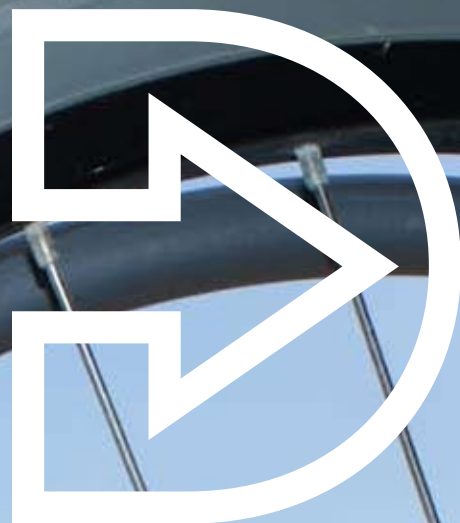


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Don Clayback is executive director of the National Coalition for Assistive and Rehab Technology (NCART). Don has more than 23 years of experience in the Complex Rehab Technology and Home Medical Equipment industry as a provider, consultant and advocate.

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Andrew Davis is the consumer advocacy and relations intern for NRRTS. **See page 58.**



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Carol Hickey is a consumer advocate and attended CELA 2011 in that capacity. She is employed by Mobility Designs in Atlanta. **See page 14.**



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CELA: PAST and Present

Written By John Zona

CELA, CONTINUING EDUCATION AND

Legislative Advocacy Conference, was tremendous this year with more than 220 legislative visits on the hill. CELA has grown every year in attendance and consumer involvement. This year, we used legislative language when speaking with our legislators or their health aides on the Separate Benefit Category for complex rehab under CMS.

CELA was established in 2008 to provide individuals the opportunity to visit with members of Congress and advocate for the complex rehab industry. It is also a cost effective way to obtain continuing education credits.

Our goal in 2008 was to educate our legislative body on the difference between complex rehab and regular HME. We brought eight consumers with us.

In 2009, we went to advocate for a carve-out of complex rehab from competitive bidding. We know we were somewhat successful, but only complex power was carved out. This was a big start, however, CMS realized we were different than standard HME. We brought 12 consumers with us.

In 2010, we set the stage for the Separate Benefit Category for complex rehab technology under CMS. We brought 21 consumers with us.

In 2011, as I said earlier, we brought a draft of legislative language for the Separate Benefit Category. This year, we brought 30 consumers with us!

It is not by chance that consumer numbers have increased every year. In 2008, eight consumers and in 2009, there were 12. In 2010, we brought 21, and this year, 30 consumers and their personal care attendants from across the country made the journey to Capitol Hill.

We realized from the start it was fine to have industry professionals, both able and disabled, state their case,

but to have independent disabled consumers tell their life stories would have the greatest impact. Giving legislators the opportunity to listen to people talk about how living life, day in and day out, without access to appropriate complex rehab equipment would be life changing. Then our legislators could see, in person, a citizen who is working and paying taxes just like everyone else; and they could hear from them how without their equipment, they would not be able to do so.

These consumers could not be funded or “scholarshipped” without the help of our fine industry sponsors.

Each year, with the incredible help of NCART, when we visit with our legislators and their legislative assistants, we form relationships. They know who we are. It is very empowering to educate our leaders on our industry. More should make the trip.

This year, we created an opportunity for those who couldn’t attend to call their legislators the day before and voice their opinions. This works. We had numerous legislative aides tell us they had calls from their constituents. We all have a voice.

The CELA date for 2012 has not been set, but watch for the date. Please attend and bring one of your consumers. We need the support of our industry sponsors again next year. This is the only

Giving legislators
the opportunity to
listen to people talk
about how living
life, day in and day
out, without access
to appropriate
complex rehab
equipment is life
changing.

time of the year we ask for sponsorship dollars for a great cause — our future. Every cent we raise goes to CELA.

In 2012, should we bring 40 consumers? ➡

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THANK YOU!



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Written By Denise M. Fletcher, Esq.

NEVER Take No for an Answer

FINDING FUNDING FOR STANDERS

NOTHING FEELS BETTER THAN HELPING

patients obtain the equipment that best meets their needs; but, unfortunately, that is easier said than done. This is definitely true in the area of standers. The equipment available today has many benefits and can be anything from a basic stationary stander to a power wheelchair with a standing component. The insurance company's goal is to keep costs down. As a result, many times the only equipment the insurance company is willing to fund is the least costly alternative. In contrast, the equipment that may be most beneficial for your patient is of higher cost and may contain features that insurance companies consider to be comfort items and, therefore, not medically necessary. In some situations, the best equipment for the patient may be the standard item covered by the insurance carrier. More often than not, it is a poor alternative and then the supplier is thrust into the position of becoming the patient's advocate. This can be time consuming; in today's economy, it is important to be as efficient as possible. When you spend extra time to get paid for an item, it cuts into your bottom line. There are a number of things you can do to properly document the patient's needs and find funding.

A key to being successful is getting the patient's family or caregiver involved in the process. The caregiver will be very passionate about the needs of the patient. This is important, because you must keep fighting and never take no for an answer. The caregiver can be the squeaky wheel and force the insurance company to expand its coverage policies.

It is important that you know the coverage criteria of the funding source. Private insurance companies are generally not required to cover any specific item and offer different products to its insured population. Arguably, the insurance contract is negotiated between the parties. In reality, the insured generally accepts what is put in front of them; and in today's time of rising health costs, what the insured is willing to accept is frequently determined by the price. The coverage details can be hidden in the fine print that no one wants to read. So, read the fine print. A good place to start is the Summary of Benefits. This details the insurance carrier's appeal process and any deadlines that must be met. Failing to meet an appeals deadline will result in a timely filing denial, and there is generally no recourse. This is the death sentence for your appeal.

In addition, the insurance plan will outline its requirements in regard to whether or not specific equipment suppliers must be used. If the plan will not cover equipment provided by your company, it may be best to refer the patient to a company that can provide the equipment. While no one wants to send a potential customer to another supplier, finding out early in the process that your company cannot provide the equipment can help prevent you from spending a large amount of time on a project that won't result in payment. Your time can be more efficiently devoted to patients that you can help.

If a state Medicaid program is the funding source, it is equally as important to know what the program covers. Coverage varies from state to state. However, the federal government does mandate coverage for certain items. Learn what the Medicaid program will cover and what criteria must be met in order for payment to be made. Be sure to take a look at Medicaid waiver programs, as these programs will cover things not included in a traditional Medicaid program. In today's

If you are ever presented with the opportunity to talk with regulators, take that opportunity to educate them in regard to the importance and need for the equipment placed by your company. economy and budget shortfalls, coverage criteria can be a moving target, so stay current on changes. If you are ever presented with the opportunity to talk with regulators, take that opportunity to educate them in regard to the importance and need for the equipment placed by your company. Let them know the time and effort involved in finding the right equipment and any other special services that go with providing the equipment. Tell them about follow-up services that also need to be provided. Many times regulators have no idea what it takes to place the equipment and mistakenly believe that

(continued on page 12)

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Technology In Motion

Never Take No for an Answer

(continued from page 10)

providing the equipment doesn't require anything more than opening a box and handing over the equipment.

You will also need to work closely with the clinician caring for the patient. Coverage decisions are made based on the quality of progress notes that are submitted with the claim. The clinician is unlikely to understand the coverage criteria, and unless educated about what needs to be addressed in the progress notes, the support documentation will not be present. Focus on the patient's medical problems and risk factors. Have the clinician demonstrate how the use of a stander will address these problems and prevent further medical issues. If you have found certain coverage criteria in the plan, then make sure the clinician also knows what criteria must be met to have the insurance carrier fund the equipment. Follow any clues found in the plan, and if possible, have the clinician track the coverage language in the progress notes. Doing so will make it easier to demonstrate that all the coverage criteria have been met. Insurance reviewers frequently go through a checklist when making a coverage determination. When an element is not met, a denial can be issued.

Focus on activities of daily living or ADL. The progress notes should discuss what problems the patient is having with his or her ADLs, how the equipment will alleviate these problems, and how it will allow the patient to function with less assistance and more independence. Ask the clinician to provide specific examples instead of broad generalizations. Providing good documentation of ADLs is particularly important with Medicaid programs, as a primary goal of these programs is to provide its recipients with the items and services necessary to attain and maintain independence and self care.

A picture is worth a thousand words, so include pictures and/or videos of the patient using and benefiting from the new equipment. If you are replacing old equipment that is unsuitable, include pictures that demonstrate the problems with the old equipment.

Ask the family and/or caregiver to write a letter stating how the equipment has made a difference in the life of the patient. Include a discussion on the physiological, psychological, emotional, and social benefits as well as the functionality of

Insurance reviewers frequently go through a checklist when making a coverage determination.

the equipment. Again, the caregiver will be very passionate about how the patient benefits from the equipment.

Look at all of your options. Maybe the insurance company will cover a basic stander, and the patient can pay for the difference in the upgrade to a power stander. Also, if

the insurance company will cover a power wheelchair and a stander separately, consider asking the company to reimburse the components that would be covered if the equipment were being provided separately. There have been cases where insurance companies that don't cover standing wheelchairs have paid for the power wheelchair base and the covered features for a stander decreasing the out-of-pocket cost to the family.

Finally, a good resource is the equipment manufacturer. Manufacturers often assist suppliers in obtaining coverage and may have worked with the insurance company denying your claim. However, keep in mind that the manufacturer's goal may be different than yours and sometimes their advice may push the envelope. At the end of the day, the supplier submitting the claim will be the one responsible to the insurance company for an inappropriate claim, or in the event a claim isn't paid, the supplier is the one who is out the cost of the equipment.

Helping a patient obtain equipment that meets their needs can be very satisfying in and of itself, but getting paid for it will keep the lights on and allow you to continue serving your community. To get paid, you have to be diligent, knowledgeable, and sometimes a little stubborn. Use all the resources available to you and don't take no for an answer. ➡

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The Little Irish Warrior's **FLIGHT** to *Freedom*

Written By Randy Christian

THE CASTLETOWN RIVER RUNS THROUGH

the 'border town' of Dundalk, Ireland, and then empties into Dundalk Bay. They call it a border town, because it rests snugly against the invisible line dividing Ireland from Northern Ireland.

Records indicate this region of Ireland has been inhabited since at least 3500 B.C. In ancient times, Dundalk was written Dundalغان, linking it to the Irish mythical warrior Cú Chulainn. You can see on the banner flowing beneath the town's classic crest the following words: Mé do rug Cú Chulainn Cróga which means, "I give birth to the brave Cú Chulainn." This larger-than-life folklore hero is best known for his displays of strength, courage and sheer determination while still just a teenager. It was prophesied by many this warrior's great deeds would be remembered forever and results in everlasting fame.

Carol Hickey, like many a young lass in Ireland, attended an all-girls Catholic school. Her school, St. Vincent's, was practically a stone's throw from her family's home in Dundalk, Ireland. In 1982, the town was much smaller than today. Everyone knew everyone. Faces were immediately recognized, and names were quickly recalled.

Even though Hickey was not excessively enthusiastic about attending St. Vincent's, she certainly enjoyed its athletic programs. At this time of her young life, as it would be in later years, it consumed her. She was especially fond of gymnastics, and as a teenager taught the sport to young children in her hometown. She took great pleasure in coaching the little ones, but she also earned money to travel to London where her hero, Nadia Comaneci, an Olympic gold medalist, would be performing at Wembley Stadium.

Hickey's passion for gymnastics was obvious, but something else had captured her young mind and heart — flight. She desperately wanted to learn to fly. For as long as Hickey can remember, flying and things that fly sent her spirit and imagination soaring. She even had a pet seagull.

"At a very early age, I was fascinated with flight. I loved airplanes and anything that could fly," Hickey said. "Yes, I did have a pet seagull, and yes, I did read Jonathan Livingston Seagull many times."

In the fall of 1982, just two months into her 16th year of life, Hickey took the day off from school to care for her mother who

was ill. She rode her bicycle to the nearby pharmacy, or chemist, as they say in Ireland, and picked up a prescription for her ailing mother. The road home was rough, very narrow and heavily traveled. Trucks of all size used it as a main artery to the docks, at Dundalk Bay, where ships loaded and unloaded freight at a frantic pace daily.

Hickey's legs churned hurriedly, moving the bike at a steady pace along the outside edge of the road that she shared with a massive 18-wheeler. Its driver was focused on little else but making it to the shipping docks before its loading ramps closed. In the opposing, single lane, two cars were approaching Hickey and the 18-wheeler. The second car suddenly decided to pass the first, and moved into the lane occupied by the 18-wheeler and Hickey. The car and the 18-wheeler were now on a collision course. Instinctively, the driver of the 18-wheeler jerked on his steering wheel moving the truck to the side of the road to avoid a head-on collision with the car. Unfortunately, he was now headed straight for Hickey and her bike.

The massive truck swerved again, trying to avoid Hickey, but still clipped the bike. Hickey went flying. Moments later, she was lying in the middle of the busy, narrow road thinking, "I've got to get up and get the medicine to my mother." Hickey could not get up. She had sustained a life threatening compound fracture of her spine. The driver of the 18-wheeler rushed to her aid. An attendant at a nearby gas station who knew Hickey was by her side in moments, too. As the ambulance and paramedics arrived, a new fear for her life came in to play. It was quickly determined she must be flown by way of military helicopter to a hospital in Dublin.

The battle for unification of the Irelands and independence from Great Britain was still very much a part of daily life in Hickey's hometown of Dundalk. Due to its adjacency to Northern Ireland, spontaneous armed clashes and brutal terrorist activity between the two rival factions were common place. Both sides of the conflict were keenly aware any acts of aggression, perceived or real, would be met with a forceful and often deadly response. A military helicopter flying close to the border would certainly be seen as such an act.

Rebellious groups such as The Irish Republican Army and Sinn Féin were ready, willing and able to launch shoulder mounted missiles capable of knocking down an enemy helicopter

(continued on page 16)



Flight to Freedom

(continued from page 14)

regardless of its mission. Hickey never knew for certain why or how the military rescue helicopter safely touched down on the road where she laid, but it did. Thank God for a few moments the life of a young girl was more important than political agendas or the pursuit of power.

