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CELA2012

April 17-19, 2012

Hyatt Regency Crystal City, Arlington, Va.

Sponsored by NRRTS and NCART in association with New Mobility Magazine

CELA 2012, presented by NRRTS and NCART in association with New Mobility magazine, is the centerpiece of our industry and profession's strategy to realize a Separate Benefit Category under Medicare for Complex Rehab Technology products and associated services. The impact of the separate benefit would extend to Medicaid and other payer sources as they historically have followed Medicare's lead.

We have been building toward this advocacy effort on Capitol Hill for more than three years. CELA 2011 brought 250 industry professionals and 40 consumer advocates to meetings with members of Congress and their staff. These meetings built awareness of the Complex Rehab issue and garnered promises of support from dozens of members.

CELA 2012 will build on the success of our 2011 efforts. We have legislative language, and if all goes as planned, we will have a bill already introduced in Congress. We will be armed with a specific ask: support the legislation to create a Separate Benefit Category for Complex Rehab Technology.

As stakeholders in the Complex Rehab Technology industry, we all need the Separate Benefit Category to stabilize our businesses, our practices and most importantly, assure consumers access to the equipment they need. To make this happen, we need you to attend CELA 2012.

REGISTRATION FEES

- **NRRTS REGISTRANT** - *$100.00*
- **FON/NCART MEMBER** - *$125.00*
- **REGULAR** - *$150.00*
- **CONSUMER** – *No Registration Fee*
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SCHEDULE OF EVENTS

TUESDAY, APRIL 17, 2012

Safe arrivals

WEDNESDAY, APRIL 18, 2012

9:00am to Noon
Keynote and Plenary Session
(.3CEU applied for)

Paul Tobin, President and CEO, United Spinal Association

Noon to 1:30pm
Lunch

1:30pm to 3:30pm
CRT Capitol Hill Orientation
(.2 CEU applied for)

3:30pm to 5:30pm
CRT State Delegation Meetings

6:00pm to 7:00pm
Opening Reception

THURSDAY, APRIL 19, 2012

9:00am to 4:30pm
Capitol Hill Visits

5:30pm to 8:00pm
Capitol Hill Debriefing/Wine and Cheese Reception

FRIDAY, APRIL 20, 2012

Safe Departures

PAUL TOBIN

Paul J. Tobin was unanimously appointed president and chief executive officer of United Spinal Association in June 2006. He served as deputy executive director from July 2003 and was a member of the Board of Directors from 1995 to 1996.

Tobin, a Navy veteran, oversees all strategic operations of the organization and ensures the execution of United Spinal's mission and vision. In addition to his service as deputy executive director, Tobin has held a variety of managerial positions, including hospital services officer, director of special projects, and group director of benefit services. He was promoted to associate executive director of benefit services in 1998.

A Long Island native, Tobin graduated from Manhattan College with a Bachelor of Science in civil engineering in 1991. Upon graduation, Tobin attended the U.S. Navy Officer Candidate School in Newport, R.I., from which he was commissioned an ensign in November, 1991 and joined the Civil Engineering Corps. With the CEC, Tobin was stationed at Naval Air Warfare Center in Lakehurst, N.J.

After sustaining a spinal cord injury in August of 1993, Tobin underwent rehabilitation at the Castle Point (N.Y.) Veterans Affairs Medical Center. Tobin has also pursued a master's degree in public health administration at Columbia University and is currently pursuing a master's degree in social work at Fordham University.

Tobin stresses the tradition of service that is the legacy of United Spinal Association and, as president and CEO, urges our membership and individuals with disabilities everywhere to continually challenge the limitations imposed by attitudes, medical technology, society and government.

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nrrts UPDATES

DIRECTIONS

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Michael Banks, ATP, CRTS® since 1999, is a seating and mobility specialist with United Seating and Mobility in Walla Walla, Wash. **See page 58.**

Paul Bergantino is president and CEO of ATG Rehab. **See page 16.**

Alan Channin, ATP, CRTS® has been a NRRTS Registrant since 1993. He works for Rehabilitation Equipment, Inc. in Bronx, N.Y. **See page 20.**

Don Clayback is executive director of the National Coalition for Assistive and Rehab Technology (NCART). Clayback has more than 23 years of experience in the Complex Rehab Technology and Home Medical Equipment industry as a provider, consultant and advocate. He is actively involved in industry issues and a frequent speaker at state and national conferences. **See page 24.**

Ann Eubank, LMSW, OTR/L, ATP, CAPS, is vice president of Community Initiatives for UsersFirst, a program of United Spinal Association. **See page 28.**

Denise Fletcher, Esq., is an attorney with the Health Care Group at Brown & Fortunato, P.C., a law firm based in Amarillo, Texas. She represents pharmacies, infusion companies, home medical equipment companies, and other health care providers throughout the United States. Fletcher is Board Certified in Health Law by the Texas Board of Legal Specialization. **See page 12.**

Allison Fracchia is the Assistive Technology Clinic Coordinator at Methodist Rehabilitation Center in Jackson, Miss. She has worked in the area of seating and mobility for 16 years. She serves as an executive board member of the Clinician Task Force (CTF). The CTF is a national group of seating and mobility clinicians working to influence Medicare and Medicaid coding, coverage, and payment policies for complex rehab and assistive technology devices. **See page 34.**

Michele Gunn, ATP, CRTS®, is NRRTS president. She works for Browning's Health Care in Orlando, Fla. and has been a NRRTS Registrant since 1996. **See page 10.**

Michelle L. Lange, OTR, ABDA, ATP/SMS, is an occupational therapist with 25 years of experience and former clinical director of The Assistive Technology Clinics of The Children's Hospital of Denver. She is a well-respected lecturer, nationally and internationally, and has written seven book chapters and more than 100 articles. She is the editor of *Fundamentals in Assistive Technology, 4th ed*. Lange is on the teaching faculty of RESNA and the University of Pittsburgh and serves on the RERC on Wheeled Mobility Advisory Board. She is a credentialed ATP, credentialed SMS and is a senior disability analyst of the ABDA. **See pages 68 & 70.**

Jill Sparacio, OTR/L ATP, ABDA is an occupational therapist in private practice in the Chicago Illinois area. A graduate of Western Michigan University, she currently provides consultation to individuals with medical fragility and developmental impairments. In addition, she consults with rehab technology suppliers and equipment manufacturers, providing clinical support and education. She is actively involved in funding issues at both the state and federal levels, currently serving on the Executive Board of the Clinical Task Force. She has specialized in seating and positioning for more than 29 years. **See page 30.**

2012 NRRTS **WEBINARS**

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The University of Pittsburgh, School of Health and Rehabilitation Sciences, Department of Rehabilitation Science and Technology Continuing Education (RSTCE) is certifying the educational contact hours of this program and by doing so is in no way endorsing any specific content, company, or product. The information presented in this program may represent only a sample of appropriate interventions. Each person should claim only those hours of credit that he or she actually spent in the educational activity.

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Tuesday, April 17, 2012 • 5:00pm-7:00pm Pacific
Mary Shea, MA, OTR/L, ATP

HOME ACCESSIBILITY: *From the Front Door to the Upstairs Bath*
Thursday, April 19, 2012 • 5:00pm-7:00pm Eastern
Cynthia Petito, OTR/L, ATP, CAPS

PATHOPHYSIOLOGY: *Duchene's Muscular Dystrophy and Spinal Muscular Atrophy (SMA)*
Tuesday, May 22, 2012 • 5:00pm-7:00pm Pacific
Michelle L. Lange, OTR, ABDA, ATP/SMS

POSITIONING VS. RESTRAINT: *Appropriate Use and Justification of Secondary Seating Components*
Thursday, May 24, 2012 • 5:00pm-7:00pm Eastern
Michelle L. Lange, OTR, ABDA, ATP/SMS

PATHOPHYSIOLOGY: *Amputation, Including Seating*
Tuesday, June 19, 2012 • 5:00pm-7:00pm Pacific
Jennith Bernstein, PT, ATP

POWER WHEELCHAIRS: *Using IR Transmission to Control Devices in the Environment*
Thursday, June 21, 2012 • 5:00pm-7:00pm Eastern
Jill Kolczynski, ATP

POWER SEATING FUNCTIONS: *Clinical Indicators for Each*
Tuesday, July 17, 2012 • 5:00pm-7:00pm Pacific
Stephanie Tanguay, OTR

ACCESS TO FUN! RECREATION FOR ALL
Thursday, July 19, 2012 • 5:00pm-7:00pm Eastern
Mary Carol Peterson, OTR

MEDICAL INTERVENTIONS AND THEIR RELATIONSHIP TO ASSISTIVE TECHNOLOGY INTERVENTION: *Tone Management, Surgeries and Orthotics*
Tuesday, August 21, 2012 • 5:00pm-7:00pm Pacific
Pamela Wilson, MD

SEATING CONSIDERATIONS FOR CLIENTS WITH HIGH TONE
Thursday, August 23, 2012 • 5:00pm-7:00pm Eastern
Sharon Pratt, PT

POWER WHEELCHAIRS: *Using the Access Method to Control the Computer Mouse*
Tuesday, September 18, 2012 • 5:00pm-7:00pm Pacific
Mike Babinec, B.A., B.S., OTR/L, ABDA, ATP

ADVOCACY FOR ALL! *Consumer Driven Change*
Thursday, September 20, 2012 • 5:00pm-7:00pm Eastern
Ann Eubank, OTR, ATP

GETTING IT RIGHT THE FIRST TIME: *Measurements*
Tuesday, October 23, 2012 • 5:00pm-7:00pm Pacific
Robert Lindholm, ATP

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Thursday, October 25, 2012 • 5:00pm-7:00pm Eastern
Michelle L. Lange, OTR, ABDA, ATP/SMS

WHEELCHAIRS AND TRANSPORT
Tuesday, November 13, 2012 • 5:00pm-7:00pm Pacific
Mary Ellen Buning, PhD, OTR/L, ATP

FUNDING: *What's New in the World of Reimbursement?*
Thursday, November 15, 2012 • 5:00pm-7:00pm Eastern
Liz Cole, PT

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Jill Sparacio, OTR/L, ATP

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Thursday, December 20, 2012 • 5:00pm-7:00pm Eastern
TD Schenck, ATP

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DEVVA

Written By **Michele Gunn, ATP, CRTS®**

I WOULD LIKE TO BE AS INVOLVED AS possible in our Outcome Measures pilot program. Unfortunately, most of the populations I serve are under the consenting age to complete the FMA forms. I am sure many of you reading this are in the same predicament. This does not mean we do not have other ways of sharing positive outcomes. NRRTS is also trying to collect case studies for DIRECTIONS. This is the perfect niche for children and the adolescent population. In fact, these are the cases where we can visually see the most change in our clients with the interventions we provide.

For instance, take my friend Devva. When I first met Devva, her mom told me a story about her birth and the meaning of her name. Devva means "goddess" or "divine" in Hindi. Although this name sounds cute and petite, it has powerful meaning. After a traumatic birth, her mom was waiting anxiously for word on her condition. She had been taken from the room and had not made a sound. Mom heard a small hitch followed by a healthy determined bout of crying from down the hall. She decided a strong name was going to be necessary for her determined child to face the challenges she would meet throughout her life.

We met in the seating clinic at school to assess Devva for a new wheelchair. She came into the clinic in a manual chair as her old power chair had been left in another state when they moved. She had outgrown it, and it had been non-functioning for a few months before they left. Bright and able to verbalize what she wanted, Devva shared what she needed the new chair to do. She wanted a power chair that would maneuver well at school between classes, yet still get into her bedroom. Devva can help with a stand pivot transfer but this was very difficult from the manual chair due to its seat to floor height. A somewhat typical teen, she was not terribly concerned about how she sat in the chair although she complained of pain from sitting for prolonged periods of time. This is the point of the assessment where the therapist took over. She was very concerned with Devva's posture and explained to her we may be able to help the pain if she was sitting correctly. Devva said she was willing to try, but did say she was not a fan of chest supports and was hoping she would not have to wear one.

When someone comes into the clinic looking like Devva did in her chair, seating 101 says step one is to get them out of the chair. So we transferred her onto the mat and commenced with seeing what moved, did not move and by how much. She sat a bit more upright by blocking her right knee and giving her a wider base of support. To help with her scoliosis, we placed a math text book open about half way under her left ischial. In the clinic, you have to use what you have available. At this point Devva,

FAR LEFT: SIDE VIEW OF OLD CHAIR
LEFT: SIDE VIEW OF NEW CHAIR

TOP: FRONT VIEW OF OLD CHAIR
BOTTOM: FRONT VIEW OF NEW CHAIR

> A pair of experienced hands for both the therapist and supplier should come standard with the price of admission for all of our clients.

the therapist and I look like we are playing Twister, but Devva's mom said she thought Devva looked great through all the arms. We knew what we wanted to do with the seating from the simulation. A demo with a power chair was conducted later at her home. Paperwork was completed and submitted for funding.

Devva received her new chair last month. Her posture was so improved it got me thinking about how we need people to see what we do. This is how we will get funding sources to quit comparing us to Internet companies. At the moment, they are only looking at the price. I am sure Devva could have received this chair through the Internet a bit cheaper than what the state of Florida paid Browning's Health Care. At the same time, I am sure she would have looked fairly similar to the picture of the old chair in the new chair. There is no method for an Internet company to complete all the steps described above that lead to this outcome.

So what is the real cost of providing quality interventions for our clients? A pair of experienced hands for both the therapist and supplier should come standard with the price of admission for all our clients.

For Devva, a frame with three to five degrees of posterior tilt: free, given you order a frame with that adjustment and actually use it. A medial thigh support and pelvic obliquity build up: $275 and $50 each. Before and after pictures like Devva's: PRICELESS!

CONTACT THE AUTHOR:
Michele may be reached at mgunn@brownings.net or 407.650.9585.

