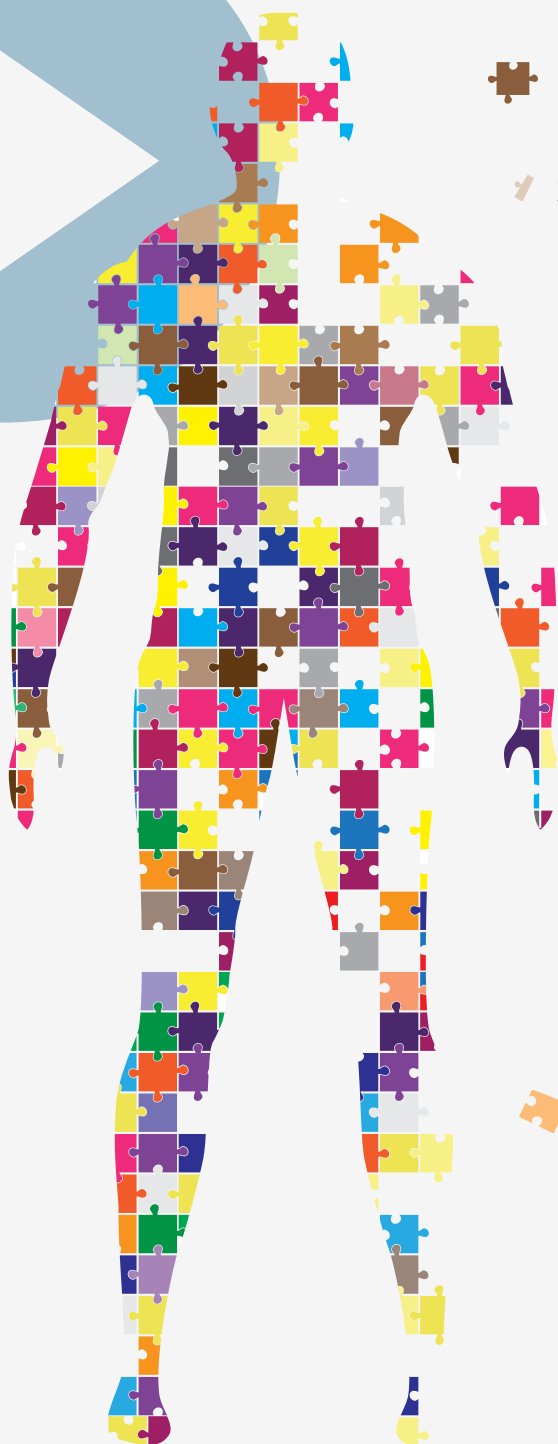
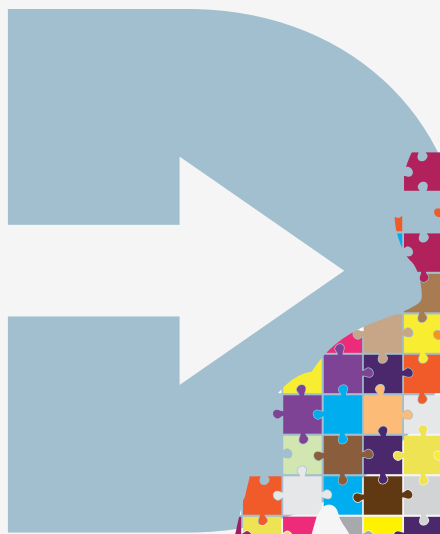


DIRECTIONS



POWER WHEELCHAIR ALTERNATIVE DRIVING METHODS

a decision-making hierarchy *CEU Article Review

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*Leadership Day
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8:30-9:30- CRT Consumer Panel
10:00-11:30- Healthcare Reform
1:00-3:00- Industry Update
3:30-5:00- Congressional Prep
6:00-8:00- CRT United Reception

*Capitol Hill Day
Thursday, April 26*

9:00-4:00- Congressional Visits
6:00-8:00- Debriefing Reception



To Register, Visit:

www.ncart.us/crtconf

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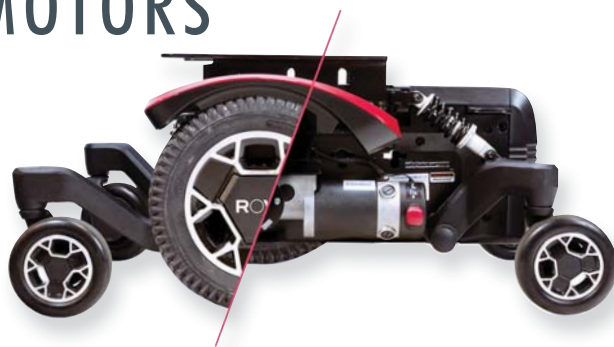
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THERE IS A LOT HAPPENING AT NRRTS!

Written by: **ELAINE STEWART**, ATP, CRTS®

AMNESTY PROGRAM

Since the announcement of the NRRTS Amnesty Program, I am excited to report that we have seen much interest. The amnesty program runs until March 31. For applicants and current registrants who meet the criteria, the CRTS® designation will be awarded.

Here are the details:

- Registrant or applicant must have documented minimum of three years of experience providing direct service to Complex Rehab Technology (CRT) consumers;
- Be an ATP in good standing for a minimum of three years at time of application;
- Complete the application for registry or renewal to the satisfaction of the review chair within the time frame.

The CRTS® designation identifies the experienced, credentialed Complex Rehab Technology Supplier.

See page 24 for more information

NRRTS CONTINUING EDUCATION PROGRAM

The lineup for this year's NRRTS webinars will present courses on a variety of topics. Last year, NRRTS awarded over 2,200 CEUs! Check it out.

NATIONAL CRT CONFERENCE

The National CRT Leadership and Advocacy Conference is also around the corner; April 25-26, 2018, in Arlington, Virginia. This is a two-day program that provides the opportunity to speak with your representative directly on the matters that affect the complex rehab community. This is a great experience to see what a small group of individuals can do to affect change on Capitol Hill. I encourage you to attend the conference and let your voice and those you provide CRT be heard to ensure that our ability to provide is not brushed under the carpet. Be part of the solution!

NRRTS AWARD PROGRAM

There are just few more days to get your nominations in for the NRRTS awards. Nominations must be received by midnight, February 28.

There are four categories:

- Distinguished Service Award
- Consumer Advocate Award
- Simon Margolis Fellow Award
- Leadership Award

Awards will be presented at the CRT Conference on April 25.

Visit our website for more details:

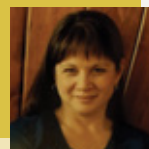
www.nrnts.org

So, you can see that NRRTS is growing and provides benefit to suppliers, consumers, clinicians and referral sources. NRRTS continues to work diligently to develop quality continuing education and keep you up-to-date on the pulse of our lawmakers. Through our publication DIRECTIONS, you are introduced to some of the wonderful people who use, manufacture and provide CRT.