This dark twist-of-fate had also turned Hickey's dream of flying into reality, but for a reason which could only be called a nightmare. The lively young athlete was instantly paralyzed from mid-chest down. The helicopter took Hickey on the first flight of her life, but there would be many more to challenge and change her life in ways she could never have imagined.

Somehow, some way, Hickey survived her horrid accident, but the newly disabled teenager quickly sensed her paralysis might not be the most limiting aspect of her new life. At this time, Ireland's socialized medicine was not particularly friendly to the disabled. It became clear to Hickey to achieve her life's goals and fulfill her dream of one day flying, she must leave her Irish home.

At a very
early age,
I was
fascinated
with flight.
I loved
airplanes and
anything that
could fly.

"By the time I was 19, I was really tired of rejection. I'd had enough of people telling me I can't do this or I can't do that. I'm the kind of person when someone tells me I can't do something, I'll find a way so I can. One thing I knew, I was going to be a competitive athlete. I didn't know what sport, but I was going to do it. I was also going to learn to fly, too. I was going to find a way," Hickey said.

Hickey kicked her tenacious spirit into high gear and began exploring, searching and researching every opportunity to fulfill her dreams. In her search, she came across a magazine called *Sports and Spokes*. This incredible worldwide publication featured the many competitive and recreational sports available

(continued on page 18)

HICKEY DURING COMPETITION



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Flight to Freedom

(continued from page 16)

to the disabled community. In one of the bimonthly issues, Hickey read about an organization in Pennsylvania called Freedom's Wings. This nonprofit international organization was created to provide disabled individuals the opportunity to fly gliders.

Powered by only the wind, these sailplanes took people with disabilities and special needs flying. Specially adaptive sailplanes even allowed the disabled to become pilots. Needless to say Hickey flew through this door of opportunity and immediately sent a letter chronicling her story to Coopersburg, Pa., the home of Freedom's Wings. In short order, Hickey was on her way to Pennsylvania, anxious to learn to fly.

"It was wonderful. I lived with a family while I was learning to fly gliders. I was told I was the first disabled woman to solo in a glider," Hickey said.

On one of her solo flights, she lost a bit of air and began to fall to earth more rapidly than planned. The grass landing strip was adjacent to a small road where a car was traveling. The car was in her glide path as she made a powerless descent to the grassy runway. Flying over, yet nervously close to the car, Hickey's landing was a bit hard, but safe. Surprisingly, the driver jumped out of his car and briskly marched toward the glider and its young pilot saying, "You know if you had an engine in that thing you could have circled and tried that landing again."

The awkward, yet lighthearted exchange was followed with information offered by the driver regarding The Royal International Air Tattoo. This oddly named program, sponsored by the British Royal Air Force, hosts one of the most revered air shows in the world and also provides scholarships to young people who want to learn to fly airplanes. It has a special focus on women and the disabled. Again, a door opened and Hickey scrambled to enter. In 1993, Hickey was one of only nine people awarded an Air Tattoo scholarship. Hickey was soon on



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her way to the United States to learn to pilot powered aircraft and partake in even more life changing adventures.

"I first went to Atlanta to learn to fly. I soon saw this was a place a person like me could easily get on a bus, find a good job and experience more freedom. I thought 'Wouldn't it be great to live here,'" Hickey said.

In 1994, Hickey received her green card, allowing her to live and work in the United States. From that moment on, Atlanta has been her home. She has not yet returned to Ireland, not even for a short visit.

With the green card in hand, Hickey found employment with the 1996 Paralympic games as program manager of Paralympic Day in Schools. This state of Georgia outreach program was created to educate and inform school children about people with disabilities and sports. Its goal was to breakdown the wall of prejudice and alienation of the disabled, which often inhabits schools. This job led to another, allowing Hickey to encourage school administrators and educators to include sports programs for the disabled in the district's curriculum.

Then Hickey also found a new sport that set her competitive spirit on fire — wheelchair fencing. Her work and her fencing workouts gradually consumed her life. In many respects, fencing became her life.

"Fencing is one of the few sports that has retained its original formalities. You must wear a complete and traditional uniform. You must properly greet your opponent and acknowledge the audience. Whether you're standing or sitting in fencing you must abide by the customs and formalities of the sport or else," Hickey said.

As her training intensified, she lunged deeper and deeper into the minutest aspect of her sport and all things surrounding it. Always asking what would give her a greater competitive edge. She would even mentally dissect the construction of her wheelchair in an attempt to determine if its size and composition allowed maximum, productive movement when in the heat of competition. Hickey worked with a sport psychologist several days a week, focusing on how to take control of her competitive environment and live in the moment while facing her adversary. Hickey's intensity and dedication paid off in 2002 when she won a Bronze Medal in the World Champion Fencing competition. She continued to compete on an international level for many years after her championship victory.

Today, Hickey works for Mobility Designs in Atlanta, where she helps people with disabilities find the right equipment for their specific needs. She also works tirelessly to find patient funding for complex rehab technology to provide the freedom

and independence so many want, need and deserve. Often those sources say, 'no,' but as we've learned the word 'no' has never and will never stop Hickey.

Like the mythical Irish warrior Cú Chulainn, Hickey's display of strength, courage and sheer determination has served her well, beginning as a teenager laying motionless and clinging to life in the middle of a busy road in Dundalk, Ireland. Her journey can only be categorized as miraculous. It's the kind of story which conjures folklore, creates legends and launches tales of how ordinary people overcome extraordinary obstacles and go on to live inspirational lives.

Everlasting fame? Maybe. Everlasting admiration? Definitely! ➡

CONTACT

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HICKEY IN HER FENCING ATTIRE



TRIPLE-THREAT LOVE

for a Sugarbee

Written By Randy Christian

ERIC WALKER COMES FROM A HEARTY

Colorado family who takes great pride in their athletic prowess. Everyone in the family, including an uncle or two, excelled in a variety of sports. They all loved the physical and mental challenges that are a primary ingredient of competitive athletics. Like so many of his family members, Walker excelled on the playing field and basketball court, both in high school and college. While attending Alameda High School in Denver, Colo., he earned five athletic letters in varsity soccer and basketball.

In college, he was a starter each of his four years at Colorado College, an NCAA Division III school. He was team co-captain for one season, then elevated to captain for his last two seasons. His legacy as a legitimate triple-threat is validated by the fact that from 1984 to 1990, he held the school's career scoring, assists and steal record. Even today, his career totals in all three categories remain in the Top 10 at his alma mater.

Walker is certainly not one to brag, but even he would have to admit he had an impressive high school and college athletic career. His brother, is a gifted athlete, and currently serves as athletic director and assistant principal at Lakewood High School in Lakewood, Colo. Surprisingly, Walker is the first to admit neither he, nor his brother, were the best athletes in the family. Without hesitation and great pride, Walker tells everyone he meets his sister is, without a doubt, the strongest athlete in the family.

Except for a brief time in the mid-80s when Walker worked for the NCR Corporation, he's worked in the medical industry in some form or fashion. First, he worked for a small biomedical start-up, and then with several respected medical equipment companies. He now serves as regional manager for VGM and Associates, a national buying group serving independent home medical equipment providers. In recent years, VGM has engaged its collective buying power for high-tech rehabilitation and respiratory providers, as well as orthotic and prosthetic practitioners. Adding these medical equipment provider associates to the VMG mix creates a network of businesses with the muscle to compete in a very challenging environment.

"Our number one goal at VGM is to do our best to level the playing field for independent businesses so they can compete with the 'Big Boys' as aggressively as possible," Walker said.

"The majority of the time when we do level the playing field, our associates kick the competition right in the rear by providing a higher level of service to the customer."

Based in his home state of Colorado, Walker currently serves clients in eight states and is, of course, always prospecting for new ones. The one thing almost everyone in his medical equipment business agrees on is the fact that times are tough. Everyone continues to deal with funding cuts and tries their best to do business in an atmosphere of uncertainty.

Even though the future is riddled with question marks, Walker and many of his VGM associates see the potential for an increase in demand for their services. The bigger question is whether national leaders find a way to meet those demands generated in large part by baby boomers, or if they will simply continue cutting funds and placing the burden and guilt on others — like those companies associated with VGM. The chaos in our nation's capitol begs the question of whether or not the future of health care will ever be resolved.

"Yes, there will be a number of people who, as they age, will require hospitalization, long-term care or nursing home care,

Walker-Haley was, by all accounts – even those of her two older brothers – an exceptional athlete. < but most would prefer to remain at home, if possible," Walker said. "When I talk with companies in our VGM family, they say folks overwhelmingly prefer to be taken care of at home, and that's the business we're in. I know I'd want to be at home, not in a hospital."

Walker believes, as do many of his colleagues, Washington, D.C., has a very vague understanding of their industry. It's such a small player in the health care world, and their voice is often not heard. Also, it would not be out-of-line to suggest the majority of those working on Capitol Hill have little or no firsthand experience dealing with someone with a catastrophic illness or serious disability. The possibility that there are only a handful of congressional leaders who have had to navigate paper work



> She is my hero.
> In spite of
> the MS, she
> has made a
> significant
> difference in
> the lives of
> many people.

and bureaucratic “red-tape” to request help would not be an exaggeration either. Add to the equation Complex Rehab Technology equipment and the number of governmental decision makers who have witnessed the hardship and heartache endured by good people who desperately want to reclaim their independence and it shrinks even more.

Ironically, Walker knows first hand the challenges associated with catastrophic illness and serious disability, not just because of his chosen profession, but on a personal level, too. His younger sister, has been battling multiple sclerosis for more than 20 years.

Kelly Walker-Haley was, by all accounts — even those of her two older brothers — an exceptional athlete. Beginning at an early age, Walker-Haley was ready, willing and able to take on the challenge of almost any sport. Her high school years became her most rewarding. She was the first female athlete to garner a letter in three different sports during three years of high school. She played volleyball, basketball and was a stand-out in track and field, too.

“She competed in the sprints and relays and did great. Weighing only about 125 or 130 pounds, she threw the shot put and discus and competed against some really big, strong gals,” Walker said. “She was without question, the best athlete in the family.”

Walker-Haley’s first signs of MS popped up when she was completing an internship in Austin, Texas. While working as an aerobics instructor and waitress to earn some extra money, she felt weakness in her legs. She would lose her balance while teaching aerobics and her vision began to blur, making it

difficult to drive. All were classic symptoms of MS. It was time to see a doctor and she did.

“The doctor was pretty straightforward with her. He told her because her vision was so poor she shouldn’t be driving a car. She hasn’t driven since. That was 23 years ago,” Walker said.

As in most MS cases, disease progression manifests itself in cruel and irreversible ways. She, of course, fought hard to participate in the activities she had enjoyed all her life, such as snow skiing. Even though she was a bit wobbly, it felt good to be in the sun and on the mountain. But soon, she was making her way from Point-A to Point-B using a walker. Next, the MS put her in a manual wheelchair. Now, she counts on a power wheelchair to maintain her freedom and independence. Even though the MS has robbed Walker-Haley of her physical athletic prowess, it has done little to subdue her competitive spirit. She’s powered her way to a master’s of science degree in wellness management from Colorado State University, where she taught in the College of Applied Human Sciences. Her devotion to her school, unwavering courage and unrivaled place as a role model for students and faculty was rewarded with a scholarship, in her honor, for deserving CSU students.

“She is my hero. In spite of the MS, she has made a significant difference in the lives of many people. She continues to be my greatest inspiration and why we started Team Sugarbee,” Walker said.

Sugarbee is the nickname for Walker’s baby sister, but it’s also the name of the team who participated in the Colorado MS 150 bicycle race. Team Sugarbee first participated in 1994 with six riders. It has grown to more than 140 riders and has raised more than 1 million dollars over the years for the MS cause. Walker’s mom, dad and friends man the Sugarbee Rest Stop for riders who tackle the 150-mile ride.

Even though MS singled out Walker-Haley to attack, it’s obvious she’s not alone as she takes on the merciless disease. One teammate, who’ll always be by her side, is her brother. Yes, she continues to inspire him on a daily basis. He also sees a little bit of her in the faces of people he and his VGM associates serve everyday. Maybe that’s what pushes this competitive guy to excel professionally. It’s also what drives him to offer up a new kind of triple-threat to all he meets — friendship, faith and hope. We have Walker-Haley to thank for that. 🍌

CONTACT

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You Never Know What You've **GOT UNTIL** *Written By Danette Baker* it's **Gone**

YOU NEVER KNOW WHAT YOU'VE GOT UNTIL

it's gone, as the old adage goes. That truism was so real for Chris Savoie, ATP, CRTS®, it brought him back home to Michigan and to the rehab technology industry.

Savoie went to Lake Superior State University after high school to study sports medicine and athletic training. He worked part-time at the local grocery store as well, where he reconnected with a high school friend employed by an orthotist in Lansing, Mich., who knew of a sister company needing a delivery person. Savoie was looking for something a little more permanent, but his experience in the field was minimal. And what he had, Savoie said, wasn't necessarily something one would share with a prospective employer.

"Truth was during our lunch breaks, we would take the old wheelchair we had at the grocery store and see who could make it farthest around the store popping a wheelie," he said. "I got pretty good at it. I could make it around the entire store twice without the casters ever touching the ground."

Savoie began his career in the rehab industry in 1992 working for Cole Rehabilitation Technologies in Holt, Mich., helping assemble wheelchairs in the back shop. He worked his way into purchasing and then began traveling on sales calls, learning on the job with the owner, Jim Cole. In fact, it was Cole who encouraged Savoie to join NRRTS.

"He saw the value of the association and was insistent we not only become registrants, but we receive the certifications available as well," Savoie said.

By 1997, Savoie passed his ATP exam, earning credentials and a desire to venture off on his own. He followed a job lead to Colorado, but ended up working retail at Sears. He knew it was time to come back home when he discovered he couldn't stay away from wheelchairs.