The REPAIR Business

Written By **Denise M. Fletcher, Esq.**

IT'S HAPPENED TO EVERYONE. A MEDICARE beneficiary shows up in your store with a power chair needing repair. The problem is you didn't provide the chair, and the supplier that did is no longer in business or just doesn't want to fix the chair. Suddenly, you are faced with repairing a chair you didn't provide. This can be challenging from both an ethical and financial perspective. This can be even more challenging in a competitive bidding area.

For rental items, any cost for repairs or replacement parts during the rental period is the responsibility of the supplier. After the title transfers to the beneficiary, the repairs are the responsibility of the beneficiary, and the beneficiary has the freedom to have repairs performed by any supplier it chooses.

The rules do not prohibit suppliers located in a competitive bidding area ("CBA") not awarded a competitive bidding contract from providing and billing for repair services. Medicare will cover the costs associated with such repairs even when a non-contract supplier repairs a competitive bid item. This article discusses (1) the services and parts that will qualify as repairs; (2) the submission of claims for these services and parts; and (3) Medicare's payment for repairs.

WHAT REPAIR SERVICES ARE COVERED BY MEDICARE?

Because the labor involved in a repair or maintenance service is not subject to competitive bidding, any Medicare-enrolled supplier may repair beneficiary-owned equipment, including equipment that falls within a product category subject to competitive bidding. For Medicare to cover the labor and parts associated with repairs, the following criteria must be met:

- The repair or maintenance service is not covered by either the manufacturer's or supplier's warranty; and
- The repair is necessary to make the equipment serviceable; or
- The service qualifies as non-routine maintenance recommended by and performed according to the manufacturer's specifications.

Medicare will cover not only the cost of labor, but also the parts involved in the repair service. Thus, when a component or an entire part, such as a battery or a tire, of the base equipment is in need of repair to make the equipment serviceable, the supplier performing the repair may furnish the needed part, even if the supplier does not have a contract and the part is a competitive bid item. Furthermore, accessories and optional features, such as elevating leg rests, seating systems, and adjustable arm rests, may be repaired by any Medicare-enrolled supplier.

WHAT ARE THE LIMITATIONS?

Items that fall within a product category subject to competitive bidding must be furnished by a contract supplier when:

- The item is not part of a repair.
- The base equipment is replaced in its entirety. Thus, when the base equipment is replaced because the equipment was lost, stolen, irreparably damaged, or used beyond the reasonable useful lifetime of the equipment, then the beneficiary must obtain the equipment from a contract supplier.
- A part or accessory is replaced for reasons other than repair of the base equipment. For example, if an accessory is altered because the beneficiary's medical condition has changed, then Medicare will not consider the service to qualify as a repair.
- The beneficiary requires a replacement seat cushion (E2601-E2608; E2622-E2625) or a replacement back cushion that is not integral to the base equipment (E2611-E2616; E2620-E2621). According to Medicare, these items can never qualify as parts required for a repair.

The rules do not prohibit suppliers located in a competitive bidding area ("CBA") not awarded a competitive bidding contract from providing and billing for repair services.

WHAT IS REQUIRED TO SUBMIT A CLAIM FOR REPAIR SERVICES?

When a service qualifies as a repair, the supplier can bill for the labor involved by submitting a claim with Healthcare Common Procedures Coding System ("HCPCS") code K0739. The claim should also include the HCPCS codes for any replacement parts furnished. The HCPCS codes for the repair parts must include the modifier "RB." If the replacement

part is subject to round one of competitive bidding, then the modifier "KG" must also be added. For replacement parts subject to round two of competitive bidding, modifier "KK" must be added in addition to the RB modifier.

Generally, suppliers will submit one claim covering the labor and parts supplied during the repair service. However, there may be situations where a non-contract supplier will submit two claims. Suppliers must accept assignment when furnishing items subject to competitive bidding. Thus, if a non-contract supplier performs a repair involving a part subject to competitive bidding, but the supplier does not generally accept assignment, the supplier will have to submit two claims. One claim will cover the labor and non-competitive bid items provided on an unassigned basis while the other claim will cover the competitive bid items that the supplier must furnish under assignment.

As with all claims submitted to Medicare, suppliers must have adequate documentation to support the claim for a repair. In the documentation, the supplier should include (1) identification of the equipment repaired; (2) the reason for the repair; (3) justification for any replacement parts furnished during the repair; (4) evidence of the labor units billed under K0739; and (5) any other documentation required in the local coverage determination policy applicable to the supplier's area.

HOW WILL MEDICARE PAY FOR REPAIRS?

Because the labor involved in repair services is not subject to competitive bidding, Medicare will reimburse suppliers based on the general payment rules for such services. Likewise, if a part needed for the repair is not a competitive bid item, then the general payment rules apply, and Medicare will pay based on the lesser of the actual charge or the fee schedule amount for the part. For replacement parts that are competitive bid items, Medicare will pay the single payment amounts set during the competitive bidding process.

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The Repair Business
(continued from page 13)

> When a service qualifies as a repair, the supplier can bill for the labor involved by submitting a claim with Healthcare Common Procedures Coding System ("HCPCS") code K0739.

Repairing a power chair provided by another supplier is one of those topics that sparks debate. The discussion usually pits the ethical and regulatory responsibility of the original supplier to repair the equipment against the responsibility of another supplier to repair the equipment. Putting the debate aside, the repair business may be a viable option for businesses that are denied a contract in the competitive bidding program. Non-contract suppliers may retain some of their existing clientele by offering repair services and may still be able to participate during the competitive bidding program through subcontracts with contract suppliers that do not provide repair and maintenance services.

CONTACT
Denise may be reached at dfletcher@bf-law.com or 806.345.6318.

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There's ROOM at the Top

Written By **Danette Baker**

WORKING IN HIS FATHER'S full-service pharmacy gave Paul Bergantino a head start in the Complex Rehab Technology industry. That knowledge, a can-do attitude and astute business acumen has Bergantino at the helm of a leading complex rehab technology supplier. Here is his take on the road to the top.

HOW DID YOU BECOME INTERESTED IN THE INDUSTRY?

I literally grew up in the industry. My father owned a full-service pharmacy in Hamden, Conn., for about 30 years, meaning he did more than just fill prescriptions. He also carried retail and institutional sales for home medical equipment and intravenous and respiratory care. During grade school, I spent many of my afternoons with the technicians, installing stairglides, delivering HME products or repairing wheelchairs.

My father sold his business to an investor group out of Hamden just before I became a working adult. I worked for the company a short time before deciding to venture out on my own. Along with a partner, I began CT Rehab in 1990 with four employees.

WHAT ATTRACTED YOU TO THE ATG GROUP?

After operating CT Rehab for almost 10 years, I met Chuck Wallace, Mike Freedman and Tim Burfield in 1999. They were known as CMT and were the three active investors, backed by a private equity group, who found our companies' missions to be in tandem.

We needed capital and acquisition know-how to grow, which was something they had in abundance. By joining forces with this proven high-integrity group, we have been able to build a leading company in Complex Rehab Technology. CT Rehab was one of their first investments and ended up being a platform for the organization.

TODAY, ATG IS ONE OF THE LEADERS IN COMPLEX REHAB TECHNOLOGY. AS ITS CEO, HOW DO YOU KEEP ATG AT THE TOP?

By keeping our team focused on daily incremental improvements and being proactive versus reactive. Trust me, it's not easy, but we focus on what we have identified as the three Ps: planning, people and process. Our leadership team is seasoned and is very effective at creating and implementing plans, recruiting the right talent and improving our processes. We are fanatical about our best practices and IT system. We literally implement enhancements every week. The power of our operating system coupled with our detailed "best practices" are the primary foundation blocks to our organization's strength and ones that will help us build upon and weather the choppy waters ahead.

WHAT ARE THE NEXT STEPS FOR ATG REHAB?

More jobs, growth and robust systems. "Smart" growth is important to all ATG Rehab stakeholders as it allows us to provide programs and stability for our customers, referral sources and ATG team.

WHAT IS YOUR ROLE IN THAT GROWTH?

Whatever it takes to build and improve an outstanding company. Many of my days are filled with conference calls, meetings and travel to move our agenda forward. I communicate and remove obstacles for and with our leadership team and am involved in all aspects of the business: setting the short and long-term plans, customer service initiatives, business development, operations, marketing, financing, creation of company culture, human resources, recruiting, IT, compliance, safety, regulations, sales, contracting, problem resolution, etc.

WHAT ARE SOME OF THE MOST SIGNIFICANT MILESTONES IN YOUR CAREER?

From a business standpoint, there are many – celebrating our 10th year in business, hiring our 700th employee, adding the second location, expanding into our 25th state, reporting $100 million in revenues — but the most meaningful and memorable are the many lives we have impacted through helping our customers be as independently functional and mobile as possible. We have always worked hard at reflecting our tagline, "Life. In Motion."

> We focus on what we have identified as the three Ps: planning, people and process.

(continued on page 19)

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(continued from page 16)

> The overall success of ATG Rehab is the result of teamwork.

The overall success of ATG Rehab is the result of teamwork. It is the tireless dedication, determination and teamwork of the ATG employees that enables us to successfully serve our customers and grow our organization.

For me, I am proud to be one of the first mobility specialists – this was pre-RTS and ATP designations. One of the first complex clients I evaluated was a teenager who had a genetic bone disorder. Up to this point, he lived much of his life being pushed around in a stroller. I remember the final fitting of his new power wheelchair (a Fortress 655FS) like it was yesterday. There was not a dry eye in the room as he began independently controlling his new wheelchair.

Literally, each day our team works to create milestones for the folks we serve – from figuring out an independent power drive control for a man who only has the use of his index finger to expediting the evaluation and delivery process of a new power wheelchair so a young woman (recently diagnosed with a progressive disease) could once again compete in the Boston marathon ... this time with her daughter.

WHO HAS BEEN INSTRUMENTAL IN THOSE ACCOMPLISHMENTS?

There are so many people who have been instrumental in these accomplishments. On a personal level, I have had four mentors: my dad, Michael Bergantino; my brother, Toby Bergantino, an ATP, who joined our company 20 years ago; Gib Harris, a Wall Street executive/investor; and Tim Burfield, an industry executive and co-fournder of ATG Rehab Inc.

My father taught me through his daily actions about moral character, work ethic and overall business acumen. Toby taught me the complex rehab business starting with turning wrenches on Everest & Jennings manual wheelchairs. While still a teenager and working for him, I was fired for the first (and last) time ever. Luckily, he hired me back!

Harris was extremely influential in our early years in helping build the foundation of our company. Burfield mentored, stretched and encouraged me these past 12 years, helping me hone my skills and focus on what matters most.

All four mentors shared a common theme as they passed on their methods of doing business: accountability, commitment and integrity. Simply put: "Say what you are going to do, and do what you say."

THE COMPANY HAS MADE A SIGNIFICANT IMPACT IN THE MOBILITY INDUSTRY. WHAT HAS KEPT YOU WORKING SO DILIGENTLY FOR ITS SUCCESS?

Our industry attracts a unique person willing to work hard who is committed and eager to help others. I find the passion of working with so many good people over the years truly inspirational and contagious. I am energized and enjoy the combination of providing jobs for many families and growing a service-focused business that exists to help others.

WHERE DO YOU SEE YOURSELF IN FIVE TO 10 YEARS?

As a company, our goal is to continue to be a force in consolidating the industry. In the next three years, we plan to double in size and to become not only the largest complex rehab technology provider, but one that helps transform the industry by setting new standards with distribution, quality and timeliness that all directly benefit the end user.

Growth alone is not the key to success, but it is a component to building an organization with a solid foundation and future. We will grow smart and thoughtfully, working hard to follow one of Starbuck's mottos: "Stay small while you grow." We realize the importance to strike the right balance between using our economies of scale and resources with the ability to provide individual service by acting small, lean and local.

As our organization grows, we will never lose sight of what matters most to our consumers, payers and referring customers: to deliver an accurately fit product in a timely manner.

On a personal level, I am completely committed to the industry and plan to continue to help ATG thrive and grow for many years.

OBVIOUSLY, YOUR POSITION AT ATG DEMANDS A GREAT DEAL OF YOUR TIME, BUT WHAT'S LIFE OUTSIDE OF WORK LIKE FOR PAUL BERGANTINO?

I've been married to my wife, Carolyn, for 19 years. Our most significant, meaningful, joys and challenges come in raising our sons, Jared, 16, and Jack, 12. Now I just hope that I can survive teaching our oldest to drive!

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Perseverance, Determination & other LIFE LESSONS *Learned* on the Links

Written By **Randy Christian**

THE GOLF COURSES AT BETHPAGE STATE Park on Long Island, N. Y., are legendary. Known as the "People's Country Club," this public golf course, laden with diabolical twists, turns, ups and downs, has challenged amateur and professional golfers for generations. More than 300,000 rounds of golf are played each year on the five courses that comprise Bethpage. Most recently the 2002 and 2009 U.S. Open championships were played on the infamous Black Course at Bethpage. This world-renowned course is home to some of the most challenging holes professional players will ever attempt to conquer. The tree-lined fairways are narrow, and the greens are pin dots compared to some on other courses on the PGA tour. The numerous sand traps, which seem to be everywhere, demand players to use brain more than brawn when calculating each shot. Some say courses like the Black are more than unforgiving and will destroy players who lack the fortitude to overcome the hazardous hardship lurking around every corner.

Those who are fans and casual participants of the game of golf easily forget the positioning of the player's body is critical for tee-to-green success. Incorrect spine angle, a tiny turn of the wrist or ankle, a slightly raised shoulder, errant weight transfer or any number of misalignments before commencing and concluding the swing can have crippling consequences on the outcome of the game. The player's timing, tempo and rhythm on every shot must have the synchronization equal to a fine Swiss watch. When all are in sync, the rewards go far beyond monetary. What was once feared and considered capable of destroying is now seen simply as one of life's challenges we can conquer.

