EAGA Golf Tournament Helps Amputees Return to Active Pursuits **Managing Idiopathic Scoliosis Foundation Helps Individuals** with Permanent Disabilities to Achieve a More Active Lifestyle Patient Profile **Teen Ath Action Des**

Getting Back in the Swing of Things... **Amputee Shines at EAGA Golf Tournament**

here's nothing like bringing home a first place trophy from a golf tournament—especially if you hadn't played golf in more than 20 years. It's even more amazing if you hadn't tried to play golf since you became an amputee.

Vietnam veteran Walter O'Brien lost his leg in 2008 as a result of exposure to Agent Orange, but since playing as part of a winning team at a tournament that welcomes amputee golfers, his interest and enthusiasm for the sport has experienced a dramatic resurgence.

The event was one of many such opportunities made possible each year by the Eastern Amputee Golf Association

which helps facilitate and organize clinics and tournaments for the Philadelphia Veterans Administration and similar groups, as well as sponsoring its own events. Its premier annual event was the 30th Eastern Regional Amputee Golf Association (EAGA) Championship held in July at the Saucon Valley Country Club in Bethlehem, Pennsylvania-which has had a significant impact on the lives of hundreds of amputees who find their way back to active participation in a favorite pastime:

Bob Buck, EAGA Executive Director, presents Chris Duckett and Adam Benza with their tournament trophies.

"I was a golfer before," O'Brien explained. "My daughters golfed for their high school, so we'd go out and practice and I'd play with them. But after I lost my leg, I never really got back into it."

Due to some difficulties with the fit and comfort of his prosthesis, he continued to stay away from the game, but when a referral took him to Jack Lawall and he was able to explore technology that allowed improved ankle rotation, his confidence also improved.

"Ever since then, I've had no problem with my leg," said O'Brien. "Lawall has a great group of people; I have the greatest regard for them."

Still, despite going to an EAGA "first swing" clinic twice, it wasn't until this spring that he agreed to give the tournament a try.

"There were a great bunch of fellows playing," he recalls. "I played with two other amputees and a VA representative. We played nine holes and we had a good luncheon afterwards. I got to meet a lot of other veterans from Vietnam and elsewhere, the weather cooperated and it was just a very enjoyable time."

He attributes his team's gratifying 1st place win to the skills of the other experienced players with whom he was partnered, one of whom was a former pro.

"I told them I'm not very good at it," he laughed, "because

I hadn't played in quite a while—but I wanted to get back into it and try it again. All three of the other gentlemen helped me out very much—and we had a great day playing."

O'Brien's story is just one example of the good work the EAGA (Eastern Regional Amputee Golf Association) is accomplishing to help veterans and other amputees at all levels return to more active and enjoyable pursuits, says EAGA **Executive Director Bob** Buck, a veteran who

also has been an amputee for 46 years.

The EAGA's stated mission is to assist in the rehabilitation of amputees and provide for their general welfare, both physical and psychological, through the medium of golf and its associated activities.

Formed with just a nuclear handful of players back in 1986, the EAGA now has more than 840 current members, drawn from 42 states. Participation in this year's tournament included 67 amputees from 16 states and Canada.

Buck identified the tournament as the largest of the events the EAGA offers throughout the year, well-attended not only by amputees, but their family members and friends, many of



whom hold associate memberships.

"For our Sunday scramble we had over 100 players, and 40 of them were non-amputees—friends, spouses, relatives. We have a division for them, with awards for the associates' division," he said.

Younger players are also welcome and can play in the tournament at no cost, competing for a junior trophy named to honor a young amputee who played with the association for a number of years before he succumbed to returning cancer at age 17.

While golf is an ideal pastime for wounded warriors to adopt, and the EAGA has strong representation from the Vietnam veterans group, Buck points to what appears to be a natural progression as younger warriors heal and mend:

"I've been doing clinics with soldiers from Walter Reed (Army Medical Center) for the past eight years," he explained, "and we have a list of about 120 who have attended. A good friend who worked for the VA—a double amputee from Vietnam—indicated that it's going to take a timetable of around 10 years or so before they're back into the mainstream of things, getting their lives started again. Golf is a perfect lifelong game for them

that involves family; but they have to think first about getting jobs and maybe getting married and having families."