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ESTEWART@NSM-SEATING.COM

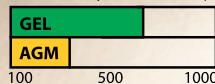
Stewart is president of NRRTS and works for National Seating & Mobility in Fort Wayne, Indiana.



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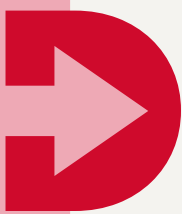


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CHANGED BUT NOT DEFEATED

Written by: ROSA WALSTON LATIMER

"At one point after my accident I developed a pressure sore from time in the saddle, and my doctor told me I couldn't ride [my horse] anymore. Well, that wasn't going to happen!" This declaration by then 19-year-old Amberley Snyder perfectly illustrates the grit and determination that has taken her from a life-altering automobile accident eight years ago to the fierce competition of the pro-rodeo circuit today.

Snyder's love of horses began when she was a child, and by the time she was a teenager, she was competing in barrel racing, pole bending and breakaway roping. In 2009, the high school senior qualified for the National High School Finals in pole bending and won the National Little Britches Rodeo Association All-Around Cowgirl World Championship. The hard work and competitive spirit that helped Snyder soar in the rodeo arena also made an impact on other areas of her life. She was elected the Utah FFA State President for 2009-2010 and was looking forward to fulfilling her leadership responsibilities, preparing for college and the competition of college rodeo events.

In early January 2010, Snyder was on her way to a rodeo in Denver, Colorado, and while driving through a small town in Wyoming glanced down at the map on the seat beside her. When Snyder looked up a few seconds later, she realized she had drifted into the other lane and was headed toward a metal beam. She overcorrected and her truck veered off the road and flipped. Snyder was ejected from the truck and forcefully thrown into a fence post. She immediately lost all feeling in her legs.

"I always wore my seat belt but had taken it off because of a stomachache. This one time of not buckling up cost me everything," Snyder said. "I saw my life in pieces around me as I was sitting in that snow bank. I felt like I was sitting in warm water from the waist down. I knew right then that something was definitely wrong."

"WHEN THE DOCTOR TOLD ME I COULDN'T RIDE BECAUSE OF THE PRESSURE SORES I HAD EXPERIENCED, MY DAD SET TO WORK TO FIX THAT PROBLEM, HE CUT THE SEAT OUT OF ONE OF MY SADDLES AND MAILED IT INTO ROHO."

Following hours of emergency surgery, Snyder received the sobering news that she would never regain use or feeling below her waist. The young rodeo star was also told she wouldn't ride or rodeo again. "That was more devastating for me than learning I wasn't going to be able to walk," Snyder said. "I soon realized that I needed to do what I could to live a full life. And that would involve getting on a horse again."

Two months after her debilitating accident, with every intention of reclaiming her life, she spoke at the Utah State FFA Convention. Two months later, using a seat belt from a junked car, some Velcro to secure her legs and a strap to center

her in the saddle, Snyder was back on her horse. But the experience was not the triumph she expected. In an interview with *People* magazine, Snyder described this as the worst time of her life.

"I was devastated. I couldn't feel the horse's heartbeat through my legs and my balance was off. I realized that every single part of my life was different on that day. Horses had always been that peaceful place. That place that feels like home. And suddenly, I felt nothing. I was a stranger on that horse's back."

Months passed before she would try to ride again.

True to form, Snyder didn't give up and did ride again reclaiming the joy of competing. "When the doctor told me I couldn't ride because of the pressure sores I had experienced, my dad set to work to fix that problem," she said. "He cut the seat out of one of my saddles and mailed it into Roho. They used the seat as a diagram to customize an air pressure seat that would match. They came up with the prototype, I approved it and then they made it. Roho provides the seating for my saddle and my wheelchair."

Snyder continues to gain independence caring for her horses and can now saddle her horse from her wheelchair. She effectively competes at a professional level in a high speed rodeo event where every second counts.

In 2013, Snyder was chosen as the runner-up for Wrangler's "Ultimate Cowgirl" and the following year she



ABOVE: Cory Snyder, Amberley's dad and a former Major League Baseball pitcher, with Amberley (left) and three of her siblings.

BELOW: Amberley with her horse, Legacy.



posted a fifth place over all finish for the Rocky Mountain Region Intercollegiate Rodeo.

In 2015, she received a bachelor's degree in agriculture education, and that same year was voted the fan exemption contestant at the world's richest one-day rodeo, RFD-TV's The American, where she competed with the best in the field. In December 2017, Snyder received her master's in school counseling from Utah State University in Logan, Utah.

Celebrating her 27th birthday last month, Snyder reflected on how she has changed since her accident eight years ago. "I have learned a lot of patience, and I have also learned to appreciate the things I can do instead of focusing on what I can't do," she said. "I've definitely developed a great appreciation for those who have helped me, and will continue to help me, accomplish my goals."

My family has been a huge support through everything I've had to deal with," Snyder said paying tribute to her parents and five siblings. "We are all competitive in our sports so we understand the dedication to what we love. My mom and youngest sister are the only ones involved with horses so we share a deeper understanding."

Snyder also acknowledges her best friend, Emmy Peterson. "Emmy served in a Utah FFA state office along with me and has not left my side since the accident. We both attended Snow College and then Utah State University. I definitely would not be as far as I am without these people!"

In addition to a very full schedule competing at the professional level in rodeos, through the spring of 2018 Snyder will travel to a half-dozen states to hold barrel racing clinics and is planning for more. "I began offering

CHANGED BUT NOT DEFEATED (CONTINUED FROM PAGE 7)

these clinics after my accident,” she said. “Because of my experiences, I can better relate to challenges in the arena. Everyone has challenges even if they aren’t in a wheelchair.”

Snyder has also developed a successful career as a motivational speaker. “I believe motivational speaking picked me after my accident, and I’m glad it did!” she said. “I had no way of knowing that my experience as State FFA President was preparing me for this.”

She shares her message with students at all levels, as well as at corporate conventions and other gatherings.

“I tell my journey from the accident to competing at the pro level and share goals I’ve accomplished along the way. Each person has challenges. We get to decide how we face them.”

A children’s book, *Walk Ride Rodeo*, written by Snyder was recently released and is available through her website (www.amberleysnyder.org) as well as from other online booksellers.

Offering practical insight into the everyday challenges in her life, Snyder produces videos, “Wheelchair Wednesdays,” illustrating a variety of topics from navigating escalators in a wheelchair to how to saddle a horse.

Before her debilitating accident, Snyder says her source of self-worth came from her awards and titles. “I realized my life couldn’t be about that anymore. I had to show myself and others who I really am. I believe that when the times are the hardest is when you are the closest to what you want to accomplish. I am very content and feel at peace when I’m on my horse. That is when I truly feel like everyone else. I get to leave my wheelchair and be on my horse. And I feel free because my horse is my legs.”



World titles Amberley Snyder won from the National Little Britches Rodeo Association in 2009.



Amberley Snyder in the pole bending event at the Junior High National Rodeo competition.