Alan Channin began playing golf when he was 10 years old and continues to play the game, even today. As a kid, he practiced and played continuously and soon became a seriously competitive golfer in the junior amateur world. He continued his quest to be the best in college. After he graduated from college, Channin set his clubs aside for a few years. Eventually, the lure of the lush green grass on the manicured fairways at Bethpage and other courses close to home, was more than enough to cause Channin to tee it up again. It wasn't long before he was back in the swing of things and reclaiming his low single digit handicap, as well as a spot on the prestigious Nassau Players, an elite group of amateur golfers who live in Nassau County on Long Island. Most of them are "scratch" golfers. Even though Channin still loves the game and takes great pride in play at consistently high levels, he is more appreciative of how it helped build a beautiful, loving relationship with his father that he will treasure forever.

"My dad's interest in golf grew as my game began to advance and improve. The better I got, the more competitive we got with each other. We either competed together or against each other pretty much up until the day he died," Channin said.

Channin shared those special times he spent with his father on the golf course with friends and family at his father's funeral. Many in attendance were unaware Channin's dad was a World War II veteran. An injury his father suffered while serving his country resulted in the amputation of one of his legs just below the knee. Channin remembers his father never complaining or using his handicap as a crutch, but excelling at most everything he pursued. His dad went on to graduate from college, then from law school. He became a respected attorney and a revered citizen. As Channin recalls, his dad was always positive and seemed to never have a bad day, even on the golf course. When asked what he learned most from the days he played golf with his dad, Channin was quick to say, "Perseverance, determination and the importance of a spirit that tells you to never give up and that you can fight through anything."

> The more Channin learned about this new area of care for people with disabilities, the more he wanted to know.

When Channin was 17 years old, he called upon that "never give up" spirit of his father. He was playing in a Connecticut junior amateur tournament and a win would allow him to advance to other state tournaments. He hadn't played well on the front nine. His spirit was very low. His confidence was even lower and determination was in short supply. Fortunately, his friend and golfing buddy was his caddy. "He told me to let it go and forget about the front nine. We had played enough golf together that he knew what was in me. He knew I could do better, and I did. I shot a few under on the back, and it was enough so I could move to the next tournament," Channin said.

Throughout his life, others seemed to know what was in Channin, too. One of those others was an older gentleman who befriended Channin when he worked at the central produce market in New York City for a short time. Channin had finished his undergraduate degree, but was a bit tired of school. He decided to work full time unloading then reloading trucks stuffed with fruits and vegetables shipped to from all across the country to NYC. He worked from 3 a.m. to 10 a.m. Most of his coworkers were union guys and most had little more than a high school education. Channin appreciated his time working in this blue collar environment, but many of his co-workers saw the college kid as a fish out-of-water. His older friend sensed there was more in store for Channin than shuffling honeydews and cantaloupes from Texas. Surprisingly, he suggested to Channin it was time for him to move on and said his son might be able to help him find a better job.

"His son worked for a pharmaceutical company and knew someone at a job recruitment firm. I never met the son, but based on his dad's recommendation, I got an appointment with the recruitment firm and then a job as a rep," Channin said. Thus, began a career enduring for more than 30 years.

As a gusher of mergers, acquisitions and HME began to take place in the pharmaceutical industry, Channin felt it might be in his best interest to consider other employment options. As faith would have it, he latched onto his first job in the HME industry with Medco Surgical in Queens, N. Y. He took to his new job as a sales representative like a fish to water. He called on many hospitals convincing them his company was the ideal solution for their patient's home care equipment needs after discharge. Even though HME was the primary focus of Medco, there was a small group of Medco staffers who were working on what would become complex rehab. The more Channin learned about this new area of care for people with disabilities, the more he wanted to know. His employer duly noted his intense interest.

In 1983, Channin was sent to Shrive, Ohio, for training and ultimately certification on equipment built by Duit-Control. The company was making alternative drive systems for power chairs for people with spinal cord injuries and cerebral palsy. Again, Channin was in the center of an industry that was experiencing a whirlwind of change. Medco was acquired by a company not particularly interested in complex rehab, yet Channin was. So, in March of 1985, a band of young, energetic rehab professionals formed Dynamic Medical Equipment. With a passion for space-age technology, the Dynamic team set out to find ways it could help people with immobilizing disabilities and reclaim their freedom and independence. Their strategy was simple: provide leading industry expertise. They did this by inviting physical therapists to become part of their sales team. Channin and the others constantly pursued more knowledge, education and certifications regarding complex rehab.

Channin was one of the first people to apply for NRRTS Registration.

In time, it was clear there was a need for something that would distinguish the expertise required to provide competent complex rehab services from HME. The seeds for NRRTS were planted, and they began to take root and grow. Channin was one of the first people to apply for NRRTS Registration. When asked why NRRTS registration was so important, he responded immediately with a one-word answer, "Reimbursement."

"In the early 90s, we'd send in a pro forma invoice to third party payers that was a cost estimate requesting payment for a client's equipment. We also sent along medical justification as to why the client needed it. It's part of a prescription from a physician," Channin continues. "We weren't getting approved. We'd get case managers calling and telling us that another company is offering a 30 percent discount. Our response would be 'What 30 percent of our services would you like us to cut?'."

It was obvious the third party representatives had virtually no idea the level of expertise, or the volume of information the complex rehab medical professionals gathered in order to accurately access the patient's needs. Hours and hours were spent collecting precise data. Even the veteran "third partyers" developed only a vague understanding of the delicate needs of their fellow human beings whose beautiful mind and courageous spirit was trapped in a body unlike theirs. Codes, calculations and an ever-changing policy and procedure manual were their Ouija board used to decide whether a request was approved or denied. The constant delays and chronic denials was the tipping point. Frustrated complex rehab professionals knew it was time to not only

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...Learned on the Links

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create an entity that would precisely define who they are and what they do, but also radically differentiate them from the "scooter guys."

So the National Registry of Rehabilitation Technology Suppliers, NRRTS, was launched by like-minded industry professionals interested in furthering the cause of complex rehab and to become members of the new organization.

Soon, Channin and other complex rehabers assembled and crafted exams that would test the skills and knowledge of those seeking NRRTS certification. In short order, continuing education was placed in the NRRTS toolbox, but it is the networking with other complex rehab professionals, both near and far, that was and is the fabric of the NRRTS. The sharing, caring and compassion of this small, tight-knit group of people who clearly understand how complex rehab can change lives, is the tie that binds.

Today, the National Registry of Rehabilitation Technology Supplies is 20 years old. As stated on its website "Only a NRRTS Registrant may use the credential of RRTS® - Registered Rehabilitation Technology Suppliers, or CRTS® - Certified Rehabilitation Technology Supplier®." It is a badge of honor not easily attained, but as Channin's dad might have suggested, with perseverance and determination, you can earn your NRRTS credentials.

There is no denying there are many twists and turns and ups and downs in the future for complex rehab, but thanks to Channin and many others, there is a collective fortitude that can help NRRTS overcome most any hazardous hardship lurking around the corner. Now, what was once feared and considered capable of destroying is seen simply as one of life's challenges that can be conquered ... together.

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Tools for TELLING the CRT Story

Written by **Don Clayback**

BE PREPARED

There's never been a more important time to be spreading the Complex Rehab Technology (CRT) message. Whether pursuing a Separate Benefit Category within the Medicare program, battling state Medicaid cuts, or dealing with a variety of other coverage and payment issues, we all need to be creating a greater awareness of CRT. Policy makers and others in positions of influence need to understand what CRT is, who uses it, the benefits it brings, how it is provided, and the access challenges that exist. While we are making inroads in certain areas, we must continue this crusade. The good news is there are some very helpful tools you can use to tell the CRT story to those who need to be educated.

TOOLS YOU CAN USE

To help tell the Complex Rehab Technology story, NCART has developed and gathered a variety of documents and materials to assist in the educational and advocacy process. The following are some of the materials available to help spread the CRT message:

CRT Video - "Complex Rehab Technology. Essential for health. Essential for life.": This video provides a solid introduction to CRT. The introduction is told from the perspectives of the individuals who rely on it for their health and independence, physicians who prescribe it, and consumer organizations working to protect access. Along with an introduction, the video highlights needed policy changes. The video should be required viewing for anyone involved in matters relating to the coverage and payment of CRT products and related services. It also can be used to increase awareness with company employees, consumer groups and other organizations.

Complex Rehab Technology - Facts and Figures: This one-page document is designed to give a quick overview of CRT and is a great concise introductory piece. It provides five key message points regarding CRT and gives supporting narrative. The five key points are: CRT products and services are significantly different than standard Durable Medical Equipment (DME); these specialized products are used by a small population of children and adults who have significant disabilities and medical conditions; similar to the provision of custom Orthotics and Prosthetics, the process of providing CRT products is typically done through a clinical model and is service intensive; CRT companies have significant operating costs and minimal profit margins; and there are only a limited number of qualified suppliers which provide these specialized products and services.

"Complex" written by Mark Sullivan: A very compelling tool. This 63-page booklet uses photographs and in-depth narratives to profile people who use CRT, explain its benefits and show how it is provided. It does a great job of telling the CRT story through the use of case studies illustrating the CRT delivery process and how it helps children and adults meet their medical and functional needs. Copies are available through NRRTS.

CRT Company Overview: This six-page document supplies an appropriate overview of a CRT supplier business. It reviews the products, people, processes and costs involved in providing CRT along with explanatory information. Also included are two exhibits covering the "Delivery Process" and "Business Costs," which can be deleted if not relevant to your intended audience.

Complex Rehab Mobility Pictorial: This one-page document with photos provides a simple visual illustration of the difference between Complex Rehab Mobility as contrasted with Standard Mobility. A description of key characteristics is also included.

CRT Company Financial Profile: This one-page chart provides a snapshot of the financial profile of a CRT company based on the 2008 financial survey conducted by the Simon School of Business at the University of Rochester. It also lists the primary "activities" within a CRT business and indicates the percentage of operating expenses each consumes.

CRT Delivery Process: This one-page document outlines the 18 primary activities in the CRT "delivery process." It highlights various staff members involved at different points and the more than 30 distinct steps in the process. The principle activities mentioned include evaluating, selecting, funding, purchasing, receiving, assembling, scheduling, delivering, fitting, adjusting, programming, training and billing.

There's never been a more important time to be spreading the Complex Rehab Technology (CRT) message.

CRT HCPCS Billing Codes: This Excel file provides a list of CRT codes that can be used in delineating CRT as compared to DME when working with payers. There are two code lists: "Separate

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Tools for Telling the CRT Story

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Benefit Category CRT Codes" and a broader list, "SBC CRT Codes and Other Supplemental Codes."

Separate Benefit Category (SBC) Documents: In the course of pursuing the SBC, a variety of documents have been developed. While these were created as part of the Medicare effort, many can also be used in other situations. The documents include: Medicare Position Paper — two pages outlining need for Separate Benefit Category; SBC Proposal — 37 pages with the background, basis, and details of the SBC project; Draft legislative language — prepared as a guideline for Congress; State Position Paper —two pages tailored to the Medicaid Program; State Outline — three-page template that can be used as a starting point to develop a state SBC proposal.

Simon Business School Financial Study: This 32-page report is based on an independent study of the 2008 financial performance and activity cost allocations of CRT companies done by the Simon Business School at the University of Rochester. It contains both commentary and a variety of data charts.

GO FORTH AND PREACH

There is a lot of information available, and you want to use it strategically. Overwhelming someone with five or six documents at once can be self-defeating. Sometimes the best approach is to start with one or two documents to provide an introduction and overview. From there, you can supply the more detailed pieces based on the issue at hand.

All of the above are available for viewing and downloading in the Educational Material section of the NCART website at ***http://www.ncart.us*** Please take advantage of these items in working with members of Congress, state Legislatures, Medicaid agencies, third-party payers and others who influence coverage and payment for CRT. Each educational conversation you have is one more step toward getting CRT the recognition needed to protect access for people with disabilities and medical conditions who depend on its availability.

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> *Visit www.ncart.us for more information.*

UsersFirst Mobility Map – PROVIDING GUIDANCE and *Empowerment*

Written By **Ann Eubank, LMSW, OTR/L, ATP, CAPS**

IN SOME OF THE PREVIOUS USERSFIRST articles, we discussed the elements of a sustained consumer movement. This is one of our community's goals – to support a unified, organized, consumer voice to speak out and challenge policies that limit access to seating and wheeled mobility. UsersFirst, in collaboration with consumers, clinicians and suppliers, has developed an easy-to-read tool to help guide, educate, empower and organize consumers and clinicians through the service delivery process of wheeled mobility. This tool is the Mobility Map, and it is now available. This online education tool provides up-to-date information about the process and opportunity to take action. The Mobility Map promotes self-advocacy.

As many of us have witnessed, self-advocacy can be very effective. A recent example of self-advocacy comes from Matthew, whose mother challenged the policies of MassHealth (Massachusetts Medicaid). After receiving a few denial letters, which appeared as though they were not based on evidence or the clinician's letter of medical necessity, Matthew's mother organized friends, family and colleagues to make calls to the insurance company in support of him receiving a power wheelchair. She then contacted the Boston Globe to tell Matthew's story of being denied mobility when he had a well-written letter of medical necessity and demonstrated the ability to operate the device. Two days after the story was published, Matthew's mother received a phone call from the insurance company stating his wheelchair was now approved.

This demonstrates self-advocacy. Matthew and his mother had the support, knowledge and resources to speak out. Matthew's wheelchair team (supplier, clinician and physician) provided them with the necessary information to articulate their needs with the correct documentation, and Matthew was then connected to a consumer organization that offered assistance through the process of acquiring his wheelchair. Self-advocacy allows the consumer and/or caregivers to represent their needs and concerns from their perspective

Before a person can speak out on his/her own behalf (self-advocacy), one must have awareness of the following: 1) One's fundamental needs are being denied; 2) One is being treated differently than others; and 30 One feels successful when attempting to self-advocate. This awareness is incorporated into the education model of a successful consumer organization.

