People who make fun of other people just have their own insecurities about themselves and they have to make other people feel bad so they can feel better. I do not let it stop me though.

People have told me that I would not be able to play basketball because you need two hands and that I would somehow slow the team down because of it and that we would lose more games, but I proved those people wrong. The first time I played basketball was in 8th grade and I remember one of the coaches from the other team coming up to me and saying, "Thank you for playing and not letting your injury stop you." I had never met this man in my life before and I caused him to have tears in his eyes because I was playing basketball and just having fun even if we were losing. I believe I'm a miracle because I was practically dead, and I came back to life and here I am. So accept me and all others around you for who they are and don't judge. We are all some sort of miracle in our own special way.



About the author

Elizabeth is a high school Junior with an ROBPI from Maine. This essay was written for an international writing project; she received an A+. Her mother posts at ubpn.org/forum as Louise H. Beaulieu.

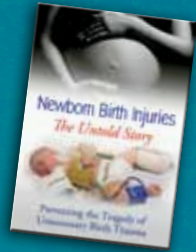
Newborn Birth Injuries: The Untold Story

Newborn Birth Injuries: The Untold Story is now airing on many PBS stations. This five-minute short documentary explains how brachial plexus injuries occur and how they can be prevented with proper care and positioning. Learn from internationally-renowned medical experts as they share eye-opening information on the cause and prevention of brachial plexus birth injuries. UBPN was fortunate to be able to produce a 25 minute companion documentary. Both the short and long versions of the

video production may be viewed at ubpn.com. DVDs are also available for \$10 each and includes the long and short versions of the documentary.

UBPN is grateful to all who participated and donated their time and money.

A special thank you to UBPN board member, Lisa Muscarella, for her tireless efforts in bringing the documentary to fruition.



The DVD is available for \$10 at tinyurl.com/ubpnstore

Please consider a donation.

You can make a real difference in the lives of those coping with a brachial plexus injury by making a tax-deductible donation. Donations support communication, education and support services that directly help the community. Please complete and return this form, along with a check

made payable to UBPN, Inc. To start making a difference. UBPN is a non-profit 501(c)3 charitable organization, meaning your contribution is fully tax-deductible. Donations may also be made securely online at paypal.com to donation@ubpn.org.

No amount is too small. All contributions make a difference.

I would like to make a donation of

☐ \$15 ☐ \$25 ☐ \$50 ☐ \$100 ☐ \$ OTHER

NAME

ADDRESS

CITY STATE ZIP

PHONE

I WOULD LIKE MY DONATION TO GO TOWARD

PLEASE MAKE MY DONATION IN HONOR OF

E-MAIL

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

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



What is a Brachial Plexus Injury?

The term Brachial Plexus Injury (BPI) refers to an injury to the complex set of nerves that control the muscles of the fingers, hand, arm and shoulder. The nerves originate at the spinal cord and are formed in three trunks located in the upper shoulder. Terms used to describe a BPI include *Brachial Plexus Palsy*; *Obstetrical Brachial Plexus Injury* (OBPI), one which occurs during birth; *Erb's Palsy* or

Erb-Duchenne Palsy, an upper trunk injury; *Klumpke's Palsy*, a lower trunk injury; *Horner's Syndrome*, when facial nerves are also affected; *Traumatic Brachial Plexus Injury* (TBPI), one which occurs by an accident; and *Burners* or *Stingers*, usually associated with sports-related TBPIs. *Torticollis* is another term sometimes used in conjunction with brachial plexus injuries.

NON-PROFIT ORG
U.S. POSTAGE PAID
COLUMBUS, OH
PERMIT NO. 5405

CHANGE SERVICE REQUESTED

Outreach
United Brachial Plexus Network, Inc.
115 FAWN LANE
BLANCHESTER, OH 45107