

March - April 2009 AST Newsletter

AST is affiliated with the ACA – Amputee Coalition of America

AST is a 501(c)(3) nonprofit limb loss support group.

With AST Chapters in Lancaster & Berks County, and State College

www.amputeesupportteam.com

"So others may benefit from us."



Great March Meeting: We had in attendance over thirty at our March 11 **AST Meeting**. Randy Stevens did an intensive presentation on shoes that are available to those of us with special foot needs. He also spoke about proper shoe fit, and proper foot care.

Later in the meeting, Jake Schrom, who is an AK, and Leader of our newest AST Chapter, demonstrated how he runs in a Prosthetic Running Blade. June will be a busy month for Jake, he will be finishing up his sophomore year at Penn State University, attending the Endeavor Sports Games with his PSU Coach in Oklahoma City, Oklahoma, and attending the ACA – Amputee Coalition Conference in Atlanta, Georgia, where he will be attending seminars and taking leadership training.

Jake, who is an ACA Certified Peer Visitor, is the organizer and Leader of our third, and newest AST Chapter, the **Nittany Valley Amputee Support Team**, hosted by HealthSouth's Nittany Valley Rehabilitation Hospital in State College, PA. The **NVAST** had it's first meeting at 6:30 PM, on Wednesday, April 1, at the Nittany Valley Rehabilitation Hospital, located at 550 W. College Ave., Pleasant Gap PA 16823. See photo of this Meeting later in this Newsletter.



Jake Schrom demonstrating his prosthetic running Blade.

LOBBY DAY, Washington, DC, March 10, 2009: Lobby Day was attended by representatives of amputee support groups, and people interested in the welfare of limb loss people from thirty-four states, PA had over forty in attendance, one of the largest groups, seven of them representing the AST, and its chapters. Some states did not have delegations as they have had the good success of having Prosthetic Parity Legislation passed in their states. Visits were made by groups and individuals to their respective U.S. Congressmen and/or Senators seeking support, or thanking them for the support they have given.

PA is one of those states in which the Prosthetic Parity Bill did not make it out of committee and did not make it into law before the end of the last session of the PA House of Representatives. Although the PP-Bill was not reintroduced in the PA House this past January as expected, the Honorable Bernie O'Neill, who lead sponsored and introduced the original PA-Bill, said: "... it should be introduced again in the next couple of weeks...." It's hopeful the PA-Bill is re-introduced before anyone gets to read this AST Newsletter.



The AST was well represented in this picture taken outside Senator Arlen Specter's Office. To the right of Senator Specter (L-R) is Sean Brame, his brother Patrick, Dick Nickle, AST President, behind Patrick is Don Hossler, AST CO-VP, and behind Dick is Sean and Patrick's dad, Mike Brame. The rest in the photo are representing their respective areas for Parity.

Now the emphases is to get passed in our U.S.

Congress HR-5615, now known as the Prosthetics and Orthotics Parity Act. The Prosthetic and Orthotic Parity Act is not another mandate! This bill simply creates a fair and consistent standard for health plans that are already offering coverage for prosthetic and custom fabricated devices. It is low cost. It saves money in the public and private sector. And it is the right thing to do!

The Prosthetic and Orthotic Parity Act is restorative. It will return people to work and will help them to reclaim their lives and do so at no additional cost to the American taxpayers. It will make certain that insured, working people can continue supporting their families.

In regards to **Lobby Day**, Morgan Sheets, Sheila Van Pay and Dan Ignaszewski, ACA's National Advocacy Team, stated in z recent E-mail:

"Dear PA [Lobby Day] Participants,

We cannot thank you enough for making the trip to Washington, DC for the ACA's second annual Lobby Day. We are still feeling the excitement of this ground breaking event. We have already heard from House and Senate offices who were truly moved by the stories they heard and who want to get involved in the efforts to advance prosthetic parity. Visit our Lobby Day page to read the ACA's follow-up press release and see photos :"

www.amputee-coalition.org/advocacy/lobby-day

Sean Brame: Age thirteen, a quad amputee, the youngest member of the AST, and an ACA Certified Peer Visitor, is not new to testifying for the benefit of others, especially those persons with insurance policies that do not sufficiently cover limb loss persons at a level to allow them to recover enough to live independent and productive lives.