As compassionate professionals, many of us have supported consumers toward self-advocacy. We are well aware of the possibilities present when consumers have the appropriate information and structure to represent themselves and speak on their own behalf. Imagine what could be accomplished with a national consumer program to support consumers and professionals who speak out with a clear message regarding policies that limit access to seating and wheeled mobility.

A national program, run by a consumer non-profit organization, providing the support of social workers offers sustained consumer involvement through peer-support and community. Sustained consumer involvement is necessary to educate, support and empower people to speak out and challenge the policies limiting access to seating and wheeled mobility – the freedom to participate in life. Evidence suggests a sustainable consumer empowerment program includes the following elements: 1) awareness of the opportunity to engage; 2) awareness of where to engage (in person, online, at the clinic, at the wheelchair supplier's store); 3) receive enough feedback to feel one's voice is being heard; 4) opportunity to engage in a peer-support relationship; and 5) ability to see one's efforts making a difference (results).

These elements describe a national consumer education/empowerment program. UsersFirst, a program of United Spinal Association is a national, consumer organization offering this program. United Spinal Association has a history of advocacy, strong legislative relationships, legal and social work staff, print and online publications and you, strengthening this consumer movement.

> This online education tool provides up-to-date information about the process and opportunity to take action.

UsersFirst offers an online guide to navigate through the service delivery process of wheeled mobility. This is a tool for all stakeholders to use for guidance, support, information and the opportunity to take action. Because the Mobility Map offers online data collection and dissemination, it is

> Sustained consumer involvement is necessary to educate, support and empower people to speak out and challenge the policies limiting access to seating and wheeled mobility.

also a mechanism to gather data regarding consumers who are affected by specific policies. For example, the Mobility Map will include simple questions related to specific policies and provide the information necessary to identify consumers affected by those policies. Someone might ask, "Have you ever been told the insurance company will not pay for a wheelchair you might use outside your home?" This may be a question related to "in the home" rule.

This program brings together the voices of all stakeholders while focusing on the empowerment of the consumer. UsersFirst has participated and listened to the needs of all stakeholders who are negatively affected by policies. As a community, we will be more successful in creating positive policy change by partnering with the authentic voice of the consumer.

The Mobility Map is an organic document and will continue to grow with your input and feedback. Our intent is for it to be useful for all stakeholders, yet written in plain language. We can make this happen. Be a part of the national consumer education/empowerment program. Let consumers know where they can be heard, supported and can take action. Please review the Mobility Map, offer feedback and refer consumers and clinicians at ***http://www.usersfirst.org*** and click on the Mobility Map button.

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DON'T FORGET to *Breathe!*

Written By **Jill Sparacio, OTR/L, ATP, ABDA**

A REMINDER OF PLANES AND ORIENTATION

IT MIGHT SEEM OBVIOUS, BUT BREATHING IS fundamental to life. Although we all do it, we sometimes forget it can be a difficult task for individuals with mobility impairments. In our everyday life, breathing is an autonomic nervous system function, happening without conscious intent or effort. For those with mobility impairments, breathing can be all encompassing and a labor intensive task. Think back to the last cold you had. A disruption in the normal respiratory pattern tends to be uncomfortable, leaving some wondering how and when the next breath might happen. Breathing is often overlooked during the seating and wheeled mobility evaluation in the pursuit of alignment. The inability to properly oxygenate the body can be life threatening. Individuals with imbalanced tone, weakness and skeletal asymmetries experience greater difficulties. The provision of postural supports in wheeled mobility systems can often improve or further limit one's respiratory efforts.

To fully understand the effects of postural supports on respiration, one needs to understand the respiratory process. Humans need to constantly move air in and out of the lungs because the body cannot store oxygen. If you think of the respiratory system as a system of passages, muscles and pressures, it is easy to understand how an imbalance can impact one's ability.

When talking about an intact respiratory system, there needs to be consideration of the necessary balance of pressures that allow respiration to occur. Mary Massery, a physical therapist who has specialized in respiration, compares the respiratory pressures to those of a soda can. Prior to opening it, there is increased pressure inside the can making it very strong and difficult to "crush" even with effort. Once the can has been opened, the aluminum can is easily crushed by a hand. The effectiveness of the aluminum can is similar to the effectiveness of the proper balance of respiratory pressures. All components are reliant on an intact system for effective use. If there is a weakness present anywhere in the system, the overall effect will be limited.

When working with seating and positioning, proper head position is imperative for adequate respiration. Individuals with extreme forward flexion often risk respiratory issues due to occlusion or impingement of their airway. Over the years, many options have been developed to assist with head control. Anterior chest supports have been touted to assist with upper trunk support, however, they tend to be ineffective with head control. Simply pulling shoulders out of protraction does not ensure upper thoracic and cervical spine alignment. Both dynamic and static forehead straps have been advertised as options for improved head control. However, if active cervical control is not present, the use of forehead straps can result in very unstable cervical positioning, which usually results in cervical hyperextension or stacking for stability. With the advancement of recent wheelchair technology, the use of different orientations of the support surfaces has been pursued. In particular, the use of open seat to back angles in conjunction with manual anterior tilt has been found effective to help provide a more upright and stable head position. Once this balanced head position is gained, improved respiratory effort is observed.

ABOVE: K'S TYPICAL POSTURE WITH HER CHIN RESTING ON HER CHEST

RIGHT: BETH MUCKLER, DPT, K AND JANIS STREET

K is a young woman with a diagnosis of cerebral palsy who has a long history of difficulty with head control. I have had the luxury of learning from her for more than 18 years. During this time, her cervical flexion and thoracic kyphosis have become so severe her "chin on chest" position impinges her airway. As a result, she has been referred to our wheelchair clinic on many occasions.

During her last mat evaluation, it was found K was frequently sleepy and lethargic. This is a common observation with individuals with poor oxygenation, often giving the appearance of boredom or disinterest. With her forward head position, her visual field focused on her lap, adding to her lack of stimulation. Efforts at active head righting were fatiguing and did not make her respiratory effort any easier. Instead, she relied on extensor tone patterns to help move her head from extreme flexion into a position of extreme cervical hyperextension. She lacked the active muscle control needed for a comfortable and balanced upright position. Numerous headrests have been used in the past to no avail. As a last resort, a Headmaster collar was fitted and issued, preventing her typical "chin-on-chest" position. K also uses a Hensinger collar for support.

Since ancillary postural supports have been ineffective for K, a new perspective was needed to help problem solve. The seating team, including myself, Dan Sullivan (rehab technology supplier from National Seating and Mobility), Beth Muckler, DPT, and Janis Street, our wheelchair clinic coordinator, decided to use simulation (in a Pindot simulator) during the evaluation process. Through simulation, angles of orientation could be tried and modified, attempting to gain a more balanced and upright head position while also providing an improved position for visual and social interaction. It is usual practice to use recline (opening seat to back angle) in the accommodation of a forward head position, however, care needs to be taken to see how this can impact function. During simulation, it was found a more opened seat to back angle was effective for K for improved respiration, however, her visual field was now directed towards the ceiling, oral motor skills were limited and opportunity for social interaction was significantly limited. Since it was successful for maintaining proper airway function, a means to re-orient the open seat to back angle needed to be found. To do this, manual anterior tilt was selected. With the PDG Stellar manual base, a very open seat to back angle could be obtained while using manual anterior tilt to re-orient K's head and trunk in a more forward facing perspective. Although pulse oximetry was not available

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> When working with seating and positioning, proper head position is imperative for adequate respiration.

TOP: K IN THE SIMULATOR.
MIDDLE AND BOTTOM: THE CAPTURED SHAPE IN THE SIMULATOR.

Don't Forget to Breathe!

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for use, it was obvious through K's appearance and level of alertness that improved respiratory effort was achieved.

Once the proper angles and orientation were identified, the evaluation process moved toward addressing the actual shapes and contours of the support surfaces. Whenever anterior tilt is used, care needs to be taken to provide surfaces that offer greater contour, working against gravity's pull when in anterior tilt. Simulation revealed the need for a deeper ischial well. To help limit her preferred posterior pelvic tilt, total contact was found to be needed across her posterior pelvis and sacrum controlling her pelvic and sacral alignment. This contact continued up her spine, providing stability just above her pelvis and then into her thoracic spine. Care was taken to provide limited contact behind her shoulder girdle region as we did not want to lock her into her preferred kyphotic and forward shoulder position. As a result of this invitation to move into a more neutral shoulder position, her upper thoracic and cervical spine found a balanced position. This offered K's respiratory effort proper alignment and stability for function. In addition, the overall posture with the anterior tilt offered an appropriate visual field for social interaction and safe oral motor alignment for meals. The use of custom molded seating was the only option to allow us to create the support surfaces and contact she needed for improved respiratory effort and function. Pindot ContourU seating was selected.

DELIVERY OF THE NEW SYSTEM WITH ANTERIOR TILT.

Once funding was obtained, K was remolded in the Pindot simulator. This was done to ensure the recommended components would still be successful. Delivery of the system revealed good support and alignment. During times when K needs to be awake and interactive, the anterior tilt is used, providing proper orientation for her upper trunk and head. When she is relaxing or resting, a more posterior position can be used. Her caregivers have expressed the system is very effective for K. The drawback is the overall length and size of the mobility base, however, it does not impose a problem in her residence or work environment. Continued use of this mobility system has resulted in good alignment and function for K.

CONTACT
Jill may be reached at otspar@aol.com.

TOP LEFT:: K IN HER NEW SYSTEM, HEAD UP AND EYES OPEN. TOP RIGHT: K AND BETH MUCKLER, DPT DURING THE MAT EVALUATION. RIGHT: K IN HER OLD TRADITIONAL POSTERIOR TILT IN SPACE SYSTEM.

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GET OFF *The Bench*

Written by **Allison Fracchia PT, ATP/SMS**

AS SPRING QUICKLY APPROACHES IT SIGNALS the beginning of baseball. I am reminded of a warm May night in Jackson, Miss. in which my then 10 year old son played on the Yankees Little League baseball team. It was the last game of the season. The smell of corndogs and peanuts filled the air. Parents sat huddled together in the stands with anticipation of their child making a big play. Coaches yelled encouragement to the team, and players sat in the dugout cheering on their friends as they stepped up to the plate. The stakes were high. The Yankees had not won a single game. The last inning was in play, and the score was 6 to 7 with the Yankees trailing by one run. The pitch was thrown and the snap of the ball off the bat could be heard throughout the field. The smallest player of the team took off running towards first base barely missing the bag as the first baseman caught the ball. Game over. Defeat. Suddenly, the dugout emptied as the little Yankees ran towards first base to give their teammate a pat on the back, cheering excitedly. It was the first time all season this child had made contact with the ball. Instead of looking at the big picture, these boys viewed the success of one play as a "win."

We all know preparation for a team is imperative for a successful season. Although baseball is a team sport, it is important the skills of each individual player are perfected. Pitching, hitting, catching, grounding and strategizing are critical to the outcome of the game. Being identical in uniform is required. Having the correct equipment is expected. A proper or improper attitude is contagious. Following a step-by-step sequence is necessary.

As the push for a Separate Benefit Category for Complex Rehab Technology (CRT) moves forward, we all must be ready to play hard. Each member of our team must be prepared. Budget cuts and a poor economy could lead some of us to think losing is inevitable and preparation is a waste of time. Yet, if we don't step up to the plate and give it our all, the game as we know it will end. Already, many medical equipment offices are closing their doors. Suppliers who have spent their entire careers with the intent to help patients are seeking employment in other arenas. Rookies in this field are rare. Most rosters have seasoned players. These players have taken many beatings over the past several years, yet for the love of the game and the admiration of the fans, they continue to show up and give it their all.

Other key players include clinicians. Again, the numbers are low. The rosters are filled mainly with veterans. The push for therapists to become interested in the field of seating and mobility is challenging. Budget cuts for therapy reimbursement make staying profitable difficult. The time and paperwork required performing and justifying a complex seating and mobility evaluation is daunting. Many seating clinics have turned their lights off permanently.

Manufacturers of Complex Rehab Technology equipment make up more players of the team. Their rosters are dwindling as well. Many manufacturer representatives have lost their jobs due to consolidation of territories and cut-backs. Gone are the days when representatives had the luxury of providing free educational in-services to therapists and suppliers during a lunch hour. Gone are the days when the representative could be present at the drop of a hat to assist with an appointment.

The end user makes up another teammate. These individuals have slowly seen choices dwindle. Reimbursement for necessary items has declined. Items that were once purchased are now rented. The service/delivery model for mobility products has been grossly affected. Consideration of the primary caregiver's involvement/needs is limited. Decreased choices have led to decreased satisfaction. Quality and reliability of products have in some cases declined.

Many of us have seen this game grow from the little leagues to the big leagues. We were in it when we carved our own foam for cushions, adjusted belt drives on power wheelchairs and when we had limited choices with steel designed E & J manual frames. We witnessed a surge in the development of new and improved products, and the industry began to explode. Research and development of new products to enhance function and limit co-morbidities was exciting. Nevertheless, the paradigm has now shifted. We have learned to adapt, to buckle down and to brush ourselves off. Yet this has not been enough to succeed. Together, we have learned in order to win we must change the strategy. We must support each other in clinical trials to prove what we have all seen and felt with seating, positioning and mobility is well-documented. We must stay in touch with our legislators regarding the issues that surround our industry. We must support them in their campaign efforts and create relationships with them before legislation is introduced so our credibility is enhanced in their viewpoint. We must be united

> We all know preparation for a team is imperative for a successful season.

As the push for a Separate Benefit Category for Complex Rehab Technology moves forward, we all must be ready to play hard.

in our efforts and voice so we will be heard when it comes to development of public policy. Being actively involved in groups such as NRRTS, CTF, RESNA, APTA and AOTA is more critical than ever before. Being identical in uniform (united voice) is required. Having the correct equipment (research/knowledge) is expected. A proper or improper attitude (don't give up) is contagious. Following a step-by-step sequence (know your legislators, get involved) is necessary.