Amberley's saddle “hook up” using a customized Roho cushion and a converted seat belt.



Amberley Snyder, Utah State FFA President, speaking at the state convention two months after her accident.



Amberley Snyder competing in a barrel racing event following her accident using a seat belt and Velcro to keep her steady in the saddle.

Snyder is a consumer advocate from Utah. Readers may learn more about Snyder by visiting <http://bit.ly/2FRE3g1>



CONTACT

Amberley can be reached at AMBERLEY.SNYDER@HOTMAIL.COM

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WILMORE SAYS QUALITY OF LIFE FOR PATIENTS IS KEY

Written by: JULIE BARNETT

Kendall Wilmore, ATP, CRTS®, describes the purpose of her 12-year career in durable medical equipment simply and concisely – paving the road to better quality of life for patients.

Wilmore graduated in 1994 from the University of Alabama at Birmingham with a degree in occupational therapy. Following graduation, she began her career as a traveling therapist working in home health where she experienced firsthand the need for quality DME providers. This ultimately led her to make a career change to the DME industry in 2005.

“A medical equipment company in my town approached me regarding a marketing representative position,” she said. Wilmore recognized that with her background as an occupational therapist and personal passion for appropriate seating and positioning, she would excel in this role. In addition, several of her colleagues recommended that with her local relationships and patient-centered philosophy, she would be highly successful as a DME marketing representative.

In 2010, Wilmore earned her ATP. As an ATP and an OT, she has certification and has made numerous connections with As an ATP and an OT, she has certification and has made in her area. She notes that those in rural areas simply don’t have access to therapists who have obtained ATP certification and prefer to work with her for their mobility equipment needs.

“It is essentially a collaborative approach that takes input from the patient, therapist, physician and ATP to facilitate the most appropriate mobility intervention for each individual patient,” she said.

“I FEEL LIKE THEIR QUALITY OF LIFE IS MORE IMPORTANT - THAT’S THE OT IN ME,” SHE STATED. “YOUR QUALITY OF LIFE IS THE THINGS YOU DO INSIDE AND OUTSIDE YOUR HOME. CAN YOU GO TO CHURCH? CAN YOU GO TO ACTIVITIES WITH YOUR KIDS? CAN YOU GO ON VACATION?”

She works directly with physician offices, home health operations and hospital case managers using a concerted approach. Moreover, she goes into the patient’s home to conduct an in-home evaluation where she measures the patient for equipment, documents the home environment and documents how assistive technology will provide independence for the end-user. Wilmore also spends a considerable amount of time and effort educating clinicians as it pertains to documentation. She also educates patients and

their families regarding insurance coverage and patient co-pay responsibility.

“Often patients don’t know about their insurance coverage,” Wilmore said. “The diagnosis-driven nature of the industry presents a constant challenge. Sadly, many

people are not able to obtain needed equipment due to the diagnosis requirements. For example, you attempt to help someone with mobility limitations (severe arthritis or amputee) and there is nothing you can do because they do not have a specific diagnosis.”

She continued, “It is extremely important to encourage doctors to document everything they know about the patient’s current status and history.”

Wilmore firmly believes that detailed notation in the face-to-face is key in a patient getting equipment – and having better quality of life. Furthermore, she views the current “in home usage” requirement used by the payers as restrictive and a deterrent to quality of life.

“I feel like their quality of life is more important – that’s the OT in me,” she stated. “Your quality of life is the things you do inside and outside your home. Can you go to church? Can you go to activities with your kids? Can you go on vacation? You need life outside the home. That’s one of the problems I have with some of the guidelines and justifications. I think a person who needs a wheelchair, such as one with a SCI (spinal cord injury) or someone who’s had a CVA (stroke), I think they should be able to go on vacations with their kids or families, be able to load themselves up and go to church.”

She believes that quality of life extends further than inside the home environment. “It seems punitive for



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individuals who are physically challenged and, in many cases, living alone to not have considerations given to their ability to safely conduct day-to-day activities such as going to their mailbox, feeding their animals, attending church or spending outdoor time safely with their grandchildren," she said.

Despite the policy frustrations, Wilmore finds her work truly rewarding and loves helping patients. She's very therapist oriented and enjoys seeing patients receive their equipment and the satisfaction of knowing how it will provide hope, independence and a better life.

Wilmore has recently accepted a position with Fuller Medical Solutions where she will continue in her life's work to improve the quality of life for mobility challenged individuals in Northeast Alabama.

CONTACT

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Kendall Wilmore, ATP, CRTS® is a
NRRTS registrant from Alabama.



KEEPING CONSUMERS ROLLING

MCCARTHY ENJOYS A SUCCESSFUL CAREER IN SALES AT MK BATTERY, FINDS FULFILLMENT IN SUPPORTING END-USERS

Written by: **DANETTE BAKER**

There are a thousand reasons why Mike McCarthy's career in the HME industry spans two-plus decades, and each has a name. "The ability to help someone move through their environment, through their professional life and through their home" solidifies the decision he made in the early 1990s to rejoin an industry that impacts lives on a daily basis, said McCarthy, MK Battery HME category manager and regional sales manager for the Eastern U.S.

It's a Cliff Notes type explanation, but McCarthy says there is no better way to describe the motivation for 10-plus hour days and spending an average of three nights on the road each week. Like most of his colleagues at MK Battery, McCarthy wears several hats for the "lean and mean globally recognized brand." He manages a sales team responsible for four territories in the eastern half of the U.S. and assists longtime MK employee Dennis Sharpe, global director of HME business, with such products sold domestically. With McCarthy's proximity to Capitol Hill—he lives in the Philadelphia suburb of Lansdale, Pennsylvania—he often lobbies with advocacy organizations such as NRRTS, NCART and AAHomecare to protect access to complex rehab products and accessories on behalf of those who need DME products, the suppliers and manufacturers.

"It's important to us that people have access to our products and that our providers can continue to use us as a trusted household name," McCarthy said. "Contrary to popular belief, a battery is an accessory, so we have a dog in the

hunt, and we will do anything we can to thwart any further cuts at the federal level."

"WE ARE AN AMERICAN-MADE PRODUCT, AND AS SUCH, WE ARE DEFINITELY NOT THE LEAST EXPENSIVE BATTERY OUT THERE. THAT'S ONE OF THE PITCHES I SHARE WITH OUR SALES TEAM WHEN VISITING WITH OUR PROVIDERS."

As a B2B, MK Battery's sales team has little interaction with end-users. McCarthy said they do, however, interact on a daily basis with those in direct contact with consumers — the ATPs, rehab technicians, etc. — and understand from them the importance of having a quality accessory such as a battery to drive assistive technology.

Early in his career, McCarthy did have a more direct role as a delivery service technician. In fact, it was that experience that drew him back after a brief hiatus.

In the early 1990s, McCarthy had made his way back to the Philadelphia area after living in Montana and discovered an opening for a service delivery technician with Young's Medical Equipment, a regional HME provider in Lansdale.