On April 16, 2009, in Wilkes Barre, Pa, Sean Brame will be testifying in support of **House Bill #255** (that amends the **Podiatry Practice Act**, establishing a state licensure requirement for prosthetists, orthotists, pedorthists and orthotic fitters).

Sean was invited to testify by PA House Rep. Scavello of Monroe County, the sponsor of **House Bill #255**, which will ensure that limb loss persons receive the necessary, and proper care when being fit with prosthetic and orthotic equipment.

Many of the co-sponsors of this Bill also co-sponsored the Prosthetic Parity Bill in the last session of the PA Legislature. We are hoping that Sean's support for HB #255 will encourage them to reintroduce the Prosthetic Parity Bill with the intention of getting it passed as soon as possible. Please read Sean's testimony on the last page of this Newsletter.

The **Amputee Support Team of Central Pennsylvania** did its share in seeking support for the passage of HB #255 by the U.S. House of Reprehensive, not to mention the efforts being made in their home state of PA, to get state Prosthetic and Orthotic Parity Legislation Passed into law soon by the PA Legislature.

It appears that there is more of a burden on the shoulders of the people at the state level, as the ACA – Amputee Coalition of America is focusing its attention on getting HB #255 passed into Federal Law. Knowing this, we need to make a concerted effort at the state level, contacting our state representatives, including Representative Bernie O'Neill, who originally sponsored and introduced HB 317 in the last term of the PA Legislature.

Did you know: As of three years ago, the prevalence rate then for amputation was 4.9 per 1,000 persons. Given this rate, there are an estimated 60,959 amputees in the state of Pennsylvania.



Sean Brame speaking to the news media at the Lobby Day Press Conference, March 10.



Pictured L-R: Gillian Mueller, Legislative Aide to Sen. Robert P. Casey, Jr., and Don Davis, Leader AST's Berks County Chapter, rear: Dick Nickle, AST President and near the Flag, Don Hossler, AST CO-VP



Jake Schrom, Leader of the Nittany Valley AST - Amputee Support Team, at State College, PA

Another Great Meeting, this one held APRIL 1 by our newest AST Chapter, the Nittany Valley Amputee Support Team: Led by Leader, Jake Schrom, the Nittany Valley AST met at HealthSouth's Nittany Valley Rehab. Hospital in State College, PA.

For the first meeting, it was well attended, and from their reaction, those attending will be returning for future meetings. A lot of credit goes to Jake, the Groups Leader, and to the support coming from Ann Foster, Director of Therapy at HealthSouth Nittany Valley, and Katie Donovan, Physical Therapist at HealthSouth. Also attending were Richard Nickle, AST President, Georgia Foltz, AST CO-VP, her husband Robert, and Fred and Stacy Schrom, Jake's parents.



Jake Schrom, white shirt, Support Group Leader in one of the discussion groups held during the April 1 NVAST Meeting.

AST Beginning & Basic Calendar for 2009:

Wednesday, May 13

HealthSouth Rehabilitation Hospital

6 PM: AST Board of Director's Meeting

6:30: PM Eric Anderson Speaks About:

"Universal Design: Making a home accessible to all people, whatever their needs."

Refreshments Provided

June 18 – 21, 2009

20th Annual ACA (Amputee Coalition of America) Conference in Atlanta, GA

Wednesday, July 22, 10 AM & 6:30 PM

HealthSouth Rehabilitation Hospital

Amputees Across America:

10 AM: Ride into HealthSouth

6:30 PM Riders Attend Our AST Meeting

Free refreshments at both times

Wednesday, September 16, 2009, 7 PM

AST Board of Director's Meeting

HealthSouth Rehabilitation Hospital

Wednesday & Thursday, September 23 & 24

HealthSouth Rehabilitation Hospital

AST & HealthSouth Celebrate both:

24th, 5 PM : National Rehabilitation Week

25th, 11 AM – 1 PM: HealthSouth Family Reunion

Refreshments provided at both events.