Personally, I have seen how members of our CTF team have successfully worked together to affect change. For example, a multi-year long-term grassroots effort by CTF members has resulted in formalized APTA and AOTA policies defining roles, responsibilities, knowledge and skills related to CRT clinical practice. These policies, used by academic programs, practicing clinicians and policy makers, will guide those clinicians interested in developing their seating and wheeled mobility expertise, inform curriculum to prepare the next generation of clinicians, and influence policies for coverage and payment for clinical services. This will help to ensure there is a broader pool of qualified licensed therapists available to work with the service delivery team. This has been a grassroots campaign by our members, and it has been thrilling to see the results of our long-game efforts. It will take ongoing continued effort to keep the momentum flowing. This is the first time CRT has been viewed as an area of practice in need of focus and attention within our professional organizations.

Looking at the big picture can make someone feel defeated before the games even begin. As rehab suppliers, clinicians, manufacturer reps, patients and caregivers, we have had many losses over the past several "seasons." But let's not forget our wins! The carve-out of CRT power from competitive bidding, recognition of CRT companies and ATPs in supplier standards, elimination of K0005, power assist and complex seating from Round 2 competitive bidding, and cancellation of prepayment review/ delay/modification to prior authorization demonstration program have all been success

(continued on page 37)

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Get Off the Bench

(continued from page 35)

> A team effort and a consistent message from the Complex Rehab Technology (CRT) industry stakeholders together has resulted in influencing significant change during the last year.

stories during the past couple of years for our industry and the people we serve. A strategy of working together has produced results. These results have been due to the effort of several people in various organizations. However, we need more people to engage and become active in the field. As in any game, the more players who join a team results in different talents and leadership on the field. Remember, although the pitcher, catcher or first baseman tend to stand out as the "stars" on the field, the game could not be played without all positions being strong. It is our professional duty to gear up, prepare, and play the game.

When I initially decided to get involved with the CTF, I was very hesitant. I wondered what a person like me could offer to a group of people who held PhDs, presented at conferences such as ISS and RESNA, spoke eloquently, seemed to know each other personally having attended many conferences, served on boards/committees together, performed research projects, and seemed to have more hours in their day to complete all of these things than I did. I was guarded because I wondered if I had enough of "me" to spread around. I already wore many hats: wife, mother, daughter, homeroom mom, community and church volunteer, would-be tennis player, friend, book club member, and physical therapist. I secretly decided if they asked too much of me then I would just quit. What I didn't realize at the time was the personal satisfaction I would gain by becoming involved. Initially, I would dial into conference calls and put my phone on mute. I didn't think I had anything to contribute to the conversation. However, month after month I would call in, and I began to understand I was learning a lot by just listening. I began to contribute to some of the conversations and discovered I felt empowered. I recognized it didn't take much time to write a letter, much effort to update the department on upcoming seating/mobility legislation, or much energy to tell patients and family members how to contact their senators and representatives to express concern or to ask for support for a particular bill. This was a group of people who were muddling through the legislative maze together. And these people were genuinely excited to have a new person wanting to participate. I often wonder what made me decide to pick up the phone and dial in to that first call. Upon reflection, I have concluded I wanted to make a difference. I became a physical therapist to serve others, and I didn't want to sit on the bench and just complain.

The industry is approaching the "playoffs," so to speak, ramping up to introduce legislation. Now is the time to build your relationships BEFORE legislation is introduced. No act is too small. The leaders of organizations can no longer carry the team alone. Write letters, make phone calls, invite the congressmen and senators to our clinics and our offices. Make appointments to visit with them at their offices. Help them out with events. If you can't help actively, then help monetarily. Don't be intimidated by their status. Remember they are simply people. People just like me and you. These people get up every morning, brush their teeth and go to work. They like pizza. They enjoy spending time with their family and friends. They listen to music. They want to be accepted and loved. You can find a common ground if you try. Remember, this work does not happen on its own. The old cliché "it's not what you know it's who you know" still holds to be true in many cases. Most successes are built on relationships. Get to know them so when it is time to ask for their help it is not the first time they have heard your name, heard about CRT, or the possible legislative solutions to address the issues.

Jackie Robinson became famous in the national scene of baseball in 1947 when he joined the Brooklyn Dodgers becoming the first African American major league baseball player since 1889. He was quoted as saying, "Life is not a spectator sport. If you're going to spend your whole life in the grandstand just watching what goes on, in my opinion you're wasting your life." At the end of the day there will be winners and losers. Each player has a role. Each coach has a goal. Each umpire has a set of rules to enforce. Each fan has a favorite. Collectively, all want to win the game. We will prevail if we have a fully functional and engaged team. Don't give up on the game. Get out of the grandstand. Success of this one play will be a tremendous "win" for all.

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Consumer ADVOCATES

Written by **Randy Christian**

The following are four questions that were asked of several NRRTS consumer advocates. Many have attended CELA. Some responded by answering each question specifically. Others choose to answer in a narrative style. Regardless of the style they all gave me even more reasons why they are my heroes. I am continually humbled by their ever-flowing courage and strength.

WHY ARE WHY ARE YOU INTERESTED IN CELA?

WHAT DO YOU HOPE TO ACCOMPLISH?

PLEASE DESCRIBE A LITTLE BIT ABOUT YOURSELF (I.E. WHAT YOU DO FOR A LIVING, YOUR FAMILY, ETC.)

IF YOU HAVE BEEN TO CELA BEFORE, WHAT ACTIONS HAVE YOU TAKEN POST-CELA TO ENSURE ACCESS FOR CONSUMERS?

Jeramy HALE

I have been interested in CELA since we first heard about it several years ago. As caregivers and consumer advocates, my wife, Molly, and I are end users and use Complex Rehab Technology (CRT)every day of our lives. We feel the need to speak out and to support CELA to help educate and inform people. This ensures CRT has its own Separate Benefit Category within Medicare and every user of CRT will get the unique assistance each of us requires to better support both daily living and our potential for continued rehabilitation.

Each year, we strive to push forward our efforts as a group to make CRT a separate category within the Medicare system. Each year there is progress. This progress will eventually reach the point where enough attention, support and education will show the changes being requested are essential and the best path for both the users and the providers of CRT.

My wife I and are the directors of Ability Production, a nonprofit that supports individuals, their families, friends and caregivers who have been impacted by a spinal cord injury, to maximize their potential for rehabilitation and for whatever recovery is possible. We are also Universal Design consultants for new and existing homes, as well as Aging in Place Specialists. Our documentary film, *Moment By Moment*, is used at universities and colleges as well as medical schools to show the potential and various possibilities of rehabilitation, and how people who have suffered a spinal cord injury have the potential to become an "outlier," or someone who goes far beyond their medical prognosis.

Molly and I both continue to inform and educate people every opportunity we have, as to the work CELA does and the importance of getting CRT its own bucket within the Medicare system.

Morgan HEINO

I know firsthand the struggle to obtain and the importance for funding of proper medical equipment. My forays from private medical coverage to state funding has caused me to open my eyes and take note of understanding my needs and rights and the red tape that causes hiccups in my care and basic living. It's an awesome opportunity to not only meet with congressional members and give them a flesh-example of why a CRT bill is crucial, but also to be brought together with other consumers and vendors to have a better understanding and awareness.

I hope to impress upon congressional folks as to why this bill and action is crucial. This group of people isn't just unhappy with what they were given based on wanting shiny and new equipment, but are a population who is better served and deserving of proper equipment to ensure their quality of life is as attainable as those who don't need equipment.

I am currently unemployed but am using my downtime to fight for my next wheelchair. The fight alone is a full-time job, all the while searching for new employment and volunteering at various nonprofits.

I have been to CELA previously. Unfortunately, soon after returning from CELA, my medical situation got crazy out of hand and unmanageable and a lot of things fell by the wayside, including CELA. However, this year my health has stabilized, and I am much more aware of what has to be done and am committed to keeping in touch with congress members and CELA folks.

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Jill WIELE

Forty-three years ago my parents welcomed me, their second baby girl, into the world. Having a 2 year old already, they thought this pregnancy would be no different ... but it was. Rather than erring on the side of caution like before, the doctor said a C-section wouldn't be needed since I was so small. It turned out the umbilical cord was too much for me at 3 pounds 2 ounces to avoid getting tangled around my neck. Christmas came early that year when I was born two and a half months earlier than expected. I was born October 17, 1968.

Say the words 'cerebral palsy' and no picture; no description will be the same. It's like spinning a roulette wheel, and according to me, I got lucky. I proved everyone wrong. Doctors told my parents to put me in an institution because I'd never be able to sit up, talk, walk, or live a normal life. It hasn't been as easy road. As a child, I struggled to reach developmental milestones, attended special education, and dreaded being in mainstream education classes from fourth through 12th grade.

Looking back, it's impossible for me to name all the people and experiences that helped shape the person I am today. Besides my family support, I am working at a junior college while still in high school through Job Training Partnership Act (JTPA), and the counselors at camp set my future in motion. "Staff at both places mistook me for being much older because I always had an opinion, some advice, and another way of looking at things. Camp counselors called me 'Dear Jill,' always asking advice about their love life. They are the reason I decided in ninth grade to get a degree in social work."

I continue to advocate for myself and others with disabilities on federal, state and local levels. As an adult, I have navigated through the social service systems of Iowa, Maine, and now Arizona. In 2008, I met via video teleconference with a judge from the 9th U.S. Circuit Court of Appeals and successfully proved a tilt system in my new power wheelchair was "medically necessary" and not a "luxury." The amount of red tape and the hoops gone through were ridiculous and demeaning. If Medicare people had actually bothered to meet and/or talk to me or my physician, then maybe I wouldn't have had to show pictures of irritated private areas to a judge. I hope the knowledge gained by attending the CELA conference makes obtaining equipment an easier, more pleasant experience.

Ana CLAVO

I became interested in CELA because, for many years, I have fought to get the equipment I need to maintain independency. I also want legislators to understand that just because we have a disability, we shouldn't have to choose from maintaining a quality of life or quantity of life. We are professionals with careers, but somehow the government punishes us for getting an education and a job by taking away the resources that aid us in maintaining that lifestyle.

I thought the government wanted everyone to be taxpaying citizens, but it shows the opposite when it comes to people with disabilities by forcing us to stay on government assistance even though we have the ability to get out of bed in the morning. I hope legislators understand the majority of individuals living with disabilities want to pay taxes, but need the equipment and assistive resources to do so, but income alone doesn't suffice. Incentive programs more than "ticket to work" need to be created to reverse the disparity between the employed and unemployed with disabilities.

I was born without arms and legs and require a power wheelchair to get around. I am fortunate my parents instilled in me a "can do attitude" and showed me how to advocate and what is needed.

I have a masters degree in social work, am currently the director of transition services for Houston Community College: VAST Academy, a program for students with intellectual disabilities. I am the current chair for the City of Houston Commission on People with Disabilities and serve on several boards in the community. During my down time, I enjoy scuba diving, playing wheelchair soccer and traveling. In 2009, I was crowed Ms. Wheelchair Texas and traveled the state with the platform of becoming the leaders of tomorrow. I am a strong believer that we must lead by example and hope by the way I carry myself in life I do so. "You must be the change you want to see in the world." Mahatma Gandhi

Fin BULLERS

Today, working through a network of advocates for people with disabilities, our coalition is planning a trek to the nation's capital for the CELA 2012 conference.

The goal? Lobby on behalf of consumers without access to Complex Rehab Technology, known in the alphabet-soup parlance of government as CRT.

The mission? Certainly not impossible: To improve and protect access to Complex Rehab Technology products and services for people like me, those with complicated disabilities and medical conditions.

Here's my story.

My name is Finn Michel Bullers, a 48-year-old, stay-at-home father of two and freelance writer. We live in a ranch house on a cul de sac in the Kansas City, Mo., suburb of Prairie Village. My son, Christian, 11, is a sixth-grader at Corinth Elementary and managing editor of his school newspaper. Along with my registered nurse, John Moyer of BrightStar Healthcare, Christian can distinguish the subtle differences in ventilator beeps and diagnose any air obstruction. My daughter Alora, 7, a second-grader, gives me insulin shots and tests my blood sugar. My wife, Anne Christiansen-Bullers, a working mother and dear wife, holds it all together. I have lived with chronic disease for decades. I am an insulin-dependent diabetic for more than 35 years. I require three shots a day, a handful of pills, balanced meals and up to four blood sugar tests a day.

Since birth, I've also managed a slow-moving, muscle-wasting disease known as Charcot-Marie-Tooth, a Lou Gehrig-type muscular dystrophy. It can attack all major muscles in the body. Those living with CMT never know how aggressive the disease can be or when it will mount another offensive strike against the body's remaining healthy muscle tissue. That's the cruel guessing game. It's not a matter of if the disease strikes, it's a matter of when. Doctors say my disease is following a "typical" trajectory, manifesting itself in an awkward gait through high school; to heavy leaning, to cane, to tripod cane in my early work years; to manual wheelchair, to scooter in the later work years to now – graduation to a complex rehab power chair, the Permobil C300, funded partially through the MDA.

I have spent a quarter of a century as a career journalist from Miami to Bismarck, N.D., to Dubuque, Iowa, to Davenport in the Quad-Cities of Iowa and Illinois. The longest stint has been the last: 15 years as a reporter with The Kansas City Star. Now, I freelance and have helped start a real-deal student newspaper at my children's school. For as long as I can remember, I have been chasing the Oatmeal Man. Always in black and white, the vivid dream invariably concludes in the hot pursuit of an evildoer.

When I was a child, my dream centered on a bully who had stolen candy from a neighbor girl. Years later, as the dream matured, the target fights became larger than life – poverty, racism and in the early 1970s, uncovering Deep Throat, the secret source of the Watergate fiasco. Always, the dream is cut short. The flesh on my legs has turned to oatmeal, unable to propel me forward, unable to right a wrong. The metaphor is hard to shake. So I turn it upside down and take it as a sign I must make the most of each day – each moment I still am outrunning the inevitable muscle wastage I know will come, but I just don't know when. I want to change the world before muscular dystrophy and juvenile-onset diabetes change me. That's why I'm headed to the CELA 2012 conference, making a preemptive strike against the Oatmeal Man. Doctors tell me for the shape I'm in, I'm in pretty good shape – a tassel-tossing graduate of hospice. But the big problem is access to Complex Rehabilitation Technology.