"My previous experience setting up hospital beds and oxygen concentrators out in the field landed me the job on the spot," McCarthy recalled. "That's what launched my career."

Over the next few years, McCarthy advanced with Young's, working in several departments until eventually landing on the complex rehab team. He earned his ATS (now ATP) credential and began working as an assistive technology supplier — a position he held with National Seating and Mobility and Pride Mobility. McCarthy said he was fortunate to work with some "terrific people" through these experiences, many who are still instrumental in advancing the industry.

At Pride Mobility, McCarthy was a member of a small, core group of "critical thinkers," including research and development engineers, that created several new manual wheelchair components as well as positioning cushions and backs that are still in the marketplace today.

“IT’S LIKE IN THE WIZARD OF OZ, GETTING TO THE DOOR AND HAVE SOMEONE UNDERSTAND YOUR MESSAGE AND INVITE YOU IN AND TELL YOU EVERYTHING IS GOING TO BE OK IN YOUR WORLD, THAT IS THE PERFECT SCENARIO.”

“Being part of a product development team and being able to see the work you contributed to in the field today, that was definitely a milestone in my career,” McCarthy said. “I’ve been extremely fortunate to have advanced through the industry, but like so many, I’m still here because I know we are making a difference for so many.

“I was told a very long time ago that to be successful in this business you need to do two things: one, return phone calls, and two, do the things you say you are going to do. I have hung my hat on that for 25-plus years; I preach it and practice it on a daily basis.”

MK Battery’s success in the mobility industry for almost three decades is one that speaks volumes to the loyalty of its products and those who work for the company, McCarthy said. The company markets sealed batteries to specialty, niche markets through original equipment manufacturers, distributors and suppliers. In addition to home health care, MK Battery also provides its products to service industries including biomedical devices, floor scrubbers, electronics/security, recreational, broadband and solar.

“As a business, we understand funding challenges, and we know what our HME providers have faced over the past seven to eight years,” McCarthy said. “Everyone is searching to get their costs down to become more profitable, and as a result, we have lost some of our customers.

“We are an American-made product, and as such, we are definitely not the least expensive battery out there. That’s one of the pitches I share with our sales team when visiting with our providers. I can’t tell you how to save money on batteries, but I can teach you how to lose less. Based on the analysis we’ve done, you can’t make money on batteries, so you might as well install quality.”

McCarthy takes great pride in helping develop the sales team. Ultimately, the business is about the people, he said. McCarthy enjoys helping individuals find their passion and see young sales professionals succeed. He said he also has a great working relationship with Rick Spiegel, MK Battery vice president of sales, and the entire executive leadership team. The collaboration, McCarthy said, “Sets our people up for success, and we grow the business and the brand.

“Everyone in sales has goals, and ultimately when my feet hit the floor this is going to be at the top of my list,” McCarthy said. “I like for my team to succeed, I like for our organization to succeed and for our brand to be in front of people who don’t know who we are. That’s a huge win and adds depth to our portfolio and our customer base, plus it makes this a fun place to be.”

The successes, however, aren’t without challenges. Outside of the funding challenges faced by every company involved with HME, DME and Complex Rehab Technology, MK Battery has been fortunate and will continue to fight for legislation to protect assistive technology such as the recent “accessories bill.”

“It’s like in the Wizard of Oz, getting to the door and have someone understand your message and invite you in and tell you everything is going to be OK in your world. That is the perfect scenario,” McCarthy said. “Being a realist, however, I know that yellow brick road has some potholes in it. We simply continue to jump those potholes. Many that we’ve faced over the last decade have been huge, huge potholes, and every time we jump them and land firmly on our feet on the other side is a win for the industry and more importantly a win for the people who use our products.”

That’s why, as an industry leader and company, McCarthy and MK Battery continue to work closely with group purchasing organizations, including The MED Group and VGM-US Rehab as well as with state associations and NRRTS.

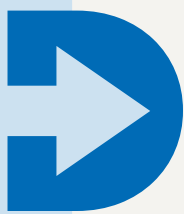
“I feel strongly based on some of the successes we’ve had recently, our industry is absolutely blessed with the people that fight the fight on Capitol Hill, and I’m fortunate to know most of them personally. They typically don’t take no for an answer; so even if there are continued challenges, which I expect there will be, the people they are protecting are going to win, it just takes time.”

CONTACT

Mike may be reached at
MMCCARTHY@MKBATTERY.COM

McCarthy is regional sales manager (Eastern US) & HME category manager for MK Battery.





WORK HARD AND BE KIND

Written by: ROSA WALSTON LATIMER

CLINICALLY SPEAKING

Dr. Sarah Blanton is an associate professor in the Department of Rehabilitation Medicine at Emory University School of Medicine, Division of Physical Therapy in Atlanta, Georgia. After earning a bachelor's degree in biology from the University of Virginia, Blanton received a master's degree and a Clinical Doctorate in Physical Therapy from Emory University. She has a specialty certification in neurology through the American Board of Physical Therapy and spent nine years working as a staff physical therapist at the Emory Center for Rehabilitation Medicine, primarily in the inpatient neurology unit.

Blanton had the opportunity to do full-time research with her longtime mentor, Dr. Steven Wolf, her graduate research advisor at Emory. She also became the project coordinator for two multisite, NIH-funded national clinical trials – the EXCITE (Extremity Constraint Induced Therapy Evaluation) RCT and the ICARE (Interdisciplinary Collaborative Arm Rehabilitation Evaluation) RCT.

“During my time on these studies, I pulled from my clinical experience and recognized that we could do more as therapists to provide family-centered care,” Blanton said. “Stroke, as with other serious conditions, affects the whole family, not just the patient.”

Blanton's research goal continues to focus on improving the delivery of family-centered care in rehabilitation. Her current research examines the impact of using a telehealth platform for the delivery of a theory-based, family-focused upper extremity intervention program for stroke survivors and their care partners in the home setting. The aim of the intervention is to reduce care partner burden and depressive symptoms while improving stroke survivor upper extremity function.

“DURING MY TIME ON THESE STUDIES, I PULLED FROM MY CLINICAL EXPERIENCE AND RECOGNIZED THAT WE COULD DO MORE AS THERAPISTS TO PROVIDE FAMILY-CENTERED CARE. STROKE, AS WITH OTHER SERIOUS CONDITIONS, AFFECTS THE WHOLE FAMILY, NOT JUST THE PATIENT.”

“I use the term ‘carepartner’ to emphasize that family members are not just a ‘giver’ of care but a true partner in the rehab process,” Sarah explained. “The underlying theme behind this work is the involvement of the patient and families.”

Currently Blanton's DISCOVER (Digital Scholarship Enhancing Rehabilitation) lab explores various ways digital scholarship can enhance rehabilitation research, education and clinical practice and promote interdisciplinary collaboration. “Working with an excellent group of Emory DPT students, we are helping to promote

awareness of sustainability through the development of the ‘Greening Physical Therapy’ website,” she explained. “The goal of this website is to be a dynamic platform to share ideas and illustrate strategies to broaden understanding of the concepts of sustainability in the physical therapy profession.”