"It was like I was having withdrawals," he said.

At the time, the woman he was dating used a wheelchair, so at night he would tinker with her chair.

"That's when I knew where I belonged," Savoie said. "Before, the job with Cole Rehab was just that, a job. I was not attached to the client nor did I realize the importance of what we did. When I moved to Colorado and was not working in the industry any longer, something clicked and I realized that what I was doing had been very enjoyable and rewarding."

He got a job with Rehab Designs of Colorado, and eventually moved back to Michigan. Today, he's back in school, studying Kinesiology Movement Science at the University of Michigan and working for the university's wheelchair seating service Homecare Division as a Certified Rehabilitation Technology Supplier®.

"One of the neatest things is I'm now learning the 'whys' behind things I've been doing all along in this industry," Savoie said. "Having the opportunity to go back and finish my degree was one of the factors that made this job so appealing."

The majority of Savoie's clients are patients at Mott Children's Hospital, where he provides custom seating for a range of needs. He finds it interesting to see the variety of equipment being used in various parts of the state.

One of the
neatest things
is I'm now
learning the
'whys' behind
things I've
been doing all
along in this
industry.

What remains constant, however, are the increasing difficulties patients face in getting funding for the specialized equipment. Sometimes it's a difficult

(continued on page 24)

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You Never Know...

(continued from page 22)

pill to swallow, Savoie says. He has been working with a 4-year-old who was injured in a car accident. Watching her in her power chair and driving it for the first time is very fulfilling, and he has helped her maintain her independence, Savoie said. But, it also hits home with him personally because he and his wife, Rachael, have three daughters, ages 6, 3 and 1.

"Yeah, I play a lot of Barbies and Daddy princess," he laughed. "But we are also a big outdoors family. We go camping a lot in the summer, and my oldest has been deer hunting with me since she was 9 months old."

Individualized equipment, such as the power chair for a 4-year-old, is key for those with disabilities to maintain their independence, Savoie said.

"And that's why it's so important to keep the issue before Congress," he adds.

He attended CELA 2011 and got the opportunity to meet face-to-face with three of Michigan's legislators.

"For me personally, I was in awe of just being at our Capitol," he said. "I was digging it, and could actually see myself there someday. But for now, I knew we had a strong message that needed to be heard."

The best way to do that, Savoie said, is to speak with one voice – that of NCART and NRRTS. Savoie joined the association in the mid90s and has served on the board as a review chair for DMAC-D, which is all states west of the Mississippi River. Listening to the likes of Dan Lipka, Simon Margolis and Ken Nelson during teleconferences gave Savoie a desire to do more than just work in the industry.

"If we don't learn to speak as one voice," he said, "we just might find this industry becoming something entirely different ... where patients no longer get a choice, and there is no longer custom anything." ➤

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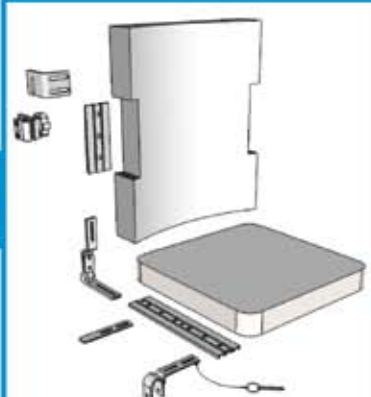
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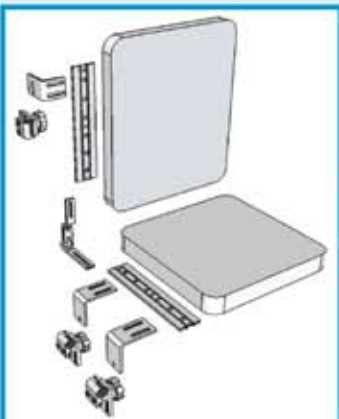
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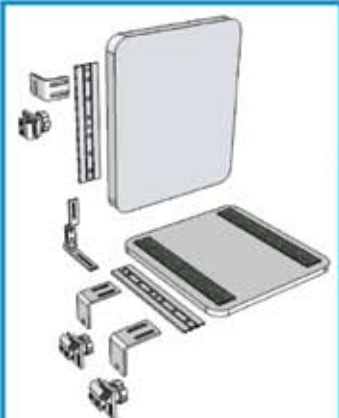
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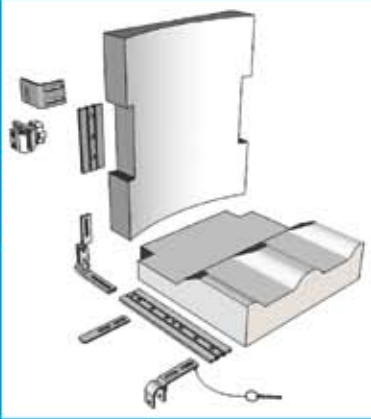
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Separate Benefit for **COMPLEX REHAB** *Technology Update*

Written by **Don Clayback**,
NCART Executive Director

MARCH 2011

AS REPORTED LAST YEAR, THE PROCESS OF

securing a Separate Benefit Category for Complex Rehab Technology (CRT) involves two distinct, but related pathways. The first pathway is legislative. We need to get Congress to pass the legislation needed to set up a separate category under Medicare's DMEPOS benefit. The second pathway is regulatory. Once legislation is passed, we will be working with CMS on the implementation of the legislation and the development of related policies and other changes.

In early February, we completed the process of preparing the proposed legislative language to create a Separate Benefit Category. The draft legislation was based on the changes identified in the proposal paper and was prepared by a well-known Washington, D.C., law firm. With draft legislation now in hand, we have begun to work with Congress to get the required legislation introduced and passed.

The kick-off of our 2011 legislative activity began at the NRRTS/NCART Continuing Education and Legislative Advocacy (CELA) Conference held in Washington, D.C., February 16 to 18. On February 17, the more than 150 attendees took to the halls of Congress with a specific request — we need Congress to introduce our proposed legislation to establish a Separate Benefit Category for CRT. We had in-person meetings with more than 220 congressional offices. The CRT advocates included industry professionals, clinicians and more than 30 consumer representatives. It was a great turn out! Special thanks goes to all the companies and individuals who took the time to attend and carry the CRT message to Congress.

Based on feedback and formal meeting reports from CELA, attendees received positive responses regarding what CRT is, who uses it, and the individualized nature of how it is provided. In many offices, there was a strong interest to learn more about the Separate Benefit Category and the leave-behind materials provided them the detailed information to review, and a draft of the legislation we seek to be introduced. One question that was raised in some offices was what the cost would be for the changes resulting from a Separate Benefit Category. The Steering Committee engaged a Washington, D.C., consulting firm in January to do an analysis of the legislation and prepare a "scoring" of the proposed legislation. We expect to have their report in April and will be able to share additional information at that time.

Because CELA has concluded, the next step is to follow up. Follow up is critical. If you met with your members of Congress at CELA, your continued follow-up is important. If you were not at CELA, we need you to set up a meeting with your members' local offices to educate them on the need for a Separate Benefit Category and ask for their help in introducing the legislation. As a follow up to your meeting, invite your member to your business so they can learn firsthand about CRT. In seeking their support, the following documents can be used:

Position Paper - a two page document that provides a quick overview of the issues and what is required

Draft Legislation - draft prepared by Washington, D.C., legal counsel to be used by Congress when preparing a bill to be introduced

ITEM Coalition Letter - a letter of support signed by 34 national consumer and clinical groups

Proposal Paper - from January 2011; a 34-page document which provides details of the proposed changes along with informative exhibits

CRT Company Overview - five page document providing an overview of CRT: what it is, how it is provided, and a financial summary of the costs involved.

These documents can be downloaded from the NCART (<http://www.ncart.us>) or NRRTS (<http://www.nrrts.org>) websites. If you are unable to do so, please email me, and I will send them to you.

As you work with your representatives, be sure you know the committees on which they serve. The key Congressional committees for us are: the Senate Finance Committee; the Senate Health, Education, Labor, and Pensions (HELP) Committee; the House Ways and Means Committee; and the House Energy and Commerce Committee. Members of these committees are particularly important. Also, keep in mind the majority status in the two chambers: Democrats in the Senate and Republicans in the House of Representatives hold the majorities for this session. However, keep in mind ALL members of Congress are important. Once we have gotten a bill introduced, it will need broad based congressional support to be passed. The support of your representatives will not be there unless they are hearing from you.

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As has been stated before, the support of consumers with disabilities, their advocacy groups, physicians, physical therapists, occupational therapists and other clinicians will be critical in taking the need and message to Congress and CMS. Through these combined efforts, the ultimate goal of improving and protecting access to Complex Rehab Technology products and services for individuals with significant disabilities and medical conditions will be achieved.

We'll keep you updated as progress is made on the legislative front. Once we have a bill introduced, the next step will be to work on getting as many co-sponsors to sign as possible. At that point, we will be able to initiate national grassroots activities among all CRT stakeholders. From there, we'll look to have the bill attached to larger legislation, brought to a vote and passed. Thank you for your ongoing involvement and support!

To share questions, comments, or suggestions regarding the Separate Benefit Category initiative, please contact any of the project's Steering Committee members: yours truly at NCART (dclayback@ncart.us); Laura Cohen, PT, PhD, ATP, Rehabilitation and Technology Consultants (laura@rehabtechconsultants.com); Elizabeth Cole, director of clinical rehab services, U.S. Rehab (elizabeth.cole@usrehab.com); Gary Gilberti, ATP, president, Chesapeake Rehab Equipment (ggilberti@chesrehab.com); Walt Gorski, vice president, American Association for Homecare (waltg@aahomecare.org); Rita Hostak, vice president of government affairs, Sunrise Medical (rita.hostak@sunmed.com); Simon Margolis, executive director, NRRTS (smargolis@nrrts.org); Tim Pederson, ATP, president, West Med Rehab (tpederson@westmedrehab.com); and Paul Tobin, president, United Spinal Association (ptobin@unitedspinal.org). ➤

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EMPOWERMENT: *Connect, Educate, Unite*

Written By Ann Eubank, MSSW, OTR/L, ATP

IT HAS BEEN VERY EXCITING AND

encouraging to be part of this community that united as we rolled into Washington for the CELA conference with a focused message. Then, two weeks later, more than 1,800 people attended the International Seating Symposium in Nashville, Tenn. We are definitely a community, and we are connected.

This remarkable community of people who dedicate their lives to prescribing and providing treatment and equipment, and who allow people with mobility limitations the opportunity to live the lives they choose has incited a social movement.

This movement is from the bottom up. It begins with each individual, moving laterally and upward, much like the spring flowers and vines that emerge from a quiet winter ground now warmed by the sunshine. Our community (consumers, clinicians, suppliers and manufacturers) does not have the funds necessary for expensive lobbyists or to influence policy makers with monetary support.

However, we have something much more significant, more powerful than money can buy. We are a community of people who believe in a common principle — to provide treatment and equipment to offer others the opportunity for autonomy, self-efficacy, competence and freedom. This equipment allows fellow citizens the opportunity for empowerment. Empowerment is something all humans desire. This may be why there is so much energy behind this movement. Empowerment is the awareness one has control over his or her life: health, home, close relationships and leisure time.

Empowerment is a powerful concept and familiar to our community. We have been providing the means to empowerment — mobility — for years. We know how one can flourish when provided with the appropriate device. Mobility offers the opportunity for autonomy, self-efficacy, competence and freedom. These terms are aspects of empowerment.

How many times have you heard, “the consumer needs to be empowered to...call their legislators...call the insurance company...”

Yet, there is a difference between telling someone what to do and providing the tools for them to decide. There is a difference between telling people what to do and inciting a movement. One is a political model; the latter is an empowerment model. Telling people what to do, what to think and how to vote is a political model. An empowerment model is fueled by people from the ground up. It provides tools, methods and action strategies to propel a movement that unites a common message. We as a community of people concerned about mobility, want to be heard, to be represented, and to live the lives we choose. We are not strangers to this.

Empowerment is for people who have been oppressed due to the lack of support and the lack of services. Those who are already on the top may have no motivation for change. People who are not winning are motivated for change, and we are not winning. We need change. Our community is ready and eager for change. In fact, we are demanding change. We must change or we will not succeed. We can no longer accept the status quo. We must advocate for change. We need change to empower our entire community.

The status quo (the erosion of funding, both public and private) negatively affects both the consumer’s and health care professional’s ability to be empowered. We have been fighting a tough battle with current reimbursement. Having been denied over and over, we may feel like we can’t change the system, like we don’t have the power to cause real change. We burn out, and

An empowerment model is fueled by people from the ground up.  our belief in our work begins to depreciate.  Our frustration with the acceptance of the status quo

has fueled this movement — a united voice with more power than any one person or organization. We each experience empowerment on a regular basis. We know what it feels like to provide a child with the first means of independent mobility. We have felt the satisfaction of providing a client with multiple

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sclerosis the means to regain involvement in the community. Empowerment is a means of using our collective experience to move our community from status quo to a united voice of "we can and we will." It is now time for us to do what we know how to do, which is provide the means and strategies for consumers to take control over their health and their access to mobility.

Consumers can have the opportunity to take the necessary action to create positive policy change.

We need to be empowered as a community. We need a united voice that relies on a structured and objective message. We are still struggling to provide the equipment and services consumers need to live their lives. But, if we are a community of 100,000 people who believe in access to appropriate mobility equipment — we have the power.

We have some choices. We can accept the status quo and continue to burn out and give up our power, or we can connect, educate and advocate — everyday.

Users First Alliance will be posting educational blogs detailing materials available to consumers, clinicians and suppliers. Get connected, become a member and ask for educational materials.