With home medical equipment stipends cut by MDA and no Separate Benefit Category through Medicare, I am unable to independently and expeditiously follow my doctor's orders – feet elevated above heart for extended periods of time. Elevating the feet reduces edema, or swelling and pooling of blood in the lower extremities. Blood pooling inhibits healthy wound healing. You see, my nifty Permobil C300 power chair,

serviced by United Seating and Mobility, is capable of elevating my feet at the push of a joystick. No nurse intervention needed, no major downtime and the great wound-healing ability to elevate the feet, allowing the blood to more easily flow to the wound.

When my original wound began more than 15 months ago on my right calf, it was a slight abrasion. Within three days, the wound was three inches wide and seven inches long. At its zenith, the flesh died, the wound deepened and the deterioration exposed a large swath of tendon that threatened to expose bone and make amputation a very real possibility. The greatest tool in my fight-back arsenal is elevation of the feet, an adaptation to my power chair not currently accessible to me because of a lack of a SBC.

Congress must pass legislation establishing a new and separate benefit category for Complex Rehab Technology within Medicare. It needs to recognize the customized nature of the technology and the broad range of services necessary to meet the unique needs of people like me with complex medical needs. In my story line, an SBC is critical for another reason. It's the same premise, but a different chapter.

My Permobil power chair has the adaptability to raise and lower as seating, toilet and bed heights vary widely. The promise: Great functionality. The Reality: No access to the technology. And with no access, for example, the power chair user is cut off from the deal, making high bar tables where – in Washington, D.C, for example – power is wielded and sausage is made into legislation.

Another problem: Medicare will only pay for medical equipment medically necessary for use "in the home." Medicare does not cover technology required to engage in the outside world – work, school, doctor appointments, grocery shopping or other activities. Dependence: 1; Independence: 0.

We can do better in the fight for personal freedom, empowerment, employment and productivity.

Jody HUNT

I'm guessing a college education might have helped me answer a few simple questions with correct punctuation. I fell into attending CELA after receiving an e-mail for an opportunity to attend CELA via scholarship. I've always misunderstood the entire process of trying to obtain a wheelchair which would fit my needs and, as it turns out, this is an ever-changing and evolving endeavor. Many times the bureaucratic bull was, let's say, OVERWHELMING! It took years of stumbling to get my current chair, and I'm still trying to tweak it to better accommodate my transportation needs. Remember, I'm only one person who can attest to the obstacles I faced in mobility freedom. I find it difficult to imagine how the others have coped with finding the correct equipment. Let's face it, we are all different, and our needs have to be addressed as such. Legislation seems to me to be the best way to address the needs of my fellow mobility aid users, and if I can contribute in any way, I'd be happy to help.

I'm a 40 year-old man with two sons who I love dearly, and I think if anyone has seen me dealing with CMT (Charcot Marie Tooth) it's them. I like to say I've been a shining example of how to approach a disability, but at times I haven't. I'm currently separated from my wife and living with my parents. My mother and father have supported and allowed me to renew my body and soul via diet and exercise. This renewal has allowed me to establish an interest in advocacy I'm hoping to continue for many years. I hope my little bit of input will influence a positive role in changing legislation.

Dan JOHNSON

In 1963, I was a sophomore in high school trying out for the varsity wrestling team. During a morning practice the day after President Kennedy was shot, I sustained a C 4-5 spinal cord injury while practicing standing takedowns during the last practice session of the day. From that day on, I have been dependent on Complex Rehabilitation Technology.

For the last 47 years, I have been active at both the local, state and national levels in helping provide access to programs, services and technologies that can help individuals with physical disabilities remain in their own homes and become actively participating members of their communities. I believe the opportunity to participate in CELA 2012 will provide an excellent opportunity to work at the national level with national advocates to get federal legislation to help people with disabilities secure the CRT they may require.

I believe my participation will allow me to return home and work with other advocates in my state to propose similar legislation that could be used to ensure our state Medicaid program and private insurance companies offer CRT. In addition, I believe I can work with advocates to develop language the Department of Health Services could use to offer CRT as a service provided by the federal home and community-based waiver our state receives.

My goal is to convey to my representatives, senators and the rest of the congressional delegation a very simple 22-word message. "We need Congress to introduce and pass legislation to create a Separate Benefit Category for Complex Rehab Technology within the Medicare program."

As an individual with a physical disability who depends on private health insurance coverage, I know this is the only way people with disabilities will continue to receive the Complex

(continued on page 48)

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(continued from page 46)

Rehab Technology products and services they need to continue their work, function as part of their families and communities, and maintain their health and well-being.

It will be my responsibility to bring what I learned back to my state to help other consumers, clinicians, suppliers and manufacturers understand the importance of these 22 words. All must know there is a problem, it will get worse each day, and it must be fixed by getting Congress to authorize CRT as a Medicare covered service. I must help people understand what happened in Washington, D.C., can happen here in our state. I need to help educate and work with advocates to assure consumers with significant disabilities and health issues receive the CRT they need to help ensure their health, function and quality of life. I have learned over the years it is not somebody else's responsibility. Making a call and bringing people together doesn't take a lot of time, but the time put into making that call and making people aware of the issues is necessary to creating change. That will be my job when I get back to my state, create a Separate Benefit Category for CRT within the Medicare program, our state's Medicaid program, and private health insurance.

My state's department of health services has employed me for the last 30 years. My responsibilities included the development and coordination of programs throughout the state for persons with physical disabilities. I have been conducting, planning and participating in development of program policy, helping to set goals and objectives to assure the delivery and coordination of services essential to foster independent living and self-sufficiency for people with physical disabilities.

Prior to my position with the state, I helped create one of our state's first four independent living centers and served as its first executive director for five years, from 1976 to 1981. In 1983, Kathy and I were married and in 1986 we became foster parents. Throughout the following 10 years, we were given 20 foster children and were able to adopt six daughters. We have one grandchild, a girl, who will be 3 in October.

Kathy and I have always enjoyed camping and were recently able to secure a wheelchair accessible recreational vehicle. This vehicle contains CRT and has allowed me to regain the independence necessary to travel again. It's hard to believe Kathy and I started out doing our camping using a tent. The past 47 years have contained some very hard lessons. I can no longer do many of the things I took for granted in the first years following my accident. I am a cancer survivor and have had a number of surgeries. My body is aging and my ability to maintain my independence has been greatly enhanced by the availability of CRT. With the support of family and friends I not only survived cancer, I am reinvigorated and ready to continue the work I started in the early 1970s. Access to CRT is necessary for all individuals with disabilities to ensure their full participation in society.

Robert MELIA

I am attending CELA because on almost a daily basis I see individuals with disabilities get denied or have to fight for wheelchairs and "add-ons" that will allow them to be more independent, functional and have a better quality of life.

I want to meet with designated legislators or their aides and educate them on the points we are trying to make so when these bills come up for a vote they fully understand what is in front of them.

I am a happily married father of two. I'm also a Cub Scout den leader, assistant football coach and leader for the local quad rugby team. My professional title is spinal cord coordinator with responsibilities throughout the continuum of care from the trauma center through rehab and community reintegration.

I continually encourage patients and their families to contact, approach and engage their legislators at both the state and national level to understand the situation they are living and the problems and obstacles that need to be fixed. Frequently, these individuals have never been advocates or politically active so educating them is very important.

Andrew DAVIS

I am interested in CELA to ensure disabled people have continued access to Complex Rehab Technology, so we can continue to have independent lives (live on my own, go to work, socialize with friends, go to the grocery store, do the same things able-bodied people are able to do). Because of the Quickie wheelchair, I was able to obtain a college degree. Without it, I would lose my independence, as I would not be able to get a hospital type wheelchair into my car. Therefore, I would be stuck at home! I want to be able to work. I want to be a tax payer/ NOT a tax user! I can only have employment by Congress voting for the Separate Benefit Category. By going to Capitol Hill, I am able to educate Congress on the importance of continued access to CRT. Without their help of voting for the Separate Benefit Category, people using CRT cannot continue to lead active and independent lives. I am interested in CELA because people on Capitol Hill are not aware of the concern of disabled people losing access to CRT. I want to educate them on the importance of having continued access as I live this everyday and can best explain my concerns if I were to lose access to such equipment. Even with the Americans with Disabilities Act, what good is it to lose CRT – the very thing helping us be independent?

I hope to educate Congress that voting for the Separate Benefit Category for CRT, it will, accomplish three goals: 1) It will guarantee suppliers will stay in business; 2) It will mean people who use CRT will have continued access to CRT, therefore, we can continue to contribute to society by being active members of the societies in which we live; 3) It will save Medicare money in the long run! What I mean by this is, if I were to lose access to CRT, I could end up with equipment I don't necessarily need, but simply helps me get by! For example, I use a tri-level ROHO cushion to no skin break down as I have a dislocated right hip. Because of this, I use the tri-level ROHO. If I were to get skin break down, it could eventually get to a point of needing a skin graft (i.e. surgery). This would mean time off from work as I am laid up in the hospital. Long story short, the ROHO cushion, because it is custom made, is $600. This sounds like a lot of money, but compared to what Medicare would pay to have a skin graft (thousands of dollars), having access to the ROHO, would mean Medicare would save money in the long run. Another point regarding the ROHO is because my right hip is dislocated, I have the risk of my spine curving, therefore, I could have breathing problems, which means MORE health issues costing Medicare money.

If I lose access to the Quickie Wheelchair, I will be stuck at home because I can't get another type of wheelchair in my car. I can't go to work or go to the doctor. I would lose my social life. Heck, because of the Quickie wheelchair I am able to go to Capitol Hill and meet with Congress and legislative aides.

I currently work with NRRTS in consumer relations/advocacy. I contact organizations around the country to educate them on the importance of having their members contact Congress to ask for their vote for the Separate Benefit Category for CRT. I have a brother who is retired Navy and currently works at the Naval Academy as a civilian. Both of my parents are retired. I like to keep active by doing outdoor things such as white water rafting, horseback riding (currently taking lessons), also running and attending Braves games with friends. I am interested in becoming a lobbyist and feel this experience with NRRTS is a good education.

This will be my fourth time attending CELA. Last year, I was at the Abilities Expo in Atlanta, Ga., as an exhibitor, educating the public on the Separate Benefit Category for CRT. I did a radio interview in Atlanta to get the message out regarding the Separate Benefit Category for CRT. In August, I drove throughout a Congressman's district to get people to sign a petition in favor of this important legislation. I received more than 450 signatures and am taking the petition with me to Capitol Hill when we attend CELA. Also, I have met face-to-face with Congressmen and their health legislative aides in their home districts to better educate them on the Separate Benefit Category. Who better to educate Congress than someone who lives it every day?

Ashley SPEICHER

I am interested in CELA because I am a Medicare/ Medicaid recipient and just recently went through the process of obtaining a new wheelchair. Needless to say, there left a lot to be desired. The paperwork is so tedious and confusing for doctors, never mind patients, that it often delays much-needed equipment being provided to patients. I have heard great things about the work CELA does in educating our elected officials about how to better serve their Medicare and complex rehab equipment using constituents.

I hope to explain to my elected official about my experience in getting complex rehab equipment and how I had to use a rental wheelchair for well over four months. This was due to my former wheelchair requiring major repairs and my current wheelchair not being approved. It is inexplicable that Medicare creates such a hardship for patients to access much-needed equipment.

I am 26 years old and live with my dog, Jackson. I work at Action Inc., which is a Community Action Program. I work with low-income and/or homeless families to help them access community supports.

This is my first time to attend CELA!

Jenny SIEGLE

This will be my third trip to Capitol Hill, but to be honest, I can't imagine what my life would be like if I hadn't been introduced to CELA. Joining forces with the people of NRRTS and NCART has opened my eyes even more to the importance of advocacy.

I have been a quadriplegic since 9 months of age due to transverse myelitis. I had the flu and my antibodies mistook my spinal cord for the illness attacking it at the C4/C5 level. I was originally paralyzed from my neck down, but after many years of therapy, I have been able to regain partial use of my upper body.

Currently, I work as an associate producer for Altitude Sports and a video production specialist for the Colorado Rockies. I am a homeowner and until July 10, 2011, I was driving. I was in a severe car accident, and my van was totaled. I broke my back in the accident and felt like I had to start over. Due to the results of my injuries, I had to get refitted for some of my medical equipment and also had to get a new power wheelchair. For these reasons, I believe in CELA more than I ever did. Complex Rehab Technology was an essential part of getting my life back on track. Without being able to have follow-up appointments with my medical providers, a seating system that fit my specific body shape, and a new wheelchair to replace the one that was damaged in the accident, I would not have been able to return to work as quickly as I did.

When I return to Washington, D.C., in April, I have a different story to share during our congressional appointments. I want to help them understand my needs, along with many others, are ever changing. I want them to see we are determined individuals who can bounce back from life's challenges. I want them to accept the bill we are presenting to them because it will allow all of us to continue to be contributors to society.

Throughout my time working with CELA, I have developed relationships with the legislative aides I have met. We have kept an open line of communication, and I truly believe the members of CELA are making progress. With each meeting, their knowledge of what we are trying to accomplish grows. They are taking us seriously because we are approaching them in a serious manner.

Last year, we were able to take legislative language with us to our congressional appointments and that made a huge difference. This year, I know we will make other strides, and I'm excited to see what those strides will be.

CELEBRATING NRRTS'

20 YEARS OF SERVICE

TO THE REHABILITATION TECHNOLOGY SUPPLIER

We've come a long way, but there's still a lot of pavement ahead.