“As editor-in-chief of the Journal of Humanities in Rehabilitation (JHR), I am dedicated to fostering integration of the humanities in rehabilitation science,” Blanton said. JHR is a peer-reviewed, multi-media journal using a collaborative model with rehabilitation professionals, patients and their families to gain a greater understanding of the human experience of disability through art, literature and narrative.

The first publication of its kind in rehabilitation medicine, the purpose of this international, interdisciplinary journal is to raise the consciousness and deepen the intellect of the humanistic relationship in the rehabilitation sciences. “The website (www.JournalofHumanitiesinRehabilitation.org) has had more than 15,000 users from 131 countries and our subscriber email list for the quarterly JHR issues reaches approximately 11,000 individuals.

“I love this opportunity to promote awareness of the humanities in rehabilitation,” Blanton said. “With this journal, we also seek to provide voices for patients and families through collaborative scholarship.”



Sally Brooks and Sarah Blanton, Mexico, Summer of 2016

Graduate student training in the health humanities is another primary mission of the journal, providing opportunities for students from multiple disciplines to gain skills in digital scholarship. “In honor of my father, who was my inspiration for the journal, my family and I founded the Frank S. Blanton Jr., MD Humanities in Rehabilitation Scholarship.” Recipients of the annual scholarship are students aligned with the life mission of the elder, specifically exhibiting a dedication to the pursuit of knowledge in the humanities, a deep desire to foster awareness of humanities in health professions, and a gentle kindness and compassion in relating with others.

Blanton grew up in the small Appalachia town of Bristol, Tennessee, and was very close to her parents. She credits their influence as shaping the type of professional she has become. Her father was a general surgeon, and her mother was a nurse. “They were kind, sincere and genuine individuals, who loved learning and helping others and were a wonderful model for me,” she said. Blanton was drawn to physical therapy at the University of Virginia after doing an internship with hospice. “I chose hospice because my mother was involved with hospice. I found the experience life-changing!” she said. “I realized that even though I was just volunteering to sit with patients and their families, I was never more present and mindful than when I was at someone’s bedside.”

The experience inspired Blanton to consider physical therapy and in particular neurologic rehabilitation because “it is such an intimate and vulnerable time in someone’s life when they are challenged by life-altering diagnoses.”

In addition to a fulfilling career, Sarah enjoys a passion for photography and travel. “I love the opportunity to combine my interest in not only visual arts, but also in poetry and literature with my profession of rehabilitation through my work on the *Journal of Humanities in Rehabilitation*,”

“I LOVE THIS OPPORTUNITY TO PROMOTE AWARENESS OF THE HUMANITIES IN REHABILITATION, WITH THIS JOURNAL, WE ALSO SEEK TO PROVIDE VOICES FOR PATIENTS AND FAMILIES THROUGH COLLABORATIVE SCHOLARSHIP.”

she said. “I just married my partner, Sally, in November. We love to cook and explore restaurants and travel.” For Blanton’s 50th birthday, the couple visited Paris and Italy including the Isle of Capri and took a cooking class in Ravello on the Amalfi Coast of southern Italy.

“The highlight of the trip was staying at the Grand Hotel Excelsior Vittoria in Sorrento, a gift from my father right before he passed that year,” Blanton said. “He had visited the bay of Naples as

CONTINUED ON PAGE 16



(Left to Right) Stephanie Larsen, Sarah Blanton, Emma Goldberg at the award dinner for Frank S. Blanton, JR., MD Humanities Scholarship award presented to Emma at the house of Maggie Edson, Pulitzer prize winning playwright of play Wit.

WORK HARD AND BE KIND
(CONTINUED FROM PAGE 15)

a sailor and vowed to stay in that hotel one day, and then he and my mom did 50 years later. So, it seemed fitting to go back and be there in their honor!”

Last summer, Blanton attended the World Congress of Physical Therapy in Cape Town, South Africa. Afterward, she and a colleague traveled to Kruger National Park on safari. “It was amazing!”

“BE MINDFUL OF YOUR HEART AND WHERE YOU FEEL NOURISHED IN YOUR PERSONAL AND PROFESSIONAL LIFE AND WHAT PULLS YOU AWAY FROM WHO YOU ARE IN YOUR SPIRIT, CONSIDER AVOIDING THE EVER-PRESENT URGE FOR THE FALSE DICHOTOMY OF A WORK-LIFE BALANCE AND CONSIDER WAYS TO DEVELOP FULFILLING WORK-LIFE INTEGRATION.”

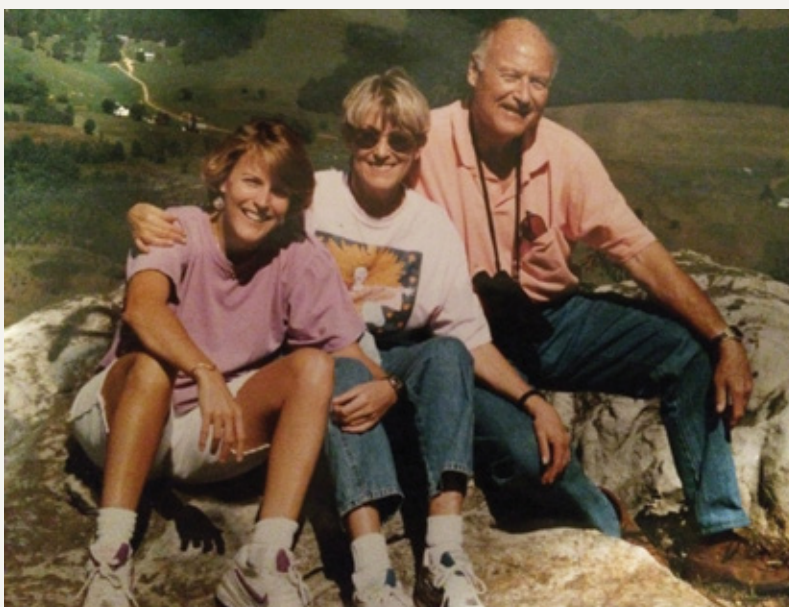
Blanton also benefits from the practice of meditation and has been in the same mindfulness meditation/yoga group for 10 years. “I also find a sense of spirituality in the Episcopal church and in nature.

“I believe working hard and being kind have opened more doors and carried me farther in my life and work than any natural talents,” she said. “It is important to be present in the moment and to find gratitude each day for the work you do.”