We can empower; we can create change. ➤

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SHEILA'S Stander

Written By Leslie Rigg, M.S., ATP, CRTS®

A CASE STUDY

SHEILA WAS 20 YEARS OLD WHEN SHE received her standing frame. She had been receiving physical therapy for close to eight years. Her therapist felt that Sheila was no longer seeing any measurable gains in her therapy, but felt she needed some way to maintain the stretching and flexibility she now experienced. Her therapist had an Altimate Easy Stand to provide evaluation and practice. He felt this would allow Sheila to be independent in stretching hamstrings and encourage extension. Due to her cerebral palsy, she had extremely tight hamstrings and hip flexors. She often experienced spasms resulting in a trip to the emergency room. It took close to five months to obtain insurance approval for her standing frame.

Sheila is a very articulate individual. She strives to be as independent as possible. Her family is very supportive.

Sheila utilizes a motorized wheelchair for her mobility. Powered mobility has allowed her to be an annual participant with the local wheelchair sports camp and recently she participated as a camp counselor. She loves being part of the community.

I spoke with Sheila six months after receiving her stander. "How are you doing with your standing frame?" I asked.

"I love it," she replied, "It is the best thing that ever happened to me. I use it almost every day for 15 to 20 minutes, usually before bed and on the weekends. It is great because it allows me to stretch my hamstrings. I stand as upright as possible and then can lower myself down some if the stretch is too much or if I get tired."

SHEILA IN HER STANDER





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Sheila said she moves herself up and down to get the stretch she needs. Her stander helps her with her hamstring stretch, which is the only one she cannot do on her own.

"The extension handle allows me to do this myself. I really wanted to be able to get in and out myself," she boasts. "I can, but I usually have my mom and dad help move me to the seat, but the rest is up to me. I usually use it in the living room but sometimes move it to other rooms. The tray is great. I can read or write or just rest my arms."

Sheila came to the store the other day with her new van. We couldn't believe almost five years had passed. She was proud to be driving herself and talked about her part-time job and online classes. I had to ask, "How are you doing with your stander?"

"I still love it," she said. "When I don't do my stretches, my tone increases and I get muscle spasms. The ability to stand helps to reduce my tone and relax my body. The ability to adjust the amount of stretch myself is most beneficial."

I asked how often she used the equipment. She said it depended on her level of activity because she can tell when her tone is increasing and her muscles are getting tight. "Sometimes I get in it every day for a week," she said. "I just need 15 minutes or so."

Sheila acknowledged when she is standing, she has increased awareness of her posture. She works to be as tall as possible; it feels good on her hip flexors, hamstrings and heel cords. Through the use of the standing frame, she is able to remain in her chair longer without fear of spasms. This allows her to participate more fully at home and in the community. It has been a blessing to maintain the results of years of hands on therapy. ➔

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Pictures Speak Louder than Words: Making a **CASE** for a *Standing Wheelchair*

Written By **Marcia Margolis, PT and Leisa Lang, ATP**

A CASE STUDY

ROD G. IS A 54 YEAR-OLD MALE WITH A

C5-6-7 spinal cord injury that resulted in quadriplegia in 1988. He has been wheelchair dependent since his injury. His neurologist reported he is developing glenohumeral osteoarthritis — causing pain which limits his overhead work, has lower extremity spasticity, decreased range of motion despite daily self-ranging, dependent edema in his feet and ankles, and has required repeated steroid injections over the last several years to minimize shoulder pain. Rod reported history of right shoulder fracture and dislocation in 2005, requiring surgical repair with a subsequent nursing home stay due to his inability to self-transfer. He developed pressure sores on his buttocks, which left him with fragile skin. He most recently suffered a heart attack on April 11, 2010, requiring one stent. He states his new cardiac medications cause leg cramps.

(continued on page 34)

BEFORE RECEIVING HIS NEW EQUIPMENT, ROD USED HIS WHEELCHAIR'S ARMREST TO PULL ITEMS OFF HIGH SHELVES.



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WITHOUT HIS STANDING WHEELCHAIR, ROD WAS FORCED TO ASK CO-WORKERS FOR HELP TO PERFORM EVEN THE MOST BASIC WORK ACTIVITIES.



AFTER RECEIVING HIS STANDING WHEELCHAIR, ROD HAS ACCESS TO THE COPIER AT WORK.

Pictures Speak Louder...

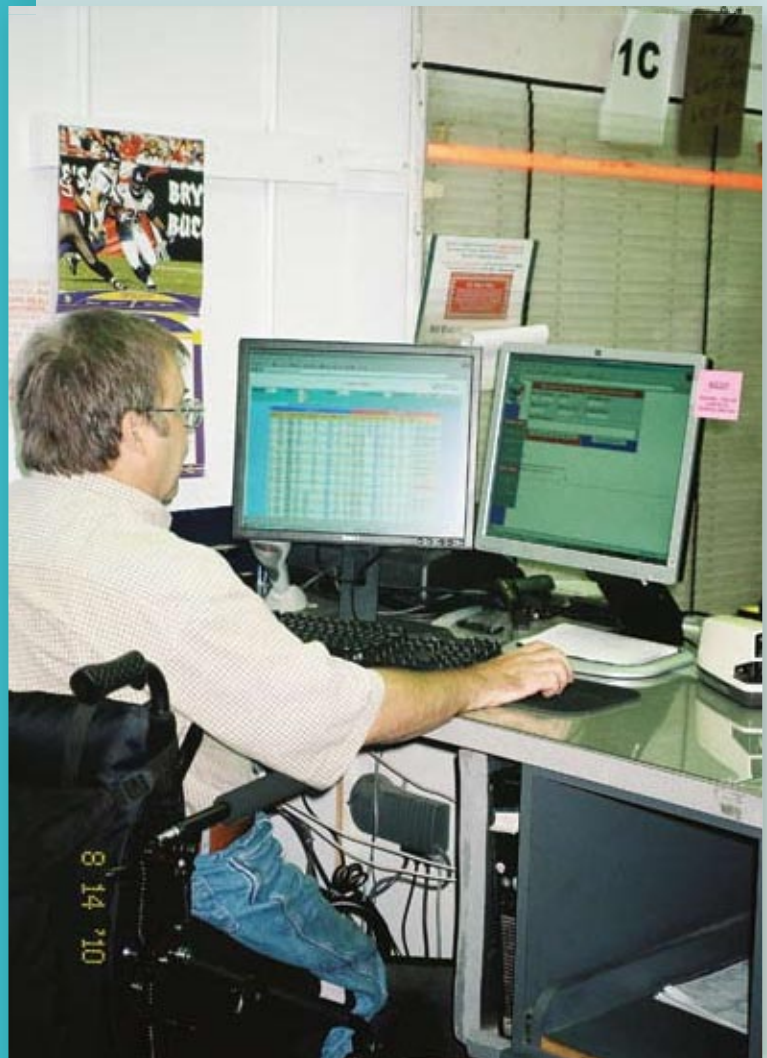
(continued from page 32)

Rod lives in a modified accessible home with his 95 year-old mother for whom he provides care. He sits in his wheelchair 12 to 18 hours per day and drives a van with hand controls. Rod also uses a standing frame regularly one to three times per week, but less frequently than prior to shoulder repair. He does all his own home repairs including changing light bulbs, re-hanging a shower curtain his mother pulled down getting out of the tub, as well as all cooking and cleaning. Rod works full-time at Delta Airlines as a work controller production scheduler and reports he previously had to ask for assistance from other employees approximately 20 to 40 times in a 10 to 12 hour work shift due to not being able to reach items.

Rod was referred to the Seating and Wheeled Mobility Clinic at University of Minnesota Medical Center - Fairview Rehab Services and was seen Aug. 3, 2010, by the physical therapist and rehab technology supplier for an evaluation for a standing manual wheelchair. He was using an ultralight manual wheelchair obtained in 1999 with a pressure distribution cushion and adjustable tension back. He carries a backpack weighing approximately 20 lbs. on the wheelchair with personal and work supplies necessary for daily functioning. He reported independence with all activities of daily living, home management, driving and community activities. Rod did admit needing the assistance of his brother for overhead repairs to his home.

Clinical and mat evaluation grossly revealed Rod's shoulder strength 5/5, elbows 4+/5, left hand 4/5 with carpal tunnel symptoms, right 3+ to 4-/5 including atrophy of interossei and thenar muscles with fingertip numbness. Sitting posture revealed posterior pelvic tilt with slightly increased thoracic kyphosis and forward shoulders, all of which were flexible.

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ROD IS ABLE TO ACCESS
ALL OF THE SURFACES IN HIS
WORKING ENVIRONMENT.

Pictures Speak Louder...

(continued from page 35)

Lower extremity range of motion was within functional limits for sitting and standing, with non-functional strength and spasticity in the left leg. Sitting measurements were taken and a plan was established for the Rehabilitation Technology Supplier (RTS) to obtain and provide trial periods of one week each of two different standing manual wheelchairs.

Rod did have a trial with both standing wheelchairs, using the wheelchair at work and home, and then met with the RTS to establish the specifications required for his definitive standing wheelchair. Those specifications were sent to the physical therapist for completion of the requisition and justification letter of medical necessity. The RTS then completed the necessary paperwork acquiring the physician's signature, submitted for authorization, ordered and delivered Rod's new standing wheelchair.

The entire process took approximately four months. ➡

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FILING WAS NEARLY IMPOSSIBLE FOR ROD BEFORE RECEIVING THE APPROPRIATE TECHNOLOGY.



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Written By **Nancy Perlich, COTA, ATP**

Who deserves to stand? A 16 year-old high school student with cerebral palsy, a middle-aged male with a T7 spinal cord injury, or a 7 year-old with metabolic syndrome? They each sit in their wheelchairs all day long and are at risk for many types of immobilization issues from contractures, pressure sores, digestion problems and more. As complex rehab suppliers, most of us would probably say they all deserve to stand.

But who will be “lucky” enough to get funding for a standing frame? I use the word lucky lightly because it is not so much luck that is needed, but work and persistence. One of my favorite quotes from Thomas Jefferson is, “I’m a great believer in luck, and I find the harder I work, the more I have of it.”

So, let’s go back to our three very different consumers. Who do you think was lucky enough to get their stander covered by insurance? Well, they all got their standers covered by insurance, but each had to take a different path. One had to take more steps and the one who most thought would have the least resistance (the youngest of the group) had to appeal three times!



Vicki

CEREBRAL PALSY, AGE 16, MINNESOTA

FUNDING:

Private Insurance paid on first submission

CRITICAL TO SUCCESS:

Good documentation, product trial information
and home standing program testimony

Vicki is an active 16 year-old high school student. She was born with cerebral palsy and has very limited use of her arms and legs. She uses a power wheelchair for mobility and drives using her head control switches.

Vicki first stood in preschool using a supine stander owned by the school. Her standing program's goal was to maintain lower extremity range of motion. After preschool they didn't do much standing therapy in school. So the family pursued obtaining their own stander for a home standing program, through the local rehab hospital. The hospital therapist did an evaluation and determined a stander where Vicki could actually stand from the seated position would be easier and safer for her than using a supine stander.

To gain funding for Vicki's stander, good documentation including product trials were a key element in the letter of medical necessity. The family also gave the payer personal testimony on how the stander would benefit Vicki at home. As a result, Vicki's stander was paid for through private insurance on the first submission.

Jeff

T-7 PARAPLEGIC,
40+ YEARS POST SCI, FLORIDA

FUNDING:

Insurance paid after one appeal

CRITICAL TO SUCCESS:

Physiatrist and case manager support/advocacy,
revision of LMN, case manager's presentation
to insurance panel

Jeff has a T-7 spinal cord injury from a motorcycle accident that happened in December 1970. As a freshman in college (and an athlete), he knew a lot of things would change after his accident. Jeff's motto is "we are born with destinies, and we can then fulfill them or screw them up; it's our choice." About a year after the accident, he re-enrolled in college. After getting his associate's degree, he went on to receive his master's in rehab counseling. Jeff began working as the director of two separate transitional living facilities in Florida and the statewide director of independent living in the state of Georgia. He understands the benefits of rehab equipment, such as standers.

In September 2004, due to hurricanes and not having power or water for more than seven days, Jeff developed a bladder infection and a significant pressure sore. The pressure sore proceeded to develop into osteomyelitis. He was put on IV antibiotics for three months as well as utilizing a "wound vac" to expedite healing. Once the osteomyelitis was eradicated, Jeff still had to deal with the pressure sore. Due to the severity of his health status, he was assigned a case manager by his insurance company. Jeff did his research and

looked at various websites with many types of standers. Next, he talked to his physiatrist, and case manager and they both agreed the ability to stand would facilitate the final closure of the pressure sore. Staff members at the hospital and the doctor's office were fantastic at writing the letter of medical necessity and advocating for the stander. Jeff finally did get it approved, but not without a lot of effort.

Jeff's case manager was relentless in her support of his need for this piece of equipment. The physiatrist and his staff wrote the letter of medical necessity and submitted it to the insurance company, while his case manager submitted it through normal channels to the panel of physicians. The request was denied! At that point, Jeff's case manager took it to appeal. She revised the letter and re-submitted it to the panel. They then gave her the opportunity to present Jeff's case to them personally. After her presentation to the panel, the insurance company finally approved the purchase and coverage of the entire cost of the stander. It took seven months and perseverance by Jeff's case manager and medical team.



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Max

**METABOLIC DISORDER,
AGE 7, COLORADO**

FUNDING

Private Insurance denied,
Medicaid paid after two appeals

CRITICAL TO SUCCESS

HME Suppliers that are “pros” at appeals,
letters of appeal from pediatrician,
rehab doctor and therapist

weight on his own. Max’s physical therapist is a strong advocate for the benefits of standing and weight bearing for children. When Max was about a year old, his physical therapist started standing him against a therapy ball and recommended getting a stander for home. Max’s family tried four different standing frames while he was in rehab before finding the right one. “He would scream and fight us with each one. He felt out of control when we put him into the standers because we had to lay him in or strap him in standing up. Sit to stand is the only reason we even attempted another stander,” said Deana, Max’s mom. “He is never upset when moving to standing because he can sit, just like he would in any other chair, before standing. It was a huge goal of ours to get him standing up. Max has always had very low muscle tone, but a great amount of strength when he uses his muscles. We found that he would use his strength best when he was fully supported to stand.”