But when that time comes, the EAGA will be there for them, offering the benefits of exercise, friendly competition, and a camaraderie like no other.

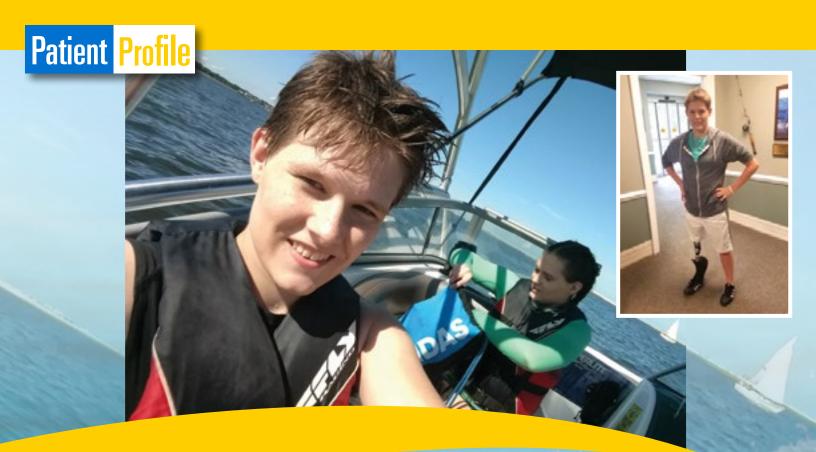
For some, it's the perfect solution; for some, like O'Brien, it's a new beginning.

"I'm not back to everything I'd like to do," he reflected. "Lawall made me a swim leg, so I go swimming now; I'm getting back into golf, and I'd like to get back into hunting, too; but I need a more flexible ankle for walking on uneven ground. That's something I really look forward to doing again."

Lawall is a proud sponsor and supporter of the EAGA and its events, and encourages participation: Annually, the EAGA conducts seven two-day tournaments and six one-day outings and scrambles, plus 22 "First Swing" Seminars and 24 "Learn to Golf" clinics within their region.

To learn more about these opportunities to improve your game or start playing for the first time, contact your Lawall prosthetist.





Teen Athlete Springs into Action Despite Amputation

Il young ladies dream dreams: but while 16-year-old Rachel Buckley is dreaming, she's also busy designing cities and kicking soccer balls with an energy and enthusiasm that raises the bar for her peers. Instead of slowing her down, the prosthetic leg and soccer-customized Cheetah foot she wears seem to motivate Rachel not only to keep up with her able-bodied teammates, but to do more—and do it faster and better every time.

Rachel's leg loss occurred as a result of twin-to-twin transfusion syndrome (TTTS), a disorder which occurs when the blood vessels of the babies' shared placenta are connected. Rachel and her identical twin sister Kim were affected by the unequal sharing of blood between them; Rachel got too much, while Kim got too little. Rachel experienced congestive heart failure in utero from the excess blood to her heart; a blood clot that likely developed in the placenta and traveled from there to the back of her right knee blocked blood flow and caused the necrotic leg she was born with.

The twins were born at 31 weeks, when Rachel weighed two pounds and fourteen ounces, and her leg was amputated two weeks later. Kim's normal development was not affected.

A random event that cannot be prevented, TTTS occurs about 15% of the time among identical twins; fraternal twins are not at risk because they do not share a placenta. Until recently, TTTS often claimed the lives of both babies, but current technology provides successful treatment options once the syndrome is detected.

Rachel received her first prosthesis when she was just 10 months old, at the time babies normally begin pulling themselves up to stand. Her parents, Dan and Sue Buckley, report that she didn't walk on her own until she was about 22 months old—a slight delay from the normal timeline. "She just had to get the confidence to let go of a hand or wall," Sue explains.

Her first prosthetist, Harry Lawall Jr. (Bud), provided her with several of the 14 prostheses she has already worn in her lifetime. His death when Rachel was 10 years old was a difficult blow for her, Sue reports. "He was great—absolutely great and losing him was rough for her."

During the following years, Rachel has received her prosthetic care primarily from Jack Lawall.

"I'd say they (the Lawalls) are probably my second family!" Rachel exclaims. "They've helped me with so much over the years. They've made me the person I am today, being able to play sports and use my leg."