Blanton also believes one should strive to embrace and learn from weaknesses as well as strengths. “Be mindful of your heart and where you feel nourished



Sarah Blanton skiing on South Holston Lake, Bristol, Tennessee, 1987



Sarah with her parents, Frank and Sally Blanton, in East Tennessee, 1994



Sarah Blanton, Cape Point, South Africa, Summer 2017



Sally Brooks and Sarah Blanton, Cape Town, South Africa, December 2016

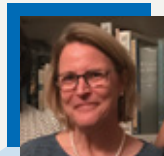
in your personal and professional life and what pulls you away from who you are in your spirit,” she said. “Consider avoiding the ever-present urge for the false dichotomy of a work-life balance and consider ways to develop fulfilling work-life integration.”

CONTACT

Sarah may be reached at SBLANTO@EMORY.EDU

WORK HARD AND BE KIND

Blanton is an associate professor in the Department of Rehabilitation Medicine at Emory University School of Medicine, Division of Physical Therapy in Atlanta, Georgia.



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LET'S BUILD ON 2017 PROGRESS

Written by: **DON CLAYBACK**

The year 2017 was a very active time in Washington, D.C., for our nation and for Complex Rehab Technology (CRT). We had a new president, a new cabinet and staff, a new Congress, and health care reform was a big topic. Thanks to the great collective work of the CRT community, we started the year with significant congressional awareness and support.

Continuing our advocacy with Congress and the Centers for Medicare and Medicaid Services (CMS) in early 2017 resulted in resolving one of the biggest threats facing CRT access. That threat being major Medicare payment cuts to accessories used with CRT Group 3 power wheelchairs, which extended beyond Medicare to other payers. The critical resolution came from a policy correction that CMS issued in late June that stopped reductions scheduled for July 1.

While this was a significant win, it was not a complete victory as the policy correction did not address cuts to CRT manual wheelchair accessories. We continue to work on this issue as described below.

As we move into 2018, let's review what's in play and what CRT advocates need to be watching and doing in the new year.

CRT MANUAL WHEELCHAIR ACCESSORIES

Since the June CMS policy correction did not resolve the CRT manual accessories cuts, a new CRT "Manual" Accessories bill was introduced in the form of HR 3730. The House bill, led by Reps. Lee Zeldin, R-N.Y., and John Larson, D-Conn., enjoyed 43 original cosponsors at introduction. Our Senate champions, Sens. Bob Casey, D-Penn., and Rob Portman, R-Ohio, also remain committed to resolving this issue.

"WHILE THIS WAS A SIGNIFICANT WIN, IT WAS NOT A COMPLETE VICTORY AS THE POLICY CORRECTION DID NOT ADDRESS CUTS TO CRT MANUAL WHEELCHAIR ACCESSORIES. WE CONTINUE TO WORK ON THIS ISSUE AS DESCRIBED BELOW."

Passage of HR 3730 is broadly supported by consumer and clinician organizations throughout the country. Congress has seen the evidence of this through letters from the ITEM Coalition (signed by representatives from 32 national organizations) and from the Consortium for Citizens with Disabilities (signed by representatives from 34 national organizations). These letters have been backed by multiple in-person congressional visits.

The plan for 2018: HR 3730 will roll over into the new year, and we are making it a priority for early 2018. We have great momentum thanks to a major CRT stakeholder push in December that has increased the total cosponsors to 82. Most importantly, the cosponsorship could not be any more bipartisan, with support from 41 Republicans and 41 Democrats.

As we look at the first quarter, Congress has several larger bills it needs to pass between January and March. These present legislative vehicles to attach to our smaller bills. We need to continue to add cosponsors and ask members to tell congressional leadership that this is must-pass legislation. Visit www.protectmymobility.org to see if your member is signed on and to access contact information.

CURES ACT MEDICAID PROVISION

As reported, the 21st Century Cures Act (passed in 2016) included a provision that limits Federal "Medicaid reimbursement" to state Medicaid programs for certain durable medical equipment to "Medicare payment rates" starting in 2018. While this does not require states to change their Medicaid rates, the risk is that states who are paying more than 2018 Medicare rates may look to reduce their 2018 Medicaid fee schedule in response to a potential decrease in federal reimbursement.

On Jan. 4, 2018, CMS issued the long-awaited Medicaid Director Letter, which finally shared details of the new regulation. Unfortunately, the letter was incomplete and confusing. As states do their evaluations, it is critical that Medicaid payment rates for CRT not be reduced as any such reductions will decrease access, increase health care costs, and hurt people with significant disabilities.

A proper assessment, incorporating the key factors below will protect a state from cost shifting and increasing overall state health care costs:

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“THE PLAN FOR 2018: THIS HAS RISKS TO BOTH CRT AND DME ACCESS, AND WE HAVE BEEN COLLABORATING ON A NATIONAL LEVEL WITH THE AMERICAN ASSOCIATION FOR HOMECARE AND STATE ASSOCIATIONS.”

- Limited Number of Codes – CMS’ annual Medicaid versus Medicare comparison only applies to 255 specifically identified DME HCPCS codes and these include 37 CRT codes.

- Total Aggregate Payments and No Requirement to Change – CMS’ annual comparison is based on the state’s total aggregate payments for the 255 identified codes, not on individual code payments, and there is no requirement that a state modify its existing Medicaid fee schedule.

- Avoid Cost Shifting and Increasing State Expenses – Reasonable Medicaid payment rates for CRT are critical to ensure access and independence and to reduce overall health care costs for children and adults with significant disabilities and chronic medical conditions. Reduced payments for CRT will cause increased health care costs and cost shifting to other areas.

The plan for 2018: This has risks to both CRT and DME access, and we have been collaborating on a national level with the American Association for Homecare and state associations. High-risk states are being identified and educational materials and assessment tools have been created. The immediate challenge is to ensure states fully understand the details of the regulation, its limited scope and the various options they have before any action is taken. Additional details will be shared as we move ahead.

LET'S BUILD ON 2017 PROGRESS (CONTINUED FROM PAGE 19)

CRT SEPARATE BENEFIT CATEGORY

As mentioned previously, legislation introduced in 2017 not passed carries over to 2018. Accordingly, HR 750, our Medicare Separate Benefit Category legislation led by Reps. Jim Sensenbrenner, R-Wis., and Joe Crowley, D-N.Y., remains a priority for passage in 2018.

Despite the needed advocacy time and attention spent on the CRT wheelchair accessories issue last year, the “Ensuring Access to Quality Complex Rehabilitation Technology Act of 2017” finished with 96 cosponsors in the House of Representatives.

The plan for 2018: As we enter 2018, we're focused on three objectives regarding the Separate Benefit Category legislation. The first objective is to continue to add cosponsors on the House bill (visit protectmymobility.org to see if your member is signed on and to access contact information).

The second objective is to get a companion bill introduced in the Senate, which we hope to accomplish in the next several weeks.

The third objective is to secure a financial “score” of the legislation from the Congressional Budget Office (CBO). The CBO score is a critical element that congressional leaders will require to evaluate the related “cost” of the legislation over a 10-year period and to move the bill forward to a vote and ultimate passage.