Max’s mom was determined to get his stander paid for through insurance. “Thankfully, our supplier is a pro at appeals. Insurance denied our claim outright, and then

it went on to Medicaid of Colorado,” Deana said. She remembers after the first denial, they received two more denials from Colorado Medicaid before finally agreeing to cover the stander. “They denied it the first two times stating it wasn’t medically necessary. Our pediatrician, rehab doctor and therapist all wrote letters to appeal,” she said. “We are very fortunate to have a truly amazing team on our side who insist on what’s best and most appropriate for Max. Even though our initial request was denied, we kept

Maximilian was born with metabolic disorder and epilepsy. He is unable to stand and bear

trying and finally got the stander approved on the third try.” It took Max’s family almost six months, but they finally got the stander, and the family couldn’t be more pleased.

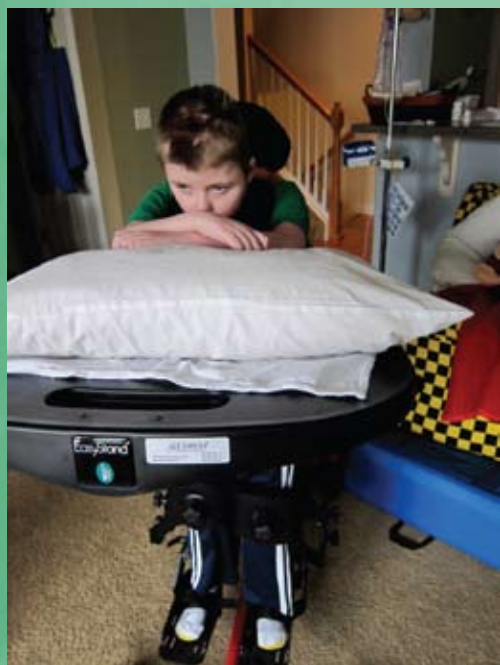
These are three successful stories of how consumers and their families were able to get a stander covered by their insurance. Yes, one was easy and the last two were more work, but where would these three consumers be without the support of their medical team? Without the advocacy of their supplier, physiatrist, therapist, or case manager would they have their standers? Or would they be dealing with ROM issues or contractures? Still fighting pressure sores, flap surgery or further wound complications? Or confined to the seated position, not able to stand and work on all their developmental potential?

We’ve all heard of standers and other Complex Rehab Technology (CRT) items being denied due to a duplication of services, not medically necessary or even “appropriately designed” research is not available. As suppliers, clinicians and manufacturers, we cannot allow this to happen. If we do, with which CRT product will it end? We all need to increase our chances at “being lucky” by helping our customers advocate for what they need. We’re not in this alone; there are organizations such as NRRTS, NCART and PAAT (Protection Advocates for Assistive Technology). NRRTS and NCART continue to work to ensure federal, state and private coverage and reimbursement policies allow for consumers to have appropriate access to CRT and services. The PAAT groups are located throughout the United States and have attorneys and advocates who are a free resource available to assist people with disabilities and their families as they seek funding for Assistive Technology.

Together suppliers, clinicians, consumers and manufacturers must continue working toward a Separate Benefit Category. By adding outcome and research studies and increasing education of CRT to payers, elected officials and the public, we can accomplish our goal. We must elevate understanding of how CRT works to empower the consumer and save money in the long run. This work will also help stabilize our businesses so we can continue to provide services and products that are necessary for quality of life to people with disabilities. ➤

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Standing Wheelchairs: **EXAMINING** the *Evidence*

Written By Amy Morgan, PT, ATP

STANDING IS AN INTERVENTION WHICH HAS

been gaining attention in recent months. In addition to the physiological benefits of weight bearing (standing), the increase in functional performance standing provides makes it a desirable feature on a wheelchair base. Let's take a look at the research supporting standing.

WHY STAND?

Standing is an activity capable individuals perform up to 70, 80 times, or more per day. There are many physiological benefits to standing and upright weight bearing. The medical benefits of standing are strongly supported by research. Likewise, the complications of immobility are also supported and include decreased bone mineral density, increased risk of pressure ulcers, increased development of joint contractures, impaired bowel and bladder function, decreased respiratory function, and increased gastrointestinal problems.¹ According to the RESNA Position on

the Application of Wheelchair Standing Devices, "Standing is an effective way to counterbalance many of the negative effects of constant sitting."^{2, 3}

Osteoporosis

- Loss of bone mineral density occurs with a lack of mechanical weight bearing through the longitudinal axes of the bone (Wolff's Law). The compromised bone is more prone to fractures and complications.^{4, 5, 6}
- Dynamic loading of the skeletal system has been shown to be the most effective for improving bone mineral density.^{7, 8, 9, 10, 11, 12, 13}

Pressure Ulcers

- Individuals also use standing for more effective pressure relief — reducing the risk of pressure ulcers without negatively affecting one's line of sight. It has been

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documented that people who perform a regular standing program have fewer pressure ulcers.^{2,3,14} When a person achieves an upright position, the pressure is most effectively removed from their seat and back surfaces — the most common areas at risk for skin breakdown in a seated individual.^{14,15}

Contracture Management/ Skeletal Deformities

- Standing is an effective way to elongate muscles, which are typically shortened in the seated posture (including iliopsoas, abdominals, hamstrings and the gastrocnemius/soleus complex.)¹⁶
- During sitting, the lumbar spine tends to flatten. The act of standing promotes a natural lumbar lordosis to establish a more erect trunk, thereby reducing the risk of kyphotic thoracic deformity, which would limit respiratory capacity and hinder upright postural alignment.

Vital Organ Function (*gastrointestinal, cardio-respiratory, bowel, bladder*)

- Standing in an upright position with trunk extension, vital organ capacity improves and is less restricted. Gravity is able to assist with digestion, bowel movements, and bladder emptying, and also provides improved breathing/chest expansion (increasing vital lung capacity and lessening the risk of pneumonia.)³ This not only improves oxygen consumption, but also will allow the standing individual to speak with improved volume due to greater breath support.

Standing also improves circulation providing cardiovascular benefits.²

- Bowel and bladder function have been studied extensively (primarily in patients with spinal cord injuries). These studies show there is reduced risk of urinary tract infections³ (likely due to gravity assisting with bladder emptying — eliminating residual volume in the bladder), decreased amount of free calcium in the urine resulting in reduced risk of kidney stones and their complications,^{17,18,19} fewer bowel

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Examining the Evidence

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accidents have been reported by users who perform a regular standing program, and fewer episodes of constipation.^{2, 3, 20}

Spasticity Management

- Weight bearing has been shown to have an immediate and significant effect on reducing muscle spasticity.²¹ This is consistent and aligns with current teaching regarding weight bearing (proprioceptive input) and its effect on inhibiting muscle tone. This enables safer transfers, and improved positioning as well as providing more effective and restful sleep.

Functional Benefits (including but not limited to the following):

- Improved vertical range of reach (kitchen counters, medicine and kitchen cabinets, refrigerator, sinks, drawers, closets, clothes hangers, thermostats, light switches, etc.)
- Improved psychological well-being as well as improved productivity at work or at school (visual stimulation, access to educational opportunities, proprioceptive input, appropriate peer interaction, etc.)
- Improved participation in Mobility Related Activities of Daily Living (MRADLs)
- Toileting - enables some male users to use a public urinal independently, upright positioning promotes bladder emptying – whether catheterizing or self-eliminating
- Feeding - promotes access to food preparation including grocery shopping, cooking, washing dishes, reaching items in kitchen cabinets and refrigerator/freezer
- Dressing - may reduce spasticity for improved ability to complete dressing tasks, improves access to closets, hanging clothes and drawers
- Grooming - increased vertical position improves access to bathroom mirrors and sinks
- Bathing - improved access to obtain bathing supplies such as towels, soap, etc.

FITTING AND USE OF STANDING DEVICES:

Not every standing device is the same. Each manufacturer/model has its own unique design, mechanism, and options for standing. Therefore, no “cookbook” exists to provide instructions for properly fitting and using ALL standing devices. However, there are some general rules of thumb.

- Proper seat depth and lower leg measurements are critical for appropriate fit.
- Accurate lower leg length measurement is also extremely important.

- Knee support placement varies with each manufacturer, but is ultimately placed appropriately by the evaluating therapist and should be snug, but not tight.
- Some standing devices have the option of using various techniques to achieve standing. It is important to understand when different standing sequences are indicated for use.
- Prone standing is beneficial to facilitate active extension and has various developmental advantages.

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Examining the Evidence

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- Supine standing allows gradual progression to upright for individuals with orthostatic intolerance. Also, dependently transferring a client in the supine position may be the safest option for some individuals.
- Sit-to-Stand standing provides the client with the ability to have multiple functional positions (sitting, standing and anywhere between) and is ideal for individuals who transfer independently. This type of standing can best accommodate hip/knee flexion contractures.
- Multi-positional standers provide use of different types of standing as needed. Some will also allow a combination of sit-to-stand and supine-to-stand which is beneficial for clients with significant weakness or paralysis – allowing the body to fully extend before gravity begins to effect the client's positioning in upright.

DOSE:

According to the unpublished Snyder Boston Study, it is feasible to have non-ambulatory children participate in a rigorous standing program. The weight bearing “dose” affects BMD at the calcaneus, but the benefits appear to be transient if the intensive standing program is not sustained. The intensive use of standing devices (seven and a half to 10 hours a week) may have a beneficial effect on BMD of weight bearing bones in non-ambulatory children.²²

More frequent standing throughout the day has been shown to have a greater impact on bone density,²³ gastrointestinal function,^{2,3} bowel/bladder function,^{2,3,20} respiratory function,³ and management of spasticity.^{2,3,21} ➔

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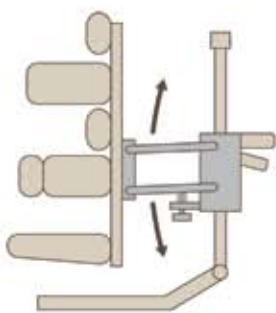
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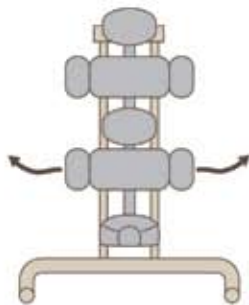
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What Ever Happened to **JIM FISS,** But *Who Would Even Ask?*

Written By Jim Fiss

IN DECEMBER OF 2007, RICK LISTON AND I sold Rehab Medical Inc. (RMI) to United Seating and Mobility. Fortunately, everyone kept a job at either United Seating or Support Surfaces. Support Surfaces (SS) started in the mid '90s to supplement slow times at RMI with ROHO mattresses, low air loss, alternating pressure and other related products for institutional and home use. SS has continued to be a viable company, and we have expanded our product line into other wound care products, including negative pressure.

As with most of us in the medical sales community, we continue to have hills and valleys in sales results and third party billing challenges. Apparently, there is no panacea in the medical community, but it is all we know, so we keep trudging on. Rick

and I work well together. I paint with a broad brush, and Rick does a great job on the pin striping, so the partnership is dandy.

On a personal level, I still race cars and enjoy it, although it's the hardest thing I have ever done. I've included pictures of the Spec Racer Ford and the LeMons race car. Yes, I said LeMons and not Lemans, like the famous 24-hour race in France. The LeMons cars have to be purchased for \$500 or less and are then prepared with roll cages, racing seats, fire extinguishers and more to make them safe for racing. This adds to the cost considerably. LeMons is also a race run over a 24-hour-period.

In the last race, we had five drivers, including Mike Fiss. I guess the old adage is true; the nut doesn't fall far from the tree. The car is a 1993 Mazda with 88 horsepower and 180,000 miles on



SPEC RACER FORD WITH ME DRIVING



JAMES, RENN, AYLA, JACK AND THAT OTHER GUY



CAROL AND ME

it. We finished 21st out of 90 cars our first time out. Our car is called the "Landshark," as the Landshark beer distributor donated a few cases of beer for off-track entertainment, along with something to bribe the LeMons judges. I might add they encourage a little bribery, although it wasn't very effective.

Some of the penalties issued by the judges for track violations include giving the judges a penny, nickel, dime and quarter, but in the same year as your car and parading around the paddock with plastic chains connecting the drivers, exclaiming, "I'm a lousy driver." Another fellow had to put on white face, stand on top of his car and pantomime his track infraction. The competition offers a lot of variety, but we have fun.

Both of my sons, Scott and Mike, are entrepreneurs, like their old man. There's the nut thing again. Scott is a partner in a company named MOXI, purchased from The ROHO Group, which manufactures therapeutic hospital mattresses and related products. His company is about a year and half old, and it's doing well.

(continued on page 52)



TOP RIGHT: RICK AND ME
BELOW RIGHT: LANDSHARK
"PLEASE NOTE THE TWO FINS"

What Ever Happened...

(continued from page 51)

Mike owns and operates Independent Medical Representatives, which has been around for more than five years with products primarily in rehab. The company seems to have a very loyal following. Those of you in the Rocky Mountain area may have run into him. The loyal following has also made his company successful. Needless to say, I'm very proud of both of them.

Carol and I also have four grandchildren — three boys and a girl. As a buddy of mine once told me, grand-kids are great — the only problem is you have to raise your own kids first.

Frankly, Scott and Mike were pretty good kids, so we were lucky.

Mike lives in the Denver area and Scott lives in St. Louis, so we don't have the opportunity to see Jack and James as much as we see Ayla and Renn. James was named after his grandpa. How about that? Travel from Colorado to St. Louis to see the kids, Mike and Jaci isn't too bad. We enjoy seeing them any chance we get. Naturally, Ayla and Renn are regulars at our home, so it's always fun.

As of January, Carol and I have been married 43 years. We actually got married when we were 11 years old, but that's another story. We still enjoy each other's company and we often play golf together with friends. Carol isn't a big fan of the auto racing. She went to one race and told me it was like watching paint dry.