Written By **Danette Baker**

Andrea Madsen, ATP, CRTS®, always thought she wanted to be a physician. However, the more she learned, the more she became disenchanted with her dream career. Frustrated by the lack of patient contact and patient involvement it seemed physicians would have with their patients, but still very interested in a professional career in medicine, the college pre-med major switched her focus to business. She later took a job with Med City Mobility, located in Rochester, Minn., an area best known as home to the world-renowned Mayo Clinic.

For the last eight years, Madsen has cut her teeth in the rehab technology industry on policies and pursuing advanced levels of technology for the patient. This eventually led to the creation of the rehab technology department at Med City Mobility, which she now manages.

"Assistive technology is really a marriage of business and medicine," she said. "It's knowing how to be the most effective with the resources you have and understanding the ramifications of the technology you apply to someone."

Ultimately, Madsen knows her role on the rehab team is important, but even in midst of Rochester's medical mecca, she has felt isolated. There is virtually every type of medical professional you can think of caring for a diverse international population, yet Madsen had really never found an ally in rehab technology until she joined NRRTS this past December.

"Ever since I began studying for my ATP four years ago, I have been well-aware of NRRTS. I've been tracking and following all of their efforts, reading about their activities and education and legislation, but really didn't take the opportunity to join until Simon Margolis participated in our MAMES (Midwest Association for Medical Equipment Services) convention in October. He was very humble, yet direct, in his approach and presented a very compelling presentation of what NRRTS stands for.

"That sealed the deal."

For the last 20 years, NRRTS has worked to ensure rehabilitation technology suppliers are considered professionals on the clinical health care team. More recently, the organization has turned its attention to legislative initiatives to assure suppliers can fulfill their goals of helping clients gain and maintain independence.

The road to establishing NRRTS was not an easy one, as early adopters can attest, but one necessary to ensure the industry's future.

"The whole idea behind starting NRRTS was to gain support for those in the industry so they would have the respect of the professional positions they held," said David Miller, former president and CEO of The MED Group. "There were too many people just hanging out a shingle trying to imply they were experts. We wanted to be thought of as more than equipment jockeys."

In 1991, a group of individuals – Miller and Executive Director of NRRTS, Simon Margolis among them – began to work on establishing a nonprofit organization that would hold credentials for individuals working as rehab technology suppliers. At the time, companies who sold and serviced rehab equipment could distinguish themselves with credentials from the National Association for Medical Equipment Services, now the American Homecare Association. However, for the individuals working among other credentialed professionals, such as occupational, physical and speech therapists, there was nothing.

The initial draft to establish NRRTS states: "The committed rehab practitioners in our industry need a more immediate, albeit interim, method of distinguishing themselves from the 'me too's' getting into rehab to escape the Medicare and Medicaid crunch in home medical equipment. These 'escapees' are already causing potential irreparable damage to the credibility of rehab in the eyes of both Medicaid and Medicare officials. Rehab is beginning to be viewed as the lift chairs, scooters and TENS units of the 90s."

This push to have individuals certified was met with some opposition, said Miller, one of NRRTS early board members.

"Understandably, the companies stood to lose employee time for testing as well as continuing education, but there was also an issue of having individuals seen as experts in their field."

In September 1991, through the work of several committed individuals, the Rehab Section and RESNA Industrial Relations Committee endorsed the term "rehabilitation technology supplier" as the preferred title for individuals providing rehab equipment. In 1992, NRRTS was officially formed and incorporated as the National Registry for Rehabilitation Technology Suppliers. The organization opened its first office in borrowed space at The MED Group headquarters, which had recently relocated to Lubbock, Texas.

There was much speculation as to whether the organization would survive and how its credentials would compare to the current company standard,

which was RESNA's ATP, or assistive technology professional, the one eventually approved by the government as the credential necessary to bid for Medicare or Medicaid contracts.

Despite initial opposition from companies, NRRTS finally came through only because of the "determination of a fairly small group of diplomatic, yet vocal people and financial backing from supporting organizations," Miller said.

Margolis, who served as chair of NAMES Rehab Section Quality Assurance Committee, in early correspondence wrote one of NRRTS' first jobs would be to "establish credibility for its programs and valuable meaning to the title of Registered Rehabilitation Technology Supplier (RRTS).

"... When completed, RRTS will have a positive and professional connotation, helping to integrate the rehab technology supplier into the mainstream of the clinical team."

Alan Channin, ATP, CRTS® , was among the first NRRTS Registrants, joining the registry in October 1993. He had been working in the industry for almost 10 years and had fought many of the 'us versus them' battles regarding professional expertise. Channin had made a career change in the late '80s from pharmaceutical sales to durable medical equipment after a downturn in the economy. He then worked for a few years at MedCo Surgical Supply, providing durable medical equipment for patients to use after being discharged from the hospital. Channin said a few of them in the company began to explore what would now be considered complex rehab.

In 1985, he and Adrienne Bergen, PT, ATP, (NRRTS' first president), Lenny Friedman, Steve Friedman and Jeff Josefson co-founded Dynamic Medical and began an aggressive campaign toward technological advancements in positioning and equipment.

"We tried to show our expertise through providing educational outreach, and pretty quickly the clinical community acknowledged that we did have something to bring to the table," Channin said.

"The industry, however, was becoming more and more controlled by insurance and all that became important was if you had a contract or not," he added. "It really came down to a bidding war between those who were just providing equipment versus those of us who had the knowledge to not only provide the equipment but to ensure it was the correct equipment. But there was nothing other than word of mouth to differentiate between the two."

Margolis related the rehab technology supplier situation to one faced by the orthotics and prosthetics industry 20 years prior in which professional credibility was questioned along with reimbursement for new technologies.

"The industry was one based solely on the business person's ability to convince the local physician and third party payers that their service was medically necessary," he wrote in a letter to Tim Waits with NAMES Rehab Section Quality Assurance Committee.

After the orthotics and prosthetics industry implemented a unifying organization and certification program, Margolis reported, "now reimbursement is almost universal with third party payers and in many states Medicaid does not require prior authorizations for devices and most devices are covered under Medicare guidelines.

"O&P are recognized, along with physicians and occupational therapists as equal members of the rehab clinic team."

To truly accomplish the original goal of establishing a professional credential, NRRTS had to be more than just an organization that collected membership dues, said Margolis, who has been executive director since 2007. He also has served the organization as president-elect, president, past president and has worked as a consultant and in marketing.

"There needed to be qualifications, which exceeded minimal standards, and I'm happy to say we have continually raised the bar to keep true to that mission," Margolis said.

David Kruse, ATP, served a term as president during NRRTS' first decade. He credits the organization's initial success to the "work of very strong leaders in the industry. Simon, Adrienne, David Miller – there also was strong support and a strong core of people who had the same vision.

"Their idea of certification was something that would bind us all together."

The industry, at the time, Kruse said, didn't have funding issues like today, although things seemed much more fragmented all around. "The playing field for reimbursement was so uneven, and we had so many new people coming to the profession, most by accident or through a family business that we were all trying to find that identity that we could relate to."

Kruse, himself, was one of those new to the field. He had a degree in criminal justice, but was having

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a difficult time finding a job after of college. Kruse moved from Oregon to Chicago to work in his uncle's medical business. "I found my niche working in rehab."

After owning two different companies, Kruse sold out to ATG Rehab in 2000. As with his own companies, Kruse said the initial years of NRRTS proved challenging just keeping the doors open, and the organization relied mostly on Registrant dues for revenue. At the same time, the advent of Internet marketing caused somewhat of a black eye to the industry as telemarketers solicited products to the end user with little or no evaluation.

"Complaints flooded chat rooms and e-mails about these practices, and we were the ones getting the calls to take care of their mess," he said.

There were also disagreements surrounding industry credentials. Testing for the ATP certification came as Kruse was set to take office.

"That was a real hot button for those who had been in the industry for several years," he said. "Now you had to pass this exam in order for Medicare to recognize you as someone who could sell complex rehab technology."

Kruse was president of NRRTS when he took the ATP credential test.

"I just remember thinking I would have egg on my face if I didn't pass it," he said.

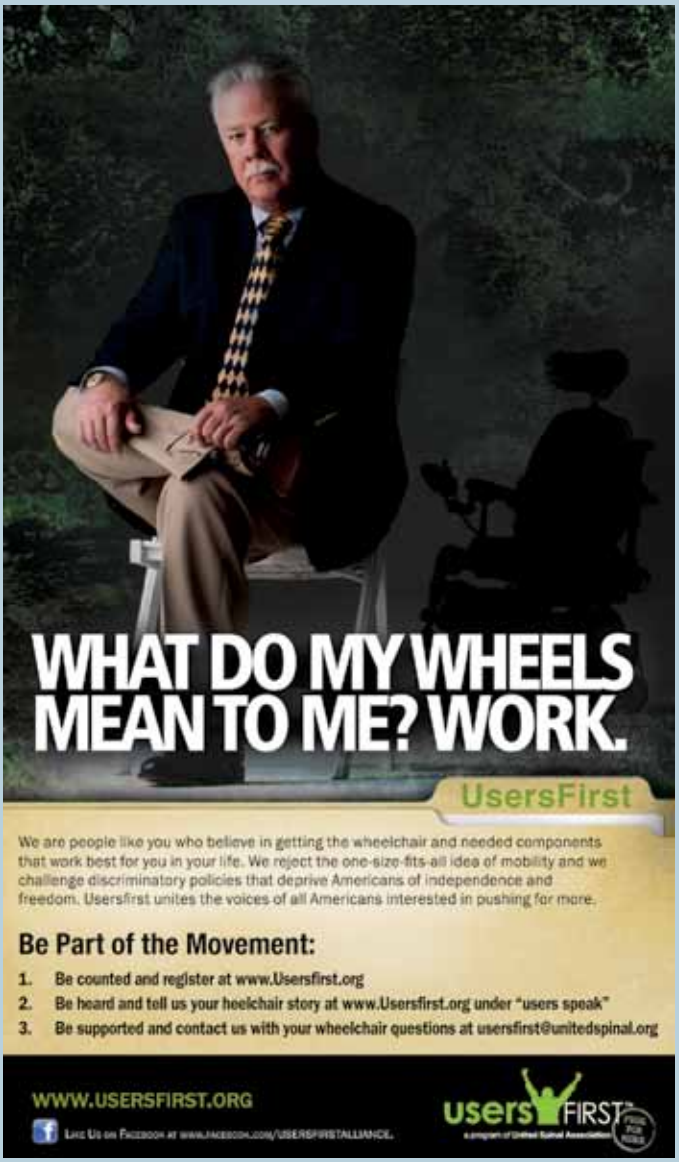
Now, he says, it's hard to differentiate between the ATP and CRTS® and wonders if there is enough room in the industry for both organizations to survive. He does, however, still recognize NRRTS as the grassroots of complex rehab technology, but he no longer maintains membership. Kruse says he struggled in the years following his term in office to see the value of so many different certifications, but remains steadfast about the industry's relevance.

"After 36 years in the business, I just long for the days of when things were much simpler. We were a band of brothers and sisters that were all there for the same goals and principles. We had disagreements, but at the end of the day we all had the same vision."

There was a time when Margolis would have agreed. "We did go through a time of organizational paralysis," he said.

Margolis had moved in and out of the organization through his 20 years in the industry. He had a successful career in orthotics and prosthetics, and later in fabrications and wanted to see changes in the industry, to move it forward. Throughout this career, Margolis was involved in various organizations including RESNA and NCART, but eventually gravitated to NRRTS.

About five years ago, the board had accepted the challenge of bringing the organization to a point in which it could play on the national stage, and asked Margolis to serve as executive director. Since that time, NRRTS has made several changes,



he said. It moved from an office-based organization to one that operates in various parts of the country – providing an opportunity for geographic diversity to match those it serves.

"We also began to manage NRRTS like a business and really took a look at our ROI. We have used reserves to sit on committees with big players like NCART, RESNA, and the American Homecare Association – by playing big you become big, which has positioned us to lobby for legislation such as that on separate category benefit for complex rehab technology."

The organization also made a transition with its publication, expanding the NRRTS Newsletter into DIRECTIONS magazine, a trade journal that not only provides critical information for Registrants, but also helps support the organization financially through paid advertising.

In two decades, NRRTS has brought many changes to the Complex Rehab Technology industry, Margolis said, but there is much work ahead. One of the most pressing issues is establishing evidence-based industry practices. The work NRRTS is doing with the University of Pittsburgh to collect patient outcomes data motivated Michele Gunn, ATP, CRTS®, to take the helm in 2011 after serving for several years on the board. The results, she wrote in her first presidential message for DIRECTIONS, will help make changes in funding of products and services.

Additionally, NRRTS has partnered with NCART for the last three years to take an advocacy role in securing legislation that will make CRT a separate benefit category for third-party payers.

"These are just a few examples of the way we have begun to embrace the concept of return on investment," said Margolis. "We are looking for ways to utilize the financial support from the Registrants in a way that serves their needs."

In just three short months, Andrea Madsen has gotten that and more. Through the NRRTS discussion boards, she has discovered an "incredibly supportive community" of like-minded professionals who openly share with one another in an effort to reach an ultimate goal of providing the right technology and information to the patient.

"It's been exciting to have that professional support," she said. "I truly feel I'm on the cusp of information as it becomes available."

Madsen often turns to NRRTS for information regarding legislation and education she in turn shares with members of the MAMES Rehab Committee, which she chairs.

"Advocacy is very important for our industry, and I believe that it is important to have a broad-based set of standards; but it is also vital to have a professional organization through which we hold one another accountable and raise the bar to see this whole industry move forward."

For more information, please contact NRRTS at info@nrrts.org.