WASHINGTON, D.C., CRT FLY-IN

A great step to get the year started is to sign up for the 2018 National CRT Leadership and Advocacy Conference hosted by NCART and NRRTS. We're meeting April 25 and 26 at the same location as last year, the Hyatt Regency Crystal City in Arlington, Virginia. You're invited to join other CRT stakeholders for a great program of education, advocacy and networking.

As many know, a major part of the conference is visiting members of Congress to push for passage of our CRT legislation and continue the CRT education process. We built important momentum last year thanks to everyone's efforts. But this year's visits are critical to getting passage of permanent fixes and comprehensive improvements.

We need as many CRT advocates as we can get taking the CRT message directly to Congress. To enable greater attendance, and recognizing the demands on people's time and dollars, we're keeping last year's condensed two-day program and the reduced conference fee of only \$199.

Attendees benefit from industry-driven topics, unique networking opportunities, regulatory and legislative updates, and Capitol Hill appointments with their members of Congress. You can get more details and sign up at www.ncart.us/crtconf. We look forward to seeing many of you there!

CONTACT THE AUTHOR

Don may be reached at DCLAYBACK@NCART.US

Clayback is Executive Director of the NCART. NCART is national organization of Complex Rehab Technology (CRT) providers and manufacturers focused on ensuring individuals with disabilities have appropriate access to these products and services. In this role, he has responsibility for monitoring, analyzing, reporting and influencing legislative and regulatory activities. Don has 28 years of experience in the CRT and Home Medical Equipment industries as a provider, consultant and advocate. He is actively involved in industry issues and a frequent speaker at state and national conferences.



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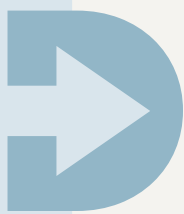
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CLINICIAN TASK FORCE: 2017 ACCOMPLISHMENTS, 2018 PRIORITIES

Written by: **LAURA COHEN** PHD, PT, ATP/SMS, EXECUTIVE DIRECTOR, CLINICIAN TASK FORCE

The Clinician Task Force (CTF) was formed in 2004 when Medicare was focused on dramatically reducing utilization of power wheelchairs. It was very clear that decisions being made would have an impact on access for people with disabilities. The situation highlighted a need for a clinical voice in the area of Complex Rehab Technology (CRT). The CTF is now comprised of 55 practicing seating and wheeled mobility (SWM) clinicians representing a range of settings including university and regional medical centers, rehabilitation facilities, home health, SNF and school based services. The group fills an important and distinctive role and is the only professional group focused on representing the clinical voice for CRT issues. Our small 501(c)(4) nonprofit organization and structure allows for CMS to cancel plans to expedite Medicare coverage on devices and gives us the ability to be responsive to CRT issues in a timely and efficient manner. Donations from manufacturers, suppliers and other organizations has allowed us to bring a strong clinical voice to the myriad issues that impact people with disabilities.

The beginning of a new year is a perfect time to pause, look back at our progress and accomplishments, and set priorities for the coming year. In addition, we are grateful to those whose contributions have allowed us to serve this important role.

In the past year, the CRT industry as a whole has had a busy agenda working to ensure individuals with mobility impairments have appropriate access to CRT products and services. It is well recognized that the CRT industry has faced more than its fair share of challenges, and it is expected that 2018 will be more of the same.

WHAT WE HAVE LEARNED:

The CRT industry is relatively small, but when all CRT stakeholders including consumers, clinicians, advocates, suppliers, CRT companies and manufacturers come together we have a strong message. When we work together on issues, we increase our ability to influence policymakers and legislators to affect positive change.

For 2018, the list of priorities is clear. The CTF is prepared to be the clinical voice to access issues, to advocate for appropriate policies and to advocate on behalf of people with disabilities.

"Coming together is a beginning; keeping together is progress; working together is success." Henry Ford

Together let's make 2018 the year we push a Medicare solution for consumer access to CRT across the finish line!

HIGHLIGHTS OF CTF 2017 ACCOMPLISHMENTS:

The CTF continues to lead the way in engaging the clinical community. Through ongoing, consistent communication, education, meetings and formal comment our teamwork has had successes worth celebrating. Following are a few highlights from our 2017 accomplishments.

1. CRT Legislation Activities – CTF members have been instrumental in influencing co-sponsorship support, in Washington, D.C., and home districts, through participation in meetings with congressional leads, target representatives, and CMS officials. We participated in Congressional briefings and advocacy activities throughout the year representing the clinical perspective and led efforts within APTA and AOTA to include CRT legislation in their respective legislative priorities and advocacy.

2. CRT Regulatory Activities – CTF members participated in multiple meetings with CMS, CMS contractors and at CRT fairs to present clinical indications for CRT accessories, technology features/functionalities and wheelchair accessories typically billed with CRT and non-CRT wheelchairs. Served on NCART-led workgroups to develop a formal request for reconsideration for MWCs.

3. Subject Matter Experts for Reports to Congress – Experts provided in-depth telephone interviews, focus groups, context, experience of policy in practice, and methodology recommendations to various contractors responsible for generating reports to Congress on the PMD PA Program and Dual Eligible Beneficiaries' Access to CRT.

4. CRT Related Technical Assistance – CTF members provided technical guidance to state protection and advocacy staff advocating for CRT access for clients denied CRT access due to issues with state Medicaid, and managed Medicare and Medicaid programs. Members kept pace with

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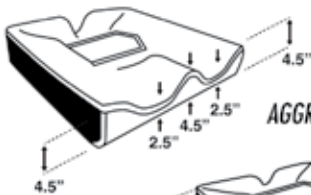
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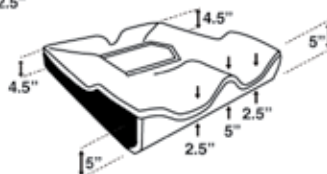
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electronic health record (EHR) documentation requirements and provided technical support to clinicians faced with migrating to electronic health records.

5. Clinical Outreach Updating Referral Sources on Medicare Wheelchair Requirements – The

CTF created educational resources (webinars, presentations and handouts) about DME and CRT policy and documentation requirements and disseminated broadly to referral sources and clinicians to replicate presentations and outreach in their organizations.

6. Led APTA, AOTA and other clinical organizations on CRT Practice Issues – CTF members have

been using the platform of the APTA and AOTA to broaden our reach and lead efforts to impact CRT-related practice issues. Members developed curriculum and six entry level modules on seating and wheeled mobility for entry level academic programs to build capacity of clinical workforce.

7. Consumer Outreach Updating United Spinal Associations (USA) Mobility Map Project – CTF is

updating USA's Mobility Map Project of resources for consumers seeking seating and wheeled mobility products and services.

2018 CTF PROPOSED ACTIVITIES

The ability of the CTF to continue to serve the important clinical role in CRT advocacy rests in the financial support we obtain from CRT stakeholder organizations this year. Consolidation and financial challenges have made it harder to raise funds. Like any other group, our ability to work on key projects is limited by donations. We will continue to be sharply focused on the top CRT priorities. To ensure CTF initiatives are focused on activities and priorities critical to protecting and promoting access to

2017 ACCOMPLISHMENTS, 2018 PRIORITIES
(CONTINUED FROM PAGE 23)

CRT, the CTF is presently completing our annual fundraising campaign and strategic planning.