Saturday, October 3, 2009, 11:30 AM – 2 PM

How to "Hurdle Adversity" by John Register

Nationally known inspirational speaker from Colorado Springs, CO

John Register just happens to be an amputee.

Sean Brame's Testimony, Scheduled for April 16, 2009, in Wilkes Barre, Pa:

Good afternoon. My name is Sean Brame and I am a quad numeral amputee.

4 years ago, I was a normal nine-year old kid who was at a soccer practice. I fell when someone tripped me. I was told to shake it off and walk around. Later that evening, my foot began to really hurt. Mom and Dad took me to the doctor's. My foot was X-rayed and we were told it was a bad sprain and to go home and rest it for a day or two.

Early the next morning, I developed compartment syndrome and then SEPSIS. On April 17, 2005, I was admitted to the PICU of the Penn State Children's Hospital. I was a patient there for over three months. I almost died. In fact, people say it is a miracle I lived through the first week let alone to be able to testify here with you today.

My recovery did not come without a price. In order to save my life, both of my legs had to be amputated below the knee. Doctors also amputated my right hand and 4 fingers from my left hand.

Fortunately, I had a talented orthopedic surgeon, Lee Segal, MD who understood the importance of proper fitting prosthetics and he introduced me to Mike Kelly a Certified prosthetist at Lawall Prosthetics of Hershey. Mr. Kelly met with my parents and my doctors before, during and after my initial amputations. Yes you heard me correctly... before, during and after my amputations.

Mr. Kelly consulted with my doctors to ensure I had the right length of stumps to be fit for below the knee prosthetics. This teamwork helped secure my mobility. A surgeon understands how to perform an amputation so a patient's health is not compromised, but a certified prosthetist understands how far to amputate so a patient's mobility is not compromised.

I will tell you that being fit for prosthetic limbs is not an easy task. You cannot just walk into to the local store and pick one off the shelf. It takes weeks of fittings and procedures to make them work properly.

Every patient and every amputation is different. For example, I am a bilateral amputee and my amputations are at different levels.

My hip alignment and height needs to be carefully monitored so I do not develop back and knee problems. Since I do not have hands, my wingspan cannot be used to help determine my height so Mr. Kelly needs to use different measurements to maintain my height. He looks at the thigh measurements, my trunk measurements and the distance from the floor to my kneecaps when I sit in a chair. It is more than 18 and some odd inches, I must use different muscles to get out of a chair and that can make me off balance.

My sockets need to be fabricated from casts that are made of my stumps. The sockets work as the lever that allows me to move. If the sockets do not fit properly, my stumps will become irritated and infection can set in and that may require additional medical treatment or surgery.

Then there are the feet. I am an active teenager who likes to hike with my scout troop, ride a bike with my friends run the sidelines of a football game while serving as the water boy and walk from class to class with my buddies at school. I need mechanical feet that will allow me to perform these tasks and yet, and are light enough so I can walk without getting exhausted. Mr. Kelly had to do a lot of research to find the right feet for me and still he was not happy with the results. He in turn consulted with the engineers at Freedom Innovations and together they made adjustments to a design that worked for me. I have a custom designed Carbon foot with a split keel that allows me to pivot and turn. This design is ads about 1.5 pounds to the weight of my legs instead of 6 pounds in the original design.

Once my prosthetic legs are made, then the fun begins. Just like breaking in a new baseball glove or a new pair of hiking boots, it takes time to get things just right. Allen wrenches are used to adjust the pitch and angle of the prosthetic feet. Pads and rubber pieces are used to make the socket fit more comfortable. Liners needs to be cut and trimmed and socks of different plies need to be ordered.