If you've read this far, you really need a hobby or something, but thanks for your interest. I miss seeing all of my NRRTS and industry friends, but I attended Medtrade in Atlanta last November and got the chance to catch up. A friend suggested I attend the International Seating Symposium, and I'm disappointed I couldn't justify a reason to go. The industry was very good to me, and I respect those of you who are still fighting the good fight. If you are ever in St. Louis and don't have anything better to do, please look me up.

CONTACT THE AUTHOR

Jim may be reached at stlrcr@aol.com.



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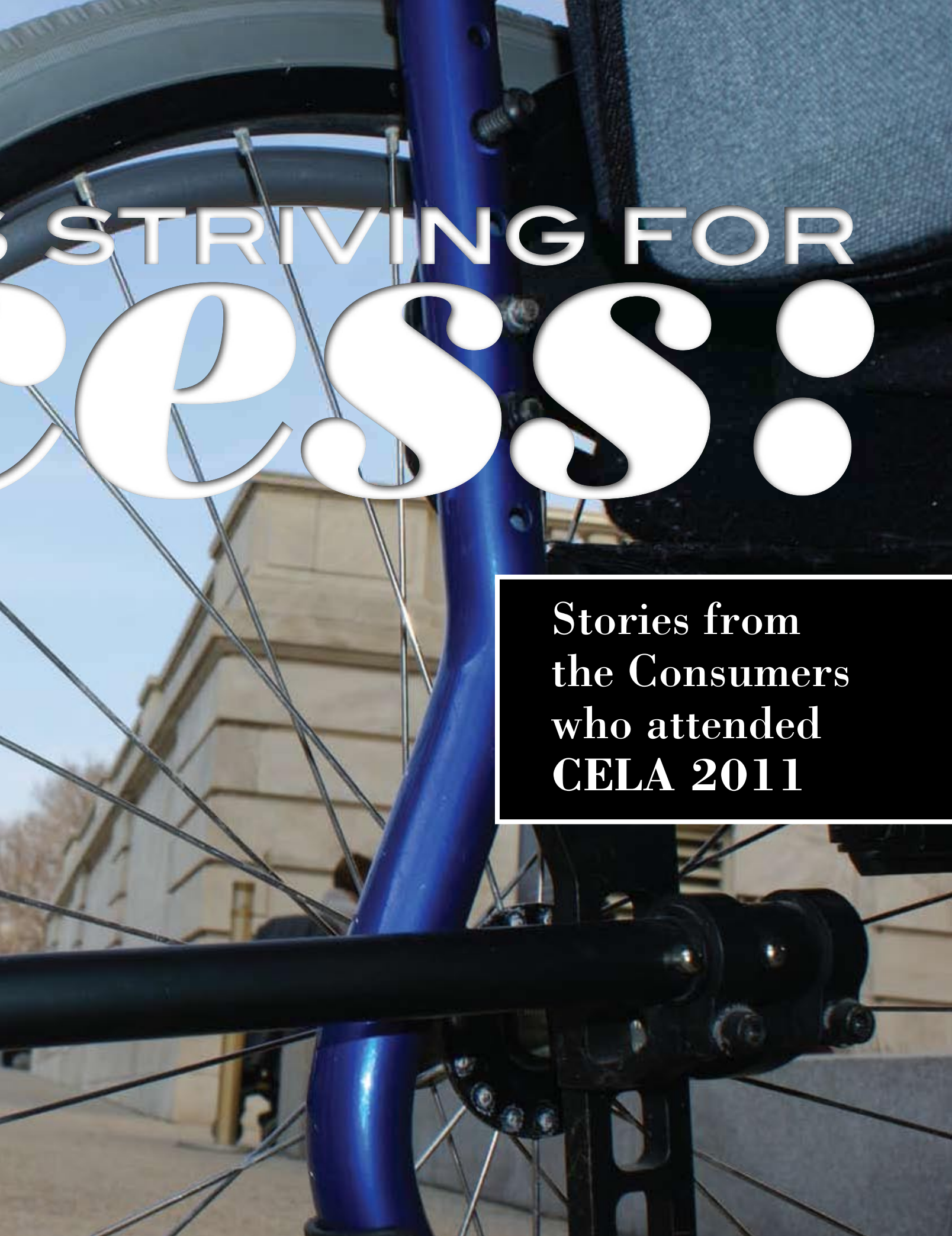
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STRIVING FOR Access:

Stories from
the Consumers
who attended
CELA 2011

frances ozur cole

I had never heard about CELA until I came across an online application for a scholarship while reading the *New Mobility Magazine* website. I'd been involved with disability advocacy shortly after my paralysis. Los Angeles, Calif., was trying to close down Los Amigos Rehab Center, one of the top 10 rehab facilities in the country. I spoke in front of the city council, was featured in an article in the *LA Times*, wrote letters to the *LA Times* editor, and was interviewed for a piece on NPR. I believe in standing up for my spinal cord injury community.

Winning the consumer advocacy scholarship to CELA 2011 was beyond anything I could imagine. This was lobbying on Capitol Hill. Nothing I'd done in the past could prepare me for one of the most meaningful experiences in which I'd participate.

During my flight to Washington, D.C., I noticed another young woman in a wheelchair who was also attending CELA. She and her mother helped introduce me to the conference. Jenny Siegle participated the year before, and I was touched by her and her mother's kindness and willingness to explain what to expect. Jenny and her mother were the first of many friends I'd meet throughout the days to follow.

Even during my three months in rehab, I had never been in a room filled with 30 people in wheelchairs. I was excited meeting other women my age using a manual wheelchair and most of all, Ms. Wheelchair New York. I was profoundly humbled. All of us had diverse disabilities, but that first day we were all the same — representing a community who needed our help.

Partnered with an industry professional, we discussed our mission and reiterated the talking points we needed to convey. I was ready to explain not only our mission, but also the basic difference

between Complex Rehab Technology and home medical equipment. I now understood why it was important for us to lobby Congress to create a separate Medicare category for CRT.

Having grown up in the Washington, D.C., area, I held a great admiration for our legislators. They were my "celebrity heroes." I was beyond thrilled to visit the hallowed halls of Capitol Hill. Meeting with each staffer was incredible. My industry professional, Robert Gouy, eloquently presented our mission, and I was able to interject with my personal experiences, demonstrating why I needed this legislation to be made into law. Each of the staffers with whom we met agreed ours was an important cause; they asked relevant questions and were most pleased to hear our legislation was variably cost neutral.

After every positive meeting, the young girl inside me needed to speed really fast, in my wheelchair, down each marble hall. Of course, I waited until the halls were empty. To me, this was the bonus of meeting with each staffer. When the day was done, I knew my life had been changed. I'd participated in a worthy cause, once again standing up for my community.

Returning home, I followed up with e-mails to every staffer, reiterating our mission and thanking them for their time. I am also sending e-mails to the local offices of each legislator offering to meet with them as well.

The experience I shared during CELA 2011 is one I will never forget. I was one among a room full of people working toward a common goal. Once again, I learned the importance of speaking up for my community's rights. I will no longer have to be asked to participate; I will be the one stepping up to plate.

Francis may be reached at marnina@att.net.

A woman with blonde hair tied back, wearing a maroon t-shirt and a patterned apron, is seated in a wheelchair in a kitchen. She is smiling and looking towards the right, where a tray of cookies is visible. The kitchen has wooden cabinets, a stainless steel stove, and various kitchen items like pots and pans on shelves.

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andrew davis

I had the opportunity once again to attend CELA this year in Washington, D.C., and meet with members of Congress and legislative aides. This was a chance to present my point of view as a consumer of Complex Rehab Technology (CRT). The primary goal was to educate the members of Congress and their staff about why it is important for Medicare to continue funding CRT. I would have to say, the more we go to Washington, the more confident I feel about the Separate Benefit Category passing. We are educating those on Capitol Hill about the importance of having a Separate Benefit Category under Medicare for Complex Rehab Technology.

We are gradually convincing members of Congress that CRT is a more complex product than crutches and bedside commodes and needs its own Separate Benefit Category. Without it, consumers, such as myself, will lose our independence, and therefore not be a contribution to society. Last year when we were on Capitol Hill, our group included physical therapists and suppliers, as well as consumers of Complex Rehab Technology. This year, we had more suppliers and 30 consumers who attended CELA to explain the importance of a Separate Benefit Category. We met with more than 220 legislative aides, representatives and senators. Unlike last year, this year we had a draft of the bill, as well as a position paper, explaining the Separate Benefit Category. This simplified the process because it made it clearer to understand our objective.

Last year, our group from Georgia met with legislative aides and this year, we had the opportunity to meet with the same legislative aides, as well as Congressman Woodall, whom we spoke with for almost an hour and a half. Every year is easier, because when we go to Capitol Hill, we are establishing a relationship with those we are asking to help us achieve our goals. This year, some of the people we met already knew about the Separate Benefit Category. Therefore, it was easier to explain the importance of having Medicare continue funding Complex Rehab equipment.

I explained because of the Quickie-2 wheelchair I have been using for 27 years, I was able to get a college education, as well as have a social life. I can take the Quickie wheelchair, throw it behind the driver's seat and go to a Braves game or wherever my friends and I want to go. I am able to live on my own, and without continued access to a Quickie wheelchair; I would lose my ability to live independently. I wouldn't be able to have a career as I wouldn't be able to get the wheelchair into my car. I would end up with a lesser quality wheelchair that weighs far more than a 25-pound Quickie. I explained to the legislative aides and representatives if that were to happen, it would mean I would end up with more unnecessary health issues, and it would be much more costly than simply providing me with the tools I need to live an independent life.

This year, the legislative aides seemed to be more engaged, and asked questions, which made me believe they are becoming better educated as to what we are trying to accomplish. I feel they are supportive of our long-term goal and are willing to work with us in the future. One of the legislative aides indicated the Congressman would be supportive of the legislation and may be interested in co-sponsoring it in the House of Representatives.

Since CELA 2011 has ended, I have been updating those organizations around the country that advocate for the disabled asking for their continued support. This is an issue not only important to those who go to Capitol Hill each year, but also to many other disabled people with challenges around the country, and there is still work to be done. Since CELA 2011 has ended, I plan to continue spreading the message of a Separate Benefit Category by making appointments with the congressmen from Georgia in their home district so I can explain, directly to the politicians, the importance of making sure American citizens with physical challenges continue to have access to Complex Rehab Technology. We want to continue to participate in American society, but we can only do this with the help of Congress. Continue encouraging your legislators to vote for this legislation so we can participate in society!

Andrew may be reached at adavis@nrts.org.



1. ANDREW DAVIS AND A CAPITOL HILL POLICE OFFICER
2. LINDA PRIEST, LAURA COHEN, KEVIN GOUY, WEESIE WALKER, AND ANDREW DAVIS WITH REP. ROB WOODALL
3. LAURA BRINKLEY AND LINDA PRIEST
4. SHANE LUECK

autumn grant

On all my previous visits to Washington, D.C., I have arrived as tourist. However, on February 16, I arrived as something much more powerful, a consumer advocate with CELA 2011. From the very beginning, I knew it was going to be an opportunity for empowerment. I had taken for granted that I receive the Complex Rehabilitation Technology I need for my independence, and it was eye opening and disheartening to hear the stories of other consumer advocates who have not received the technology they require. I can only imagine these stories will become more common if a separate benefit category is not created.

By the end of the first day, we were all armed with a message, just 22 words long: "We need Congress to introduce and pass legislation to create a Separate Benefit Category for Complex Rehab Technology within the Medicare program." The message was indeed simple, but we knew our impact would be great.

I have to admit, I was nervous as we made our way to our first appointment of the day with a legislative aide from Sen. Scott Brown's office. I was a little unsure of what I could add personally to the conversation, especially since I was accompanying some brilliant industry professionals. However, when the conversations opened up, I found it easy to add in my own personal stories as a user of complex rehabilitation technology. I was able to explain and demonstrate every piece of technology on my chair serves a purpose which either improves my health or increases my independence.

By the end of the day, I visited three congressional staff offices and met with Rep. James McGovern, who represents my native city of Attleboro, Mass. After each meeting, I became a little more comfortable with what I was doing and a little

more confident about asserting my experiences. I am hopeful the myth that some Complex Rehabilitation Technology is just "bells and whistles" and gave a clear impression of both the health and independence benefits it can offer when used by the right individuals.

My work as a consumer advocate with CELA did not end when I left Washington at the end of the conference. I noticed, and I am sure others CELA participants noticed, there were many groups on Capitol Hill that day meeting with Congress members and legislative aides. Many of those groups were just as large and just as passionate about their proposals as we were with CELA. Our visits to Capitol Hill cannot be the only contact with our elected officials and their offices regarding a Separate Benefit Category. We cannot allow the Separate Benefit Category to get lost in all the other proposals congressional offices receive each and every day. It is imperative we follow up with all the offices we met with, whether their initial response was warm or cold.

We learned so much at our congressional meeting and debriefing, and we must share these new insights and potential allies with offices we met with. Equally important is for us to spread the word about the Separate Benefit Category to our family and friends and getting them to contact their Congress members as well. I have actually had several people ask me how they can learn more about the Separate Benefit Category after talking to them about my experiences at CELA 2011.

On all of my previous visits to Washington, D.C., I have left as a tourist; however on this trip, I left as a consumer advocate for Separate Benefit Category for Complex Rehab Technology and I continue to be one today.

Autumn may be reached at mswheelchairmass06@yahoo.com.

molly hale

CELA 2010 was our first opportunity to participate as consumer advocates in preparing, presenting and educating the legislative bodies about the need for a separate category within Medicare for Complex Rehabilitation Technology, CRT. At the 2010 conference in April, Jeramy and I had modest knowledge about the topic, the people running the show, the people attending and the format. What we did know was we would be visiting with and potentially talking to senators, representatives and/or their aides in their offices on Capitol Hill.

The preparations and content of the first day of the 2010 conference, meeting the key players from NRRTS, the manufacturers, equipment providers, physical and occupational therapists, and other consumer advocates was an important bonding experience. Because of the excellent materials, webinars and a full day of presentations made by the CELA organizers, we understood where the process of creating the particular piece of legislation stood and the necessary talking points when visiting Capitol Hill offices.