**OUR PROPOSED
ACTIVITIES INCLUDE:**

- 1. Promote, Pass and Enact CRT Legislation/Regulation** – CTF members will continue efforts to gain support for key CRT legislation/regulation regarding payment for CRT wheelchair options and accessories as well as the Separate Benefit Category (SBC).
- 2. Work closely with NCART regarding state Medicaid programs response to provisions related to 21st Century Cures Act.**
- 3. Influence payers in the development of policies that ensure access to CRT –**

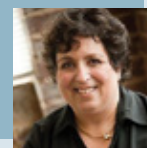
Members will utilize CTF clinical subject expertise to interpret the evidence, communicate best practices, and describe the clinical and consumer impact of proposed policies; finalize the requests for reconsideration for MWC LCD, WC seating LCD and Wheelchair Accessories LCD.

- 4. Build capacity of clinician workforce to provide skilled CRT clinical services for SWM** – CTF members will provide support to dedicated SWM clinics to justify existence and provide technical guidance for compliance with new CPT coding and reporting requirements.

CONTACT THE AUTHOR

Contact Laura at LAURA@REHABTECHCONSULTANTS.COM

Cohen is the executive director of the Clinician Task Force, (CTF) 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. The CTF provides clinically relevant information about seating and wheeled mobility device assessment and decision making to policymakers to ensure appropriate access for individuals with disabilities.



AMNESTY PROGRAM ANNOUNCED

Beginning January 1, 2018 until March 31, 2018, the NRRTS Board of Directors has approved an **Amnesty Program for awarding the CRTS® designation** to new or current Registrants who meet the following criteria:



- *Registrant or Applicant must have documented minimum of 3 years of experience providing direct service to CRT Consumers*
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HAPPY 2018!

Written by: **ALEX BENNEWITH, MPA**

ADVOCACY ALLIANCE

With a new year comes new opportunities to advocate for consumer access to wheelchairs and wheelchair technology. Thanks to wheelchair manufacturers, providers, technicians, therapists and consumers alike, advocating with coordinated messaging, we ended 2017 with a great surge in new sponsors on HR 3730. As many as 25 co-sponsors signed up just in the month of December and, as of this writing, another five co-sponsors in January, bringing the total to 82! HR 3730, introduced by Reps. Lee Zeldin, R-N.Y., and John Larson, D-Conn., provides for the non-application of Medicare competitive acquisition rates to complex rehabilitative manual wheelchairs and accessories.

United Spinal Association hopes to be able to fix the disparity in access to appropriate equipment that power wheelchair users and standard wheelchair users face regarding competitive bid products and services, and we will continue to advocate on this important issue for our members and the broader disability community. We were able, together, to obtain a favorable ruling from the Centers for Medicare and Medicaid Services last June, permanently exempting Complex Rehab Technology (CRT) power accessories used with Group 3 CRT power wheelchairs from competitive bid pricing. Now our attention is focused on wheelchair users' access to complex manual wheelchairs and accessories.

Another opportunity for improving consumer access to the right wheelchairs is refocusing our efforts on HR 750 – known as the Separate Benefit Category – that ensures appropriate payment, coding and coverage for CRT. This year, I am cautiously optimistic about what we may be able to achieve together. Stay tuned for more on that in the coming weeks and months.

“JANUARY MARKS THE LAUNCH OF UNITED SPINAL'S NATIONWIDE ADVOCACY NETWORK WITH DESIGNATED REGIONAL ADVOCACY COORDINATORS AND CHAPTER ADVOCACY REPRESENTATIVES SO THAT WE CAN STRENGTHEN OUR VOICES ACROSS THE COUNTRY AT THE STATE AND LOCAL LEVELS TO ADD TO OUR PRESENCE IN WASHINGTON, D.C., AND AT UNITED SPINAL'S ROLL ON CAPITOL HILL EVERY JUNE.”

In addition to the important issue of CRT, United Spinal will also be focusing its attention in 2018 on seat which is, incomprehensibly, a non-covered feature under Medicare, but for all users who are able to use it, medically critical. It enables users to perform their mobility-related activities of daily living. United Spinal will also continue to focus on improving consumer access for wheelchair users as it relates to competitive bidding and titanium wheelchair coding issues. In December, United Spinal and other advocacy groups, had a favorable meeting with MedPAC where Jim Mathews, executive director, stated that they will not address

competitive bidding in their March and June reports and will reevaluate their position on competitive bidding in the fall. Mathews and other MedPAC staff seemed to understand the distinction between commodity versus customizable products. United Spinal and others will, of course, continue advocating on all

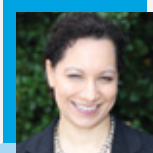
these issues both with the relevant agencies and with Congress.

For 2018, United Spinal has exciting news to share. January marks the launch of United Spinal's nationwide advocacy network with designated regional advocacy coordinators and chapter advocacy representatives so we can strengthen our voices across the country at the state and local levels to add to our presence in Washington, D.C., and at United Spinal's Roll on Capitol Hill every June. United Spinal looks forward to working more closely with wheelchair manufacturers, providers, technicians and therapists across the country on state Medicaid and other issues impacting the spinal cord injury and disorders community to make a difference for wheelchair users across the country.

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AMYOTROPHIC LATERAL SCLEROSIS

Written by: **MICHELLE L. LANGE**, OTR/L, ABDA, ATP/SMS

Amyotrophic lateral sclerosis, or ALS, “is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord” (www.alsa.org). Amyotrophic means “no muscle nourishment” and refers to the muscle atrophy that occurs in this disease. Lateral refers to the area of the spinal cord that is affected, and sclerosis refers to the scarring that occurs in the areas that degenerate.

WHAT DOES ALS DO?

ALS causes degeneration of the motor neurons. Motor neurons transmit signals from the brain to the spinal cord and from the spinal cord to the muscles. The motor neurons affected control voluntary movements and muscle control. ALS is most common in people who are between 40 and 70 years of age. It is estimated that 6,000 people are diagnosed each year, and more than 20,000 people have this disease at any given time in the United States.

WHAT TYPES OF ALS ARE KNOWN?

Two major types of ALS have been identified. Sporadic is the most common and accounts for 90 to 95 percent of cases. Familial is inherited and accounts for only 5 to 10 percent of cases. In these families, there is a 50 percent chance each child will inherit the gene mutation and may develop the disease. A third type, Guamanian, refers to a very high incidence of ALS that occurred in Guam in the 1950s. ALS was first discovered in 1869.

diseases can have similar symptoms and yet be treatable. ALSA.org has a list of clinics and specialists across the country.

When symptoms begin in the arms or legs, this is sometimes referred to as