Adjusting so many times to a lifelong series of prostheses has really not been difficult from Rachel's perspective. "It's pretty much the same story each time. When I was 11 I was changed to a different knee, and that took a little longer; but overall, I just did what I usually do, and adapted to it."

Apparently practice makes perfect. "Jack Lawall has always said they could probably just put a stick on my leg and I could walk on it in 15 minutes!" she laughs. "I guess I've learned to be adaptable."

Lawall agrees. "Rachel is an amazing patient: very energetic, friendly, outgoing; and nothing stops her!"

Adapting for Soccer—and Much More

Soccer is just one favorite of the many sports and activities that Rachel has tried. She began playing at age four, and sister Kim quickly joined her on the field as a defender. Rachel got a running leg so she could run and keep up better on the field, but although she loved the bouncy feel of the energy-storing Cheetah foot, its J-shaped single carbon strut was not designed for kicking the ball.

Jack Lawall initially realized that the Cheetah foot answered her need for sprinting and moving side to side quickly; but attempted kicks using the bare curve of the prosthetic foot usually resulted in the ball just rolling over the top of the foot—a frustrating failure.

Known for developing creative solutions to solve unusual patient problems, the Lawall team customized a fitted cover of very strong and durable leather, which Rachel could take off and on, as needed.

"We have four full-time leather craftsmen in our custom leather department," he noted, "so we were able to design and make the shoe very quickly—in about three days. The job of orthotists and prosthetists is not always straightforward; often you've got to think outside of the box like this in order to help people, and we enjoy that challenge."

Although the foot with its added leather weight felt heavy and somewhat awkward during her first attempt to use it, true to form, Rachel is determined to give it another

try and believes she can get used to it.

Sue acknowledges that Rachel was probably much more aware of the weight difference because she started the game with her regular leg, and tried to switch it out mid-game.

"Now that it has the solid foot, it works a lot better," Rachel adds. "I tried it a little bit and it does seem to work out really well; I'm thankful for that,"

The twins are the youngest of the Buckleys' five children, all of whom have been active in sports and continue to set a supportive example for the twins.

Brother Danny is oldest, at 27; followed by Amanda, 25, and Lyndsey, 22—who plays softball competitively and alongside

her mother Sue. "Rachel has always wanted to be as active as her siblings," Sue "When explains. they were little, she took gymnastics. She took dance. They watched Lyndsey and me playing ball since they were born, and Rachel was actually first, at three, to start in T-ball, and her twin joined her soon after that. She loves almost

any sport; it's her



A list of the sports and active pursuits Rachel has tried would require a lot of type: a list of the sports and active pursuits Rachel hasn't tried might be easier and shorter—but here's a sample of what she's already done for fun:

- Hiking Tubing
- Boating
 Kayaking
- Trampolining
- Biking
 GoKarting
- Surfing
- Lazer Paintball
- Soccer
 Beach Biking
- Softball Ice Skating
- Swimming
 Bicycling
- Tennis Archery
- FencingI
- Parasailing

In between, she has ridden a Segway hoverboard through the streets of Philadelphia, attempted snowboarding, wakeboarding and skateboarding, and piloted an airplane. She's shared family fun on trips to museums, arboretums, concerts, monster truck rallies, and more. She continues to explore her artistic talent, designing the original motif that adorns her prosthetic leg, and preparing for a possible career as a civil engineer by learning to design cities and the buildings that comprise





favorite thing to do."

An eager learner, Rachel also serves as a mentor to others, supporting Lyndsey, who coaches eight-and-under-softball. "Rachel loves to go and hang out with them and sort of cocoach and help out," Sue explains.

Her enthusiasm for exploring new and different athletic pursuits appears inexhaustible-- Rachel is eager to try a world full of new possibilities that are open to her—and to approach doors to others that might open, if only she tries. Her mother mentions tennis, kayaking, hiking, and much more:

In fact, through a recent experience at an Amputee Coalition summer camp, she has added yet another interest: sitting volleyball. The U.S. Paralympic team came to the camp and demonstrated the sport and let the campers play—and now the Buckleys are hunting for a site and opportunity where Rachel can gain more experience in the sport.