Central American THANKSGIVING

Written By **Michael Banks, CRTS®**

It was nine years ago I responded to a post on the NRRTS listserv placed by David Richard, founder of Wheels For Humanity, and current president of UCP/Wheels For Humanity. By March of 2003, I found myself absorbed in fitting wheelchairs for two weeks in Hanoi and Thanh Hoa, Vietnam. That experience was enough to hook me for life, and although regular trips have not been possible, I have managed to collect hundreds of chairs for donations abroad over the years. My wife, Marianne Alderson, and I were lucky enough to be invited on the distribution in Alejuela, Costa Rica, during the week of Thanksgiving in 2011. I kind of felt like we were part of the chosen few for this trip. Our friends and WFH veterans Greg Skolaski, OT, and Eva Ma, OT, were going. Skolaski and Ma have been on more than 50 wheelchair distributions between them! Skolaski and Ma met on a WFH trip to Mexico City in 2004 and are now "an item," even in the legal sense of the phrase.

Skolaski was gracious enough to arrive ahead of us by a couple days to help ready the chairs. Also along on the trip were volunteers Jim and Joan Swinehart of Metalcraft Industries, and we learned not long before departing Richard was able to join us, too. It was indeed going to be a very fun trip. One of the things making this destination so special is that UCP/Wheels For Humanity has a long history in Costa Rica. Richard's first trip there was in 1997. The Lion's Club (Club de Leones Aeropuerto) and Margarita's B&B make it feel more like a vacation than work. I almost feel guilty calling it a humanitarian trip because of the festive feel of the whole experience. My hat is off to those volunteers who have done this kind of thing under much more trying circumstances. Still, after getting things ready and families began showing up, everyone was focused on fitting as many chairs as we could. I felt like we hardly picked up our heads from the work, and the day was over. We were tired, but felt we had done well.

Costa Rica has nationalized medical care, but no equipment benefits. People arrived by car, taxi, motor bike and bus. Some had travelled all day to get to the clinic at The Lion's Club. Clearly, they took this opportunity very seriously.

The equipment we had to work with was a combination of donated chairs, and UCP/Wheels For Humanity chairs. Most of the chairs were tilt-in-space. We had boxes of spare parts, a luxury we did not have in Vietnam. With fasteners, clamps, laterals, brackets, and headrests, I felt excited and enabled to do a decent job fitting chairs. Overall, the chairs were excellent. Many of these children have a diagnosis of cerebral palsy, but we saw a broad range of conditions including Guillain-Barre, TBI, muscular dystrophy and spina bifida. We had a lot of combined experience and maybe some luck with this team and managed to match client needs to available equipment in a manner beyond my expectations. No one was turned away without a functional chair.

It helped a lot to be surrounded by the Lions who are all about good will, but it seemed the people who came with their family members were so happy. It made for an all around good feeling for us.

We are looking forward to another UCP/Wheels For Humanity trip. In the meantime, we will find means of getting donations from eastern Washington to Portland where FedEx has provided a trailer on numerous occasions, destined for UCP/Wheels For Humanity in North Hollywood. There is an ongoing need for chairs. Consider contacting Hope Haven, or UCP/Wheels For Humanity to see if there is a distribution point in your area.

CONTACT THE AUTHOR:
Michael may be reached at mbanks@unitedseating.com.

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1. ADJUSTING THE POSITIONING STRAPS, A FINAL STEP.

2 MOTHER AND DAUGHTER SHARING A HAPPY MOMENT.

3. IN SOME CASES ENTIRE FAMILIES TRAVELED OVER A DAY TO ATTEND THE DISTRIBUTION.

4. MARIANNE AND EVA ON THE COFFEE TRAIL, OUR FAVORITE SHORTCUT BETWEEN MARGARITA'S AND THE LION'S CLUB. WE MANAGED ABOUT 6 KILOS THROUGH CUSTOMS ON THE WAY HOME. COFFEE, THAT IS.

5. GREG SIZING UP THE INITIAL FIT.

6. YOUNG LIONS WITH THEIR MENTORS LEARNING ABOUT COMMUNITY INVOLVEMENT AND "GIVING BACK".

7. MICHAEL WORKING WITH A YOUNG BOY FROM SAN JOSE. THANKFULLY, WE WERE ABLE TO PLACE SOME PRETTY GOOD "SELF-PROPEL" CHAIRS.

8. GREG ASSESSING OUR READINESS.

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1. AMONG ALL THE WHEELCHAIRS, A FEW GAIT TRAINERS EMERGED WHICH EVA SKILLFULLY AND EFFICIENTLY ADJUSTED.

2. MICHAEL AND MARIANNE GET ANOTHER READY TO ROLL.

3. EVA AND GREG TAKING SOME QUICK REFRESHMENT BEFORE THE NEXT WAVE.

4. EVA AND JIM MAKING A CUSTOM FIT.

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!. WE WERE HONORED BY THE GUANACASTE FOLK DANCERS (SOME OF WHOM ARE LION'S CLUB MEMBERS) PUTTING ON A SHOW FOR US THE LAST NIGHT.

2. MARIANNE GETTING THE PELVIC BELT JUST RIGHT. WE HAD SOME GREAT SURPRISES WHEN SOME KIDS JUST STARTED PROPELLING FOR THE FIRST TIME.

3. JOAN CONNECTING WITH THE KIDS.

4. CHAIRS GETTING DRY IN THE SUN AFTER THEIR FINAL CLEANING BEFORE DISPENSING.

5. PERENNIALLY PERKY EVA.

6. YOUNG BOY AND HIS MOTHER WAITING PATIENTLY AS WE INEVITABLY TRIED TO BALANCE SPEED AND A QUALITY SETUP FOR EVERYONE.

7. COMING BACK FROM OUR WALK TO THE TOWN SQUARE. PEDESTRIANS HAVE TO KEEP ON THEIR TOES IN ALEJUELA.

8. A YOUNG GIRL AND HER FATHER FROM THE NORTHWEST COASTAL AREA.

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!. EVA AND DAVID FITTING A UCP/WFH CHAIR.

2. MICHAEL AND DAVID REWORKING THE FRAME FOR A CLIENT. PRETTY SURE WE VOIDED THE WARRANTY.

3. : MARIANNE AND MICHAEL WITH A HAPPY NEW WHEELCHAIR OWNER.

4. LIKE AT HOME, SOME TOOK A LOT MORE WORK THAN OTHERS, BUT IN THE END, A SATISFIED NEW USER AND MOM.

5. XENIA, A DEDICATED LION AND FOLK DANCER. SHE WAS A GREAT HELP TO US DURING THE DISTRIBUTION.

6. A LION'S CLUB SIGN WITH CHARACTER.

7. JOHNNY AND MARGARITA, OUR HOSTS, AND KNOWN TO MANY UCP/WFH VOLUNTEERS.

8. EL GREGO,TOTALLY FOCUSED.

9. THIS LITTLE CHARMER IS READY TO GO HOME WITH HER NEW CHAIR.


UCP
United Cerebral Palsy
Wheels for Humanity

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CLUB DE LEONES
LIONS
L
AEROPUERTO

6


PENDLETON

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PATHOPHYSIOLOGY of *Muscular Dystrophies*

Written By **Michelle L. Lange, OTR, ABDA, ATP/SMS**

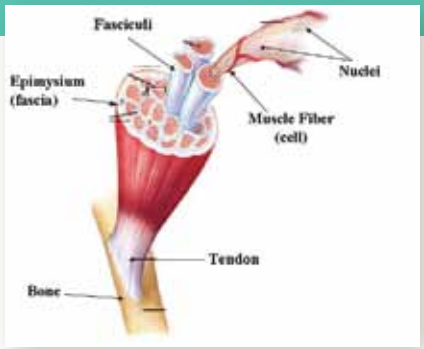
WE OFTEN EVALUATE CLIENTS WITH A wide range of diagnoses for assistive technology interventions. It is easy to jump in and identify client needs and develop recommendations, especially when we are short on time. However, backing up and understanding the pathophysiology of a specific diagnosis can improve client outcomes. Pathophysiology includes etiology (the cause), symptoms, tests, pathology (the effects of the disease), prognosis and treatment.

The most common form of muscular dystrophy is Duchenne or Pseudohypertrophic. This is caused by a defective gene for dystrophin, a protein in the muscles, and is generally hereditary, though can be caused by a spontaneous mutation. This disease occurs primarily in boys. The muscle fibers are destroyed and replaced by fat leading to progressive muscle weakness. Symptoms typically develop before age 6 and include fatigue, cognitive impairment, muscle weakness and progressive difficulty walking. Weakness tends to begin in the legs and pelvis, leading to frequent falls. Many clients initially present themselves as becoming more and more "clumsy" despite having very "strong" legs. Parents will often point out apparently strong calves, which is really an indication of the muscular dystrophy itself. Calf pseudohypertrophy occurs in about 80 percent of clients. Testing to confirm the diagnosis includes EMG (electromyography), genetic testing, muscle biopsy and serum CPK to check for protein in the blood.

Pathology includes cardiomyopathy, as the heart is also a muscle. Spinal curvatures are common as the muscles weaken and can no longer adequately support the trunk. Osteoporosis occurs as the client is no longer weight bearing. Respiration is ultimately affected as well, due to progressing muscle weakness. Sensation remains intact and discomfort is a primary complaint in this population. So is resistance to change, which makes assistive technology intervention more challenging. Keep in mind studies have shown cognitive impairment in about 70 percent of Duchenne clients. This can affect understanding of equipment choices and use. The average lifespan without assistance with respiration is about 20 years of age.

Spinal muscular atrophy (SMA) is the most common childhood progressive disease and the second leading cause of neuromuscular disease. This group of inherited diseases causes progressive muscle degeneration and weakness. There are four types of SMA. This is a hereditary disease caused by an autosomal recessive gene and most of the time the client must get a defective gene from both parents. SMA is a motor neuron disease that affects all the muscles in the body, though proximal involvement is often more severe. Cognition and sensation remain intact. Motor neurons are nerve cells in the spinal cord that send out signals to the muscles. A missing or mutated gene (SMN1) typically produces survival motor neuron protein. Without this protein, motor neurons shrink and die.

SMA type I, or Werdnig-Hoffman disease, is the most severe form. These children are born with very little muscle tone, weak muscles and feeding and breathing problems. SMA type II is less severe during early infancy, but then the child becomes progressively weaker with time. Type III (Kugelberg-Welander or Juvenile SMA) is the least severe form of the disease with symptoms often not appearing until the second year of life. Type IV, or adult onset SMA, is rare with symptoms typically beginning after age 35.



Symptoms of SMA include muscle weakness, low muscle tone, little spontaneous movement, lack of deep tendon reflexes and muscle fasciculations. pathology includes severe muscle atrophy and spinal curvatures, as well as difficulty breathing, feeding and managing secretions.

Understanding the Pathophysiology of Duchenne Muscular Dystrophy and Spinal Muscular Atrophy can be enlightening and rather disheartening at the same time. Assistive technologies, such as seating and mobility, play a primary role in providing postural support, comfort and independence for these clients.

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Michelle will be presenting a NRRTS webinar on Tuesday, May 22, 2012, from 5:00pm to 7:00pm Pacific that focuses on Duchenne's Muscular Dystrophy and Spinal Muscular Atrophy. Please see page 8 in this issue of DIRECTIONS for more details on registering.

POSITIONING vs. Restraint

Written By **Michelle L. Lange, OTR, ABDA, ATP/SMS**

RESTRAINTS ARE A RED HOT TOPIC IN THE world of positioning. Restraints were once solely a concern in long-term care facilities, but this issue is now creeping into a variety of settings, including some schools. The underlying concern is a valid one, but the practical implications can be maddening. In the past, certain "seating" components were often used in institutional settings to intentionally restrain clients. Sometimes this was to prevent falling, such as when a client would attempt to get out of bed or stand up and walk away from a wheelchair, but was non-ambulatory. More often, restraints were used to limit aggressive behavior (self-directed or otherwise), to control behavior or as a consequence to poor behavior. Over time, policies were developed to protect clients and to reduce or eliminate improper use of restraints. Unfortunately, in an attempt to protect clients from being restrained, many clients are now unable to receive the postural support they need, particularly in certain settings. Sometimes exceptions are made, often with quite a bit of red tape.

If you are working with a client who can benefit from seating technologies to meet positioning goals, yet others may view the solution as a restraint, be sure to stress the clinical indicators in your justifications. If the client is in a setting where restraint policies are in effect, find out what the requirements are. Sometimes a physician letter is required that places an "order" in the chart necessitating these components. Don't give up – each challenge is a chance to educate others and to meet your client's needs.

So what about the client who may not need these components for positioning, but is at risk for falling and may attempt to get up? This is a tough issue. A variety of strategies is often incorporated to avoid restraining the client, though some level of restraint may be indicated for safety and would then have to comply with any restraint policies for the setting. Facilities receiving federal funding must follow regulations from the Omnibus Budget Reconciliation Act of 1987 (OBRA). These state "Restraints may only be imposed: 1) To ensure the physical safety of the resident or other residents, and 2) Only upon written order of a physician that specifies the duration and circumstances under which restraints are to be used."

Is using seating technologies explicitly as a restraint ever indicated? Yes, but fortunately not very often. Some clients are compulsively self-abusive, meaning this behavior is not within their control. This can occur with some clients with Cornelia de lange syndrome and clients with Lesch-Nyhan syndrome. I have worked with several clients with Lesch-Nyhan who required complete restraint while in their wheelchair to prevent self-injury, as well as injury to others. In these situations, the entire team – including all caregivers and the client – must be on the same page with the same goal: protecting the client from injury, not imposing restraint as a behavioral consequence.

With increasing concern regarding secondary seating components being viewed as a restraint, it is more essential than ever that we document the clinical indicators for every component that is part of the wheelchair and seating system. In doing so, we will not only be justifying the equipment itself, but its intended use.

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Michelle may be reached at michellelange@msn.com.

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Michelle will be presenting a NRRTS webinar on Thursday, May 24, 2012, from 5:00pm to 7:00pm Eastern that focuses on Positioning Versus Restraint. Please see page 8 in this issue of DIRECTIONS for more details on registering.

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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. 19 through March 7, 2012. For an up-to-date verification on Registrants, visit www.nrrts.org, updated daily.

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