The four meetings Jeramy and I attended in 2010 were successful, both personally and educationally. Each meeting found us expanding our understanding of the receptivity of our targets and our delivery became more polished as we moved from one office to the next. At the end of the day, it was clear we would participate again in a heartbeat.

An invitation to the 2011 CELA Conference found us well-prepared and looking forward to how we could move the CRT legislation forward. The conference calls we participated in during the weeks before the conference brought us up-to-date regarding the legislation, allowing questions to be answered and listening to other people's comments. Once again, the day on-site in Crystal City was spent re-engaging participants from the prior year and fine-tuning the content of our message as each speaker provided useful information.

Armed with the knowledge two important changes had occurred during the year, the precedent setting inclusion of a Separate Benefit Category for prosthetics and orthotics and the removal of CRT from the competitive bidding process, Jeramy and I were enabled to have more powerful and compelling conversations within our assigned meetings. We both felt well-received and certain our meetings had positive outcomes in relation to a CRT Separate Benefit Category. We addressed the savings that would be generated from creating a Separate Benefit Category, which is not the way legislators tend to think when they approach a new bill. They look at "costs" only, and yet, were swayed by the cost effectiveness in relation to backing or co-sponsoring the legislation.

We spent a few days in Washington, D.C., after the conference with a family who has been involved with Capitol Hill for decades and received some great coaching and suggested names to continue getting the backing this legislation needs. Returning home, we have found ourselves talking to both able-bodied and compromise-bodied folks about this legislation and its importance. I have been e-mailing all my support group members, people I mentor and any and all people and non-profits who have an investment in this legislation, encouraging their education in this arena and their participation in its future.

Jeramy and I are both looking forward to what 2012 brings and would be delighted to continue our advocacy on Capitol Hill.

Molly may be reached at molly@abilityproduction.org.

susan houston

When the company I work for, Hudson Seating & Mobility, asked me to attend this year's CELA conference I was very excited. Although I have attended a few legislative conferences in the past, I knew CELA was unique because of the mix of people they bring together. Clinicians, manufacturers, custom rehab providers and, most importantly, end users all brought together to work for the rights of people with disabilities. Because that really is what creating a separate Medicare benefit for Complex Rehab Technology (CRT) is about — the right of people with disabilities to have access to the equipment they need.

From the moment I arrived, I was impressed with how organized everything felt. We spent the first day being educated on the importance of creating a separate Medicare benefit for CRT, the talking points to discuss with our representatives and senators, and reviewing the appointments scheduled for the following day with our legislators. We also heard from Ann Eubank, executive director of Users First Alliance, a non-profit grassroots organization whose mission is to ensure appropriate access to seating and mobility equipment to end users through educating and advocating. What a great partner to have for this issue.

On Thursday, we headed to the Hill. I was again impressed at the organization involved in getting all of us wheelchair users transported to the Capitol. There were multiple wheelchair vans available, as well as information for taking the transport system. Although we arrived at our drop off point a little later than planned due to our vans needing to be checked by explosive sniffing dogs, (a little excitement to start the day) my co-worker and I made it in time for our first appointment with a minute to spare. The complete Massachusetts group attended our first appointment with Sen. Scott Brown's office.

We met with one of his aides, and she seemed very receptive to our proposal. The highlight of my day was having a face-to-face meeting with Rep. James McGovern. When we first arrived at his office, we were informed he was stuck in a hearing, and we immediately assumed that meant there wouldn't be a meeting. To our surprise, his aide went on to say the congressman had requested we be brought to where he was so he could spend a few minutes with us to hear our concerns. Rep. McGovern was very gracious and obviously knowledgeable of Medicare issues, as he promised his support of the bill. He even took the time to pose for a picture with our group.

After a full day on the Hill, we all came together to discuss the feedback from our appointments. I really enjoyed this part of the day because it was an opportunity to network with so many new people. I especially liked connecting with the consumer advocates, hearing their stories and making new friends in the process.

The last day of the conference was spent on education, which I think is also a unique aspect of CELA. Two educational tracks were offered, one business track and a clinical one geared toward the end users and clinicians. I attended one of each and took valuable information from both of them that I will use in my daily life.

If you haven't attended a CELA conference, I urge you to attend next year. First, because we need everyone's support to make sure the proposed bill for a separate Medicare benefit for CRT gets introduced and passed. Secondly, because everyone should feel the sense of empowerment given by visiting and speaking with your legislators. It truly makes you believe one voice can make a difference. Imagine what we can do with hundreds of voices.

Susan may be reached at
susan.houston@hudsonmobility.com

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kelsey little

What an experience! Being part of CELA and what its cause represents has had an amazing impact on my life. It's a wonderful feeling to be brought together with amazing people who know what you are going through and are willing to sacrifice their time to fight for people who can't fight for themselves. When you walk (or roll) on Capitol Hill, the adrenaline completely fills you, and the determination to fight for such an amazing and life-changing cause drives you to speak to these politicians in such a way they feel and understand where you are coming from.

Many of the health aides and assistants I met with in my meetings were empathetic. I just very plainly stated, "It stinks. We don't want to live on the system or be stuck in our homes. We want to be equals and get out of our homes, get jobs and be productive in society just like everyone else. If we are stuck with generic wheelchairs, then we are limited to the things we can accomplish. If you have ever met a person in a wheelchair, then you know we are hell-bent on making the most of what we have." And it was that easy.

After introducing the bill to senators and congressman, I feel like all I really have to do is get them to see from my level. I have to send pictures of myself acting out my everyday life so they can get a feel of what it is like to be me, plus give them a reminder of who I am so they can take me seriously.

In the near future, I want to be able to set up an appointment when they are in back in their home offices in Mississippi and have two extra wheelchairs — a generic hospital one and a custom one like I am using. I would like them to experience first hand how difficult it is to function in both. I always use the example of watching ice skating. They make it look so easy that no one has a lot of respect for their grade, and being in a chair is the same way.

We wheelchair users make everyday living look like a piece of cake, so when people see us out and about they don't even have the capacity to understand how hard it is to park, get a wheelchair in and out of a vehicle, reach for high things, pop curbs, open doors and especially fit into bathrooms. Imagine doing all of these day-to-day activities in a chair that is too heavy, big, bulky, and uncomfortable! Post CELA, I want to be able to bring our reality into their dream-ality and hope we can all be reading the same book.

I pray more people will join our cause and spread the word of the "cripples" because we are a unique group of characters and all of our stories are interesting. We need to open EVERYONE'S eyes and make it known we did not bring this on ourselves, this was a random act and it can happen to anyone at anytime. It doesn't stop with us.

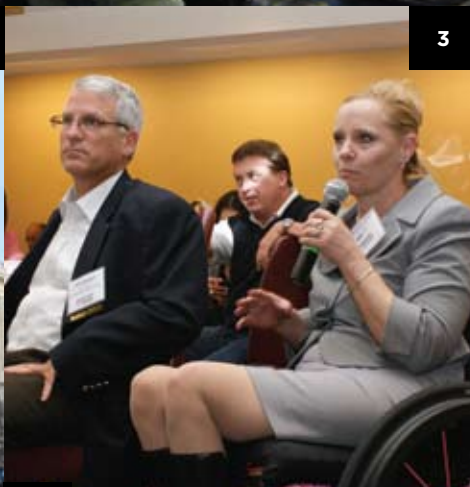
Kelsey may be reached at klittletgh@gmail.com.



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1. JILL GIRARD, MIKE LAKY, BOB MELIA, DR. PORTÉE, SALLY GANFIELD, MICHELE GUNN, THANA FRANCE, AND MARTY BALL AT SEN. MARK RUBIO'S OFFICE
2. JERAMY HALE AND SIMON MARGOLIS
3. RICK SPIEGEL AND MADONNA LONG
4. GARY GILBERTI WORKING ON BOB MELIA'S CHAIR
5. KELSEY LITTLE, JENNY SIEGLE AND BARBARA SIEGLE

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5



4



1



2

3



4

1. UNITED STATES CAPITOL
2. JENN WOLFF AND SUSAN HOUSTON
3. JOSH ANDERSON
4. LIZ COLE



linda priest

Accepting an invitation to come to Washington, D.C., in the middle of February brought with it many doubts about my ability to travel in the snow and the need to purchase warmer clothes than my Atlanta climate usually requires. What a superb surprise! The weather was spectacular for the whole week... one of the warmest on record. The gods were definitely smiling on our mission, which was to visit with as many congressional members as possible to spread the word about the sorry state of providing Complex Rehab Technology within our antiquated Medicare/Medicaid system.

I have been aware of this problem for some time and had been talking about it with my polio support group (the Atlanta Post Polio Association) for a couple of years. I take these issues very personally because I am a user of complex rehab technology, and I am a Medicare client. I had polio at the age of 2, but unlike many polio survivors I did not miraculously get up from my bed and walk after the acute phase was over. In fact, I have been in a wheelchair virtually all of my life. I started out in a huge, heavy wooden cane-back chair with bricks built up on the footrest so my feet would reach. As the saying goes, "we have come a long way baby" since then.

It has been an incredible ride (no pun intended) to witness the change in rehab technology over the years. Most of my life I have used a manual chair, but as I have aged and with the coming of post-polio syndrome, I now use a wonderful chair designed by Permobil and prescribed by the seating clinic at the Shepherd Center in Atlanta. I am one of the lucky ones to live in a large metropolitan area with access to one of the most prestigious rehab hospitals in the country. Few people in my situation are so lucky. The bad news is that because of early retirement due to a multitude of factors including post-polio syndrome, I no longer have medical insurance and my wonderful Permobil will soon need to be replaced. I am in a scary place, because I have no idea what my next wheelchair will be. There are no truer words in my situation...we are only as independent as our rehab equipment allows us to be.

The current problem: Medicare processes Complex Rehab Technology within the same category as all home medical equipment. The system was created some 40 years ago to assist the elderly with devices as they aged. These devices are not specialized and to a great degree can be used by most people interchangeably. On the other hand, the chair I sit in today was prescribed, designed and fitted just for me with my specific needs and deformities. There is no comparison between the two. We need a separate benefit category for Complex Rehab Technology within the Medicare program to insure that qualified people are prescribing this equipment and that qualified technicians are available to service them. The current Medicare process is so fraught with antiquated rhetoric and requirements it has created an environment that makes reimbursement for these products and services untenable for those professionals who are the best in their field and the most appropriate for designing and providing the equipment. The proposal prepared by the Complex Rehab Industry and profession addresses all of these issues.

It was an honor to work with the NRRTS, NCART and other professional organizations involved in CELA over a five-day period. I visited my senator's offices, and all of the offices of my representatives. It was a huge job, and I was exhausted at the end of the day, but the work was very rewarding.

I am a full-fledged member of the Separate Benefit Category bandwagon, and I believe completely in what needs to be done. Since I've been home, I have written to each office that I visited thanking them for their time and reminding them of how important this proposal is. In addition, I have attended a disability day at the capitol in Atlanta that was coincidentally slated for the week after my return from D.C., and currently I am working on an appointment with my U.S. House (District 7) Representative. He is a "newbie" in Washington, having just been elected this term. He seemed truly touched that we had traveled all the way to Washington to speak to him, and he promised me a meeting when he returns to Georgia.

I am pumped, and I hope that you are! What we want is to right a wrong! It makes sense and it needs to happen, not when they some day overhaul all of the problems with Medicare, but NOW. This issue can't wait.

Linda may be reached at lindaleepriest@gmail.com.

jenny siegle

Fighting for what you believe in is something everyone should be accustomed to. For me, it has to be a way of life.

I have been paralyzed since I was 9 months old, so living everyday as a quadriplegic is not unfamiliar territory. I work as an associate producer for Altitude Sports & Entertainment and a video production specialist for the Colorado Rockies. I drive my own van and I recently purchased my first home. Living my life the way I have always dreamed of is attributed to one thing — Complex Rehab Technology.

In 2009, I was at an appointment at Aspen Seating to have my seating system evaluated. While I was there, I was able to catch up with a dear friend, Tom Hetzel. I was updating him with everything going on in my life, and he told me I would be a great consumer advocate at the upcoming CELA (Continuing Education and Legislative Advocacy) conference.

Since I didn't know much about CELA, I did some research and immediately knew it was something I wanted to be a part of. CELA has one main goal and that is to get a Separate Benefit Category for Complex Rehab Technology. To get that accomplished, a bill must be passed, and the members of Congress need to be educated about what we are asking for.

The best way for me to provide that education was to take my message to Capitol Hill. I applied for a scholarship and was able to join other consumer advocates and industry professionals at CELA 2010 in Washington, D.C.

Without a doubt, it was one of the best experiences of my life. First of all, everyone I met was nothing short of amazing. The board members of NRRTS (National Registry of Rehabilitation Technology Suppliers) and NCART (National Coalition for Assistive and Rehab Technology) were so genuine. They provided the consumer advocates and industry professionals with the knowledge to be able to speak confidently during our appointments at Capitol Hill.

During my congressional appointments, I felt like I received mixed reviews. Some really listened, while others just didn't seem to understand the importance. However, it did open lines of communication and laid a foundation to build upon.

Before I returned to Denver, I was asked to serve on CELA's consumer advisory board and return to Washington, D.C., in 2011. It was an honor which I accepted immediately because I knew I wasn't just fighting for something I needed, but there were many others who would benefit as well.

The time seemed to have flown by and before I knew it, I was back in Washington, D.C., for CELA 2011. Once again, I was speaking to some of the legislative aides who I developed a relationship with over the past year.

This time around, I was pleased with all the responses and feedback we received. In every one of our congressional appointments, the legislative aides were engaged in the conversation. I felt that was due to the work the board members of NRRTS and NCART put in. We were able to bring legislative language with us, and I believe that was why we were taken more seriously.

I have already been in contact with all the legislative aides I spoke to in February. They all seem eager to learn more and be given information during the possible passing of this bill. I also hope to meet with someone from their local office at a Complex Rehab Technology provider or even at Altitude's studio so they can see first-hand what we are all fighting for.

I truly believe in what CELA is trying to accomplish, and I won't stop working until the Separate Benefit Category bill is passed. So, as far as I'm concerned, CELA 2012 is already penciled in on my calendar.

Jenny may be reached at jenny_siegle@yahoo.com.



1. CELA 2011 BAG
2. KELLI BAKER
3. SUSAN HOUSTON, REP. JAMES MCGOVERN, AUTUMN GRANT AND KEN BERGERON
4. KELLI BAKER, MARITA NIQUETTE AND MARCIA CECCINI
5. PAT CHELF, MARCIA MARGOLIS, NANCY PERLICH, SEN. AMY KLOBUCHAR, LAURIE TOMASZEWSKI, AND LISA MICHAELS

Another **VOICE** for the **INDUSTRY**

Written By **Danette Baker**

Dr. David Portée attends CELA 2011, becoming the first physician to advocate on Capitol Hill for a Separate Benefit Category for Complex Rehab Technology



DR. PORTÉE AND BOB MELIA IN WASHINGTON, D.C.

Imagine being alive, but not being able to move. Now imagine there are therapies available which, when prescribed, could give you the freedom to move, but you can't have them because your insurance won't pay for it.

This could happen to patients with Parkinson's or diabetes if they didn't get the type of medication prescribed by their physician.

It's unthinkable, right?

Then why should those with disabilities be expected to accept anything less?

This is the message Dr. David Portée took to Capitol Hill during CELA 2011. This was a first for Portée, a physiatrist who serves as medical director at the Orlando Health Rehabilitation Institute in Orlando, Fla.

"I thought basically, we would have to give them a very elementary introduction of the need," he said. "It turned out they were very aware of what we were there to talk about, and we were able to hold high-level conversations regarding the need for specialized equipment for these patients."

One patient Portée has worked with doesn't have the major bones in her limbs as the result of a birth defect. She requires special adaptations to her power wheelchair, such as back and seat cushions, in order to operate it independently. Without them, Portée said, she could not keep her balance in the chair.

To give this young lady her independence requires a physician, a therapist and a rehabilitation technologist working together to identify the type of individualized equipment she needs — and get it paid for. Without it, he said, her future would be much different.

“She probably would be confined to a manual chair, dependent on someone else for mobility,” he said. “She could possibly end up bed-ridden or in a nursing home because she would not have the structural support to keep her body upright. I met this young lady a couple of weeks ago, and while she had some difficulty speaking, she was absolutely delightful and bright. She was not just alive. She was living.”

Portée said patients such as this young lady, and many others, are often doing everything they can to contribute to society. Yet they depend on others, and often on specialized equipment, to help them.

“Some people need specialized chairs just to survive, but others need them to work, to raise families, to live without pain,” he said. “When I saw this young lady, and many others, and looked behind the scenes and realized how much work it takes to get them in that chair, you realize you can just let legislation happen.”

Prior to CELA, Thana France, ATP, CRTS®, and Robert Melia asked him to make phone calls to legislators. Portée then decided it was time to personally become involved in the fight to get legislation for separate Complex Rehab benefits.

“I expressed my interest in going, and it just happened from there. I highly respect Bob and Thana, and it seems as if we are at a critical point. They are really behind making this thing work, and I thought if I could help, then I’d like to do what I could,” Portée said.

Portée earned an undergraduate degree in computer engineering from the University of Michigan, so, as a second-year medical student, he was fascinated by the physician’s lecture on nerve functioning.

“He was talking about the amplifiers and such,” he said. “As an engineer, he was speaking my language.”

When it was all said and done, Portée had an externship working with the physician on a neurodiagnostic study on electromyography and nerve conduction. His job was to collect data, so there was minimal patient interaction. However, Portée said one thing was extremely clear — all of the patients seemed to be doing the best they could to recover and stay engaged.

Little did Portée know at the time, but the externship was also a way to entice medical students into rehabilitation medicine, a relatively obscure field, but one vital to helping patients with disabilities. Portée completed his medical degree at the University of Michigan and his residency at the Rehabilitation Institute of Michigan.

As a physiatrist, Portée treats those who have neuromusculoskeletal conditions, either from disease or injury, ranging from genetic conditions to traumatic brain injuries. At the Orlando Health Rehabilitation Institute, Portée oversees a 45-bed inpatient facility, helping patients with pain management and mobility.

“We work closely with the entire rehabilitation staff — nurses, social workers, PTs, OTs, speech therapists — and we’ll oversee therapy as the patient makes the transition home,” he said.

Being a key part of the process of rehabilitation, physicians should also be aware of the environment outside of medicine, he said.

“Those working in the industry should make contact with the entire medical network in their respective communities, like Thana and Bob did with me,” Portée said. “As physicians, we should have a vested interest in what happens to our patients after they leave the clinic environment.”

So next year, Portée said, he would like to see a stronger push for the national call-in day, getting local coverage throughout the states prior to CELA. He would also like to see more of those calls being made by physicians.

“Ask them to become another voice for this industry,” he said. ➤

CONTACT THE AUTHOR

Dr. Portée may be reached at david.portee@orlandohealth.com.

TAKING PREVENTATIVE MEASURES

Benjamin Franklin is credited with the phrase, “an ounce of prevention is worth a pound of cure,” but Dr. David Portée put the idea into practice. In 2005, Portée led a community-wide effort involving the Orlando County Public Schools, City of Orlando, The Ninth Judicial Circuit Court, Orange County Sheriff’s Office, Winter Park Police Department and Orange County Community Traffic Safety Team in producing a video called “If You Don’t Die.”

The father of three said he had seen too many 18-year-olds come through the Orlando Health Rehabilitation Institute because of accidents related to substance abuse. The video presented two scenarios aimed at informing students about using alcohol and drugs while driving and as a passenger. Filming the message brought the risks even closer to home for Portée, whose daughter played one of the teens injured.

In 2005, the Florida Safety Council honored Portée’s efforts, presenting him with the Golden Start Safety Award. The award recognizes an individual “who has demonstrated exemplary commitment and has made significant contributions in safety and/or health that enhanced the quality of life for the citizens of Florida.”

“I was very honored they would recognize what we tried to accomplish,” he said.

The video has been used in Orlando County schools along with the Mock DUI Project, and by other school districts and community organizations at the state and national level, according to Portée.

NEW REGISTRANTS

Congratulations to the newest NRRTS Registrants.
(Jan. 18, 2011 through March 15, 2011)

Jill Barron, ATP, RRTS®

Rehabilitation Medical Supply
1100 W. 41st St.
Sioux Falls, SD 57105
Telephone: 605-782-2444
Toll Free: 800-584-9294 x.4444
Fax: 605-275-4013
Registration Date: 2/3/2011

Gregg Blanchard, ATP, RRTS®

Hudson Seating & Mobility
101 Fairchild Ave.
Plainview, NY 11803
Telephone: 516-833-1797
Toll Free: 800-321-4442
Fax: 516-576-0011
Registration Date: 3/8/2011

Prak Kim, RRTS®

South Bay Home Health Care
1349 El Prado Avenue
Torrance, CA 90501
Telephone: 310-618-9555 x.118
Fax: 310-618-0614
Registration Date: 1/26/2011

Sarah Kubal, RRTS®

Reliable Medical Supply, Inc
9401 Winnetka Ave. N
Brooklyn Park, MN 55445
Telephone: 763-255-3817
Fax: 763-255-3917
Registration Date: 1/31/2011

Angel Nello Pardo, RRTS®

DMR-Doctors Medical Rentals, Corp.
14641 Oak Lane
Miami Lakes, FL 33016
Telephone: 305-666-9911 x.202
Toll Free: 800-851-0312 x.202
Fax: 305-666-1601
Registration Date: 3/1/2011

CRTS® CREDENTIALS

Congratulations to NRRTS Registrants recently awarded the CRTS® credential. A CRTS® receives a lapel pin signifying CRTS® or Certified Rehabilitation Technology Supplier® status and guidelines about the correct use of the credential. Names listed are from Jan. 18, 2011 through March 15, 2011.

Sarah Anderson, ATP, CRTS®

Cook Medical Supply
Morton, MS

Roy C. Brown, ATP, CRTS®

Prescription Medical Equipment & Supplies, Inc.
Mesquite, TX

Gregory Allan Moorhouse, ATP, CRTS®

Active Home Medical Supply
Lapeer, MI

William C. Skipworth, ATP, CRTS®

Holland Medical Equipment
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WILLIAM ALONZO BUDDY ROWELL

Written By Mike Daniels

A “friendly competitor” is an oxymoron — kind of like “happily married.” But with everything, there are exceptions. William Rowell was both of these oxymorons. In the 15 years I knew Buddy, I literally never heard anyone say anything bad about him, nor did he say anything negative about anyone. That is the absolute truth. I see folks admonish people after they are gone and tell little white lies about what a good person they were and so forth. That happened at my Uncle Bill’s funeral. While it was a fact my uncle was a good guy, he was also a drunk who liked to chase women.

When I first started in this business 15 years ago at the age of 19, the very first competitor I met was Buddy. I remember, to this day, as I walked into Waycross Children’s Medical Services, Connie Barfield introduced us and told us to “be nice to each other” — jokingly of course. Buddy and I spent every other Thursday together in that ortho clinic for five years. After state budget cuts, changing the clinic to once a month, and offering off-site vendor status, I stopped attending every clinic. However, Buddy and I kept in touch. At the clinic, we came up with a gentleman’s agreement about business. No need for me to step over dollars to pick up nickels in his backyard of Waycross, Ga., nor was there a need for him to come to my backyard of Valdosta, Ga. Homerville, Ga., was our agreed cut off, specifically the red light in Homerville.

One of the best attributes about William was his loyalty to everything he valued. To his wife, kids, friends, co-workers, God and even his specific place of employment, Buddy was as loyal as they come. I offered him a job once and without hesitation, he told me while the pay raise would be nice, where he worked at had “invested in me” and “I just couldn’t do that to my co-workers.” Never again did I try to hire him. However, if he ever would have asked, a new employee file folder would have surely been made. William was also always true to his word. Unfortunately, that is a quality you just don’t see in many folks anymore.

Well if you believe the Bible, William’s chosen career is useless in heaven, as there is no sickness whatsoever. I’ll step out on a limb and say Buddy is all right with that. One thing is for sure, he was by far my favorite competitor and I miss him. Oh, and one last thing, like Buddy, I have three children. My youngest of which, Miller Lawson Daniels, won’t answer to Miller. He won’t even answer to Lawson, but he does answer to “Buddy.”

FORMER NRRTS REGISTRANTS

The NRRTS Board determined RRTS® and CRTS® should know who has maintained his/her registration in NRRTS, and who has not. Names included are from Jan. 18, 2011, through March 15, 2011. For an up-to-date verification on Registrants, visit www.nrnts.org, updated daily.

Tanya Eulenfeld Augusta, GA
 Kathy Fauria, ATP Portland, OR
 James A. Glaes, ATP Metairie, LA
 Allen Newsome Vista, CA
 Gary D. Pehrson Morrison, CO
 Steven Lee Still, ATP Columbia, SC



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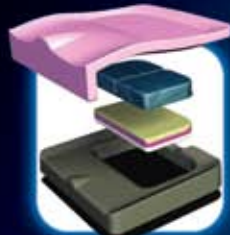
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.....

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2011 WEBINARS

ROLLABILITY

Tuesday, April 19, 2011 · 5:00pm to 7:00pm Pacific
Jim Black and Lois Brown

LOOK ME IN THE EYE

Thursday, April 21, 2011 · 5:00pm to 7:00pm Eastern
Leslie Johnson Fitzsimmons, PT, ATP

BACK TO THE FUTURE OF COMPLEX REHAB

Tuesday, May 17, 2011 · 5:00pm to 7:00pm Pacific
Julie Piriano, PT, ATP

EARLY INTERVENTION OF POWER MOBILITY

Thursday, May 19, 2011 · 5:00pm to 7:00pm Eastern
Maria Jones

POSITIONING THE TRUNK: STABILIZING THE CORE

Tuesday, June 21, 2011 · 5:00pm to 7:00pm Pacific
Michelle Lange, OTR, ABDA, ATP

OUTCOMES

Thursday, June 23, 2011 · 5:00pm to 7:00pm Eastern
Dr. Mark Schmeler

PELVIC CONTROL

Tuesday, July 19, 2011 · 5:00pm to 7:00pm Pacific
Allen Siekman

PRESSURE SORE MANAGEMENT

Thursday, July 21, 2011 · 5:00pm to 7:00pm Eastern
Darren Hammond

POSITIONING THE EXTREMITIES: COMPLETE THE PROCESS

Tuesday, August 16, 2011 · 5:00pm to 7:00pm Pacific
Michelle Lange, OTR, ABDA, ATP

POWER ASSIST

Thursday, August 18, 2011 · 5:00pm to 7:00pm Eastern
Theresa Berner, OT

MOUNTING ASSISTIVE TECHNOLOGY DEVICES TO WHEELCHAIRS

Tuesday, September 20, 2011 · 5:00pm to 7:00pm Pacific
Michelle Lange, OTR, ABDA, ATP

TOPIC & SPEAKER TBD

Thursday, September 22, 2011 · 5:00pm to 7:00pm Eastern

TOPIC & SPEAKER TBD

Tuesday, October 18, 2011 · 5:00pm to 7:00pm Pacific

TOPIC & SPEAKER TBD

Thursday, October 20, 2011 · 5:00pm to 7:00pm Eastern

TOPIC & SPEAKER TBD

Tuesday, November 15, 2011 · 5:00pm to 7:00pm Pacific

TOPIC & SPEAKER TBD

Thursday, November 17, 2011 · 5:00pm to 7:00pm Eastern

TOPIC & SPEAKER TBD

Tuesday, December 13, 2011 · 5:00pm to 7:00pm Pacific

TOPIC & SPEAKER TBD

Thursday, December 15, 2011 · 5:00pm to 7:00pm Eastern

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