"She always gives it a shot," Sue notes, regarding any new idea or opportunity for sports and recreational fun. "We've never discouraged her. We've tried rock climbing with and without the leg," she laughs. "Sometimes she does better at things without the leg, because it can be a hindrance."

--and if she doesn't succeed the first time, she tries again if not boldly and immediately, then later, with determination and persistence undaunted by injuries.

"She ends up in the goal a lot when playing soccer, because it doesn't involve running—and she'll dive for the ball. She's been sort of falling all her life, and so she knows how to fall safely," Sue explains with wry humor.

Although soccer and softball are favorite sports in season, Rachel confesses that, forced to choose a favorite, she'd probably pick surfing, even though she hasn't been practicing much.

It's been a dream of hers since she was inspired by the experience of professional surfer

> Bethany Hamilton, who lost her left arm in a 2003 shark attack, but recovered and continues to compete successfully. Hamilton has quite a fan following—including Rachel.

Her third surfing les-

Rachel and her mother enjoying Country Concert Night at the Phillies game.

Rachel piloting an airplane.

son was disastrous, however. She fell off the board near the shore, and a wave slammed it into the back of her head, giving her a concussion that kept her out of school for eight weeks.

Is that the end of surfing for Rachel?

"I have a bit of anxiety," she admits, "but I definitely want to get back out there!"

Taking Obstacles in Stride

The surfing setback was only one of a number of accidents, falls, and injuries that Rachel has experienced and risen above, Sue reports.

"Rachel was in the ninth grade, recovering from the concussion and ready to go back to school, but decided to go golfing first. She had ulnar nerve issues and irritation—aka 'golfer's elbow'. She ended up in surgery, having her ulnar nerve transposed."

Again, during the same 9th grade year, Rachel underwent surgery to get nerves oblated in her back in order to eliminate some of the discomfort she was experiencing as a result of her legs being different lengths, and her tendency to hop around without wearing her prosthesis, at times, her mother reveals.

Despite pain, discomfort, and physical limitation, she's always in there, trying her best and trying to make a difference.

One of her coaches told the team following a recent soccer game, "If everybody on the team had given as much as Rachel did tonight, we would have won!"

Her fearless "can-do" attitude in the face of obstacles and painful setbacks is an inspiration to others; and, conversely, the feedback she receives from others who respect her extra effort inspires her, as well.

"Last year I played soccer against another town, and the coaches came up to me and said, 'Never stop doing what you do' and told me how I always inspire them," she recalls. "Even during the handshakes following the game, sometimes (competing) players will just say, 'You inspire me,' or 'You're amazing!'—and that really makes me feel good. I just want to be able to play with them, but it feels very nice that they acknowledge me for what I do."

"Rachel has done pretty well because she's dealt with this all her life," Sue reflects. "At camp she met some people who lost their leg later in life, and I think she sees that it can be a little bit more difficult to adapt to at that point. But we've seen people be successful then, too; so even if you're in that situation, I think she would encourage you: Believe you can do what you want to do; you just have to work at it."

"Definitely!" affirms Rachel.

Throwing one's heart, soul, and body boldly into the fray can be stressful to one's prosthesis, as well, however, and Rachel has experienced her share of "broken legs"—a family joke shared each time the prosthesis succumbs to excessive use. While she has a prosthesis for daily use, one designed for the beach, and the running leg with Cheetah foot, it's difficult to ambulate with the wrong foot for the job.

When Rachel breaks her leg, Sue warns, "...it's a good idea to have a pair of crutches handy; this is something that happens. People have recommended the computerized leg for her, and they are wonderful! But she's going to break it. She's tough on the legs, so the simpler, the better, at this point."

What Lies Ahead?

At 16½, Rachel is preparing to take on yet another new challenge—both twins are learning to drive, in a car of their own. And Sue explains that what is a simple process for her sister has been a "little ordeal" for Rachel.

"We found that in order to get a driver's license in the state of New Jersey she has to go through a rehab center and have special driving instructions and be cleared medically—and getting things scheduled at their limited locations has been a little difficult. The state also requires her to have a different license and an adaptive pedal that activates the accelerator."

Her mother, a medical technologist, has gained a lot of experience in surmounting such obstacles, and is happy to share her knowledge with others.