The legs I have on today were originally made in August. I out grew the sockets in January. They were replaced just last month. I am still working with my prosthetist to get things just right.

Like I explained earlier, I am on my fifth set of legs. Each time I get a new pair, I must begin the process all over again. Each time my prosthetist must research the newest technology to ensure I am receiving the best prosthetic component to meet my needs. My prosthetist knows me inside and out and that relationship makes fitting my legs a lot easier. Mike can look at the way I walk or limp and he knows right away what needs changed, tightened or realigned.

As you have just heard, making the legs that allow me to walk and run takes a lot of time and effort. I can't go to a store and ask for a size 9 leg, pop it on and have it fit. I must work with a team of prosthetic professionals and doctors who not only understand how to make a leg, but how to fit the leg to match an amputee's mobility.

On top of the issue of getting the proper fit, many amputees face the problem of insurance coverage for prosthetics. In Pennsylvania there are insurance providers who permit one leg per lifetime or impose financial caps on an annual basis. I fear that some amputees may be forced to accept inferior products because their insurance company is concerned about the bottom line.

Today, I am here asking you to consider Bill #255 requiring state licensure for professionals who make prosthetic and orthotic devices. I plan to go to college and study Kinesiology and biomedical engineering with a goal of becoming a prosthetic designer. I want the people who fit my designs to be properly licensed so amputees will benefit from the latest technology.

I watch the news and I understand that our country is in a healthcare crisis where services are so expensive the average American can no longer afford them, however, properly trained, certified, and licensed prosthetic and orthotic professionals will actually save taxpayers money because if the fit is correct, additional medical intervention and equipment will not be needed.

Thank you.....Sean Brame

DID YOU KNOW? The Maryland and Virginia state legislatures recently passed parity legislation. This is incredibly exciting, but we still need a federal bill in order to provide protections for health plans regulated at the federal level.

Peer Training Class: The Berks County (Reading, PA area) Amputee Support Team, an AST Chapter, completed it first ACA Certified Peer Visitor Training Class on April 4, 2009 (See photo right).

Held at the Reading HealthSouth Rehabilitation Hospital, the graduates of this intensive one-day training class make up a core of amputees trained and certified by the ACA – Amputee Coalition of America to do intervention with potential, or new amputees. Peer Visits and intervention are only done when invited to do so by a medical facility, nurse, caregiver, a family member, and the Individual being visited must give their approval.

Don Davis, the leader of the Berks County AST, is the coordinator, and when requested, will assign an ACA Certified Peer Visitor to do an intervention with a potential, or new amputee. Don can be reached at: donaldsdavissr@aol.com / 610-310-1508



Front row L-R: Dick Nickle, PV Trainer, Don Davis, Berks County AST Leader, Rick Milen, Prosthetist, Barb Freethy, amputee, Ron Ferguson, amputee. Standing rear L-R: John Falter, amputee, Scott Schaffer, amputee, Clay Luffey, Prosthetist, Roy Fuchs, amputee, Beth Sattizahn, amputee.



Postage

Richard K. Nickle, President
14 Southern Cross Drive
Boiling Springs, PA 17007-9741

“So others may benefit from us.”

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TO:



AST is a 501(c)(3) non-profit limb loss support group.

Learn more about AST at: www.amputeesupportteam.com

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See Inside the Latest About Prosthetic & Orthotic Parity Legislation

Our next AST Meeting:

Wednesday, May 13

HealthSouth Rehabilitation Hospital

6 PM: AST Board of Director's Meeting

6:30: PM Eric Anderson Speaks About:

“Universal Design: Making a home accessible to all people, whatever their needs.”

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Register NOW: The 20th Anniversary ACA Conference

June 18-21, 2009 at the Renaissance Waverly Hotel, Atlanta, Georgia.

Hotel reservations are now available.

Call toll free 1-888-267-5669, or go On-line at www.amputee-coalition.org/conference

AST thanks Mrs. Jan Zink's Boiling Springs HS Life Skills Class for assembling & labeling our Newsletters.