She has supported the March of Dimes each year for 13 years, because the twins were preemies in the NICU. "Rachel and Kim always march along with me—living proof that whatever happens after they get out of the NICU, you still move on—and there's a future for a lot of these children, and they do well," Sue explains.

"I've always been very open about other kids showing interest in Rachel's 'robot leg'. It's okay—they can look—they can ask. They shouldn't be afraid of it. They should ask about it and understand it. When she first started kindergarten, they asked

if I wanted to come in and talk to the class about her prosthetic and I said, 'No—let her do it. She knows about it.'

"So they had a little show and tell session, they asked questions and that was it."

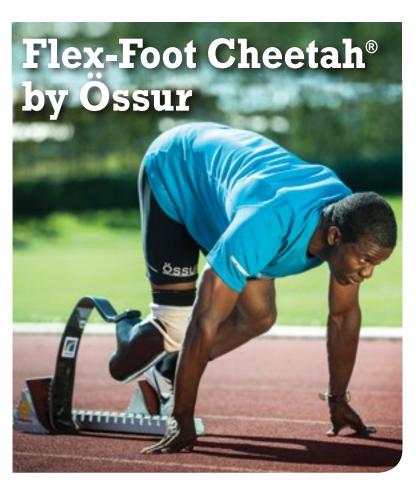
Such family activism, and the positive influence her parents and siblings provide, have played a significant role in developing Rachel's clear-headed and practical outlook on life: The toughest thing about wearing a prosthesis, she says, are not social or psychological issues, but purely logistic problems like how to deal with excessive perspiration issues that sometimes cause slippage in the prosthesis' socket that causes its vacuum attachment system to fail. (Lawall is already addressing potential solutions that involve prescription-level antiperspirants and/or a new liner.)

"They always work with us with her craziness!" Sue laughs.

"I'm so blessed," Rachel adds. "Everyone treats me just the same. I have heard of people getting bullied, but I've actually never, ever had a problem with that."

Her family has always done what families do for each other: "They've treated me like a normal person," Rachel says earnestly. "They let me fend for myself. Sure, they ask me if I need help sometimes, but they've let me adapt, and given me that help when I needed it. Overall, I'm thankful that they have let me grow into the person I am today—and be myself."

To others with limb-loss limitations, she says simply, "Never give up. Definitely never give up. You can really do anything with the support of others—and your own self will."



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New Peer Support Group Offered in Bucks County, PA

St. Mary Rehabilitation Hospital is starting a new amputee support group for all patients and their families and friends. The group will be hosted by members of St. Mary's clinical team.

Peer support groups like the new one at St. Mary provide an invaluable place for individuals with new amputations and their family members to connect with others who have overcome similar challenges. These groups offer a chance for amputees to hear from others who are in the same situation or who've already gone through much of the problem solving process that accompanies limb loss. One can pick up some new techniques to deal with everyday activities, learn about new components on the market, or ask questions about moving forward in life after the loss of a limb.

The group meets the last Tuesday of the month at 6:30 PM in the dining room on the upper level of St. Mary Rehabilitation Hospital. 🦋



The Challenged **Athletes Foundation Now Accepting Grant Applications**

The Challenged Athletes Foundation (CAF) is an amazing organization started in 1997 whose purpose is to help individuals with permanent disabilities achieve a more active lifestyle. The organization is currently accepting grant applications.

The CAF supports their members with adaptive sports equipment, training and assistance with competition expenses. Throughout the year, they host various camps and clinics in cities around the United States. These events provide support and coaching to help challenged athletes grow through sports.

If you would like more information on upcoming clinics and grant information, visit their website at www.challengedathletes.org and talk with your Lawall representative to learn how we can assist you. 🦋



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Managing Idiopathic Scoliosis

diopathic Scoliosis (IS), is a condition in which the spine begins to curve, also exhibiting a three-dimensional element of rotation in that curvature. The IS patient profile varies widely regarding age of onset, and size land flexibility of the curve; these factors are vital in determining the most effective path of treatment.

Some outward signs of scoliosis can be uneven shoulders or hips; one scapula appearing more prominent than the other; or a sideways shift of the trunk and chest. The Adams Forward Bend Test is often used as an indicator: imbalances in the rib cage or other deformities along the back are more evident as the child bends to touch his toes.





In the X-ray above, the curvature and rotation of the spine caused by Idiopathic Scoliosis is apparent. One of the Thoracic Lumbar Sacral Orthosis (TLSO) bracing options available for the treatment of scoliosis is the Wilmington Jacket graciously modeled here by Greta Schroeder.

Idiopathic Scoliosis usually affects children and adolescents through age 18, and is more prevalent in girls, most frequently presenting itself during a pre-adolescent growth spurt. The earlier the onset and the greater the curve, the more likely it is that the curve will progress. "A worsening of the condition can be described as a "race between curve progression and the maturation of the growth process." (Gavin, 14.)

An initial X-ray allows the orthopedic surgeon and the orthotist to measure the curvature of the spine utilizing the Cobb method, and then determine the most appropriate treatment plan.

The Cobb angle, which assesses the degree of curve, is formed by the intersection of two lines drawn on a spinal X-ray. Curves between 20 and 40 degrees are most often addressed orthotically, with the goal of preventing the curve from increasing, thus obviating the need for surgical intervention.

An "orthosis can be efficacious in the treatment of IS, and their use is the only nonsurgical method shown to positively alter the natural history of the disease." (Gavin, 15)

Several bracing options are available for the treatment of scoliosis. The most common is a Thoracic Lumbar Sacral

Orthosis (TLSO), which is made of lightweight material and worn under clothes for 18-20 hours a day. One TLSO choice has a thin polyethylene outer shell with a soft inner lining. A brace for nighttime wear only is an attractive option for some patients; it works by aggressively over-correcting the patient's curve during

The popular Wilmington Jacket was developed by Lawall in conjunction with orthopedic surgeons at Nemours Alfred I. DuPont Hospital for Children.

Measurement processes vary depending on the type of brace prescribed. The Wilmington Jacket requires a cast of the patient and an X-ray while in the cast to ensure optimal in-cast correction of the spine. Other braces may require special table measurements or circumferential measurements that a CAD system utilizes to produce a positive plaster image.

Research strongly supports the effectiveness of bracing as a treatment for scoliosis. Overall, braces prevent 60-70% of spinal surgeries. (Nemours). Nonetheless, compliance remains a major factor in how successful bracing can be; the perfect brace design is valueless if it sits in the closet.

Surgeons and orthotists are not naive about the challenge of asking a teenager to wear a TLSO for 20 hours a day. Therefore, to encourage compliance, it is imperative that the patient and his/her parents understand the complexity of idiopathic scoliosis and recognize research that supports bracing's effectiveness.

While it is not a life-threatening disease, idiopathic scoliosis can significantly impact the health, well-being and function of a patient if left untreated. Historically, preventative screenings were performed in schools and in pediatrician well child visits, but school screenings were recently discontinued due to concerns over misdiagnoses and costs. Screenings during routine pediatrician visits remain necessary and important. (Schultz).

Lawall's Heather Michalowski, CO, has started a peer support group with Nemours Children's Hospital in Delaware, which allows IS patients to address the problems and frustrations they face by sharing with others dealing with the same issues. For more information, call Lawall's Delaware office at 302-429-7625.

Other resources for patients and parents include an online support organization at www.curvygirlsscoliosis.com, started by Leah Stoltz in 2006 when she was 13 years old and began wearing a scoliosis brace. Leah's original group of four has attracted hundreds worldwide—from Australia to Turkey and beyond. She was honored with the HALO award from TeenNick in 2009 for her work in supporting teens with scoliosis and their parents. (Fairley)

The etiology of scoliosis still remains unknown and, to date, unpreventable. It is best to catch it early and to seek treatment with an orthopedic surgeon who specializes in idiopathic scoliosis. Lawall's pediatric orthotists who specialize in scoliosis bracing are happy to answer questions.

Thomas Gavin, "Points of Consensus: Idiopathic Scoliosis," JPO Vol. 15, Num. 4, 2003, pp. 14-16.

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Miki Fairley "Adolescent Idiopathic Scoliosis: Helping Kids Meet the Compliance Challenge" The O&P Edge April 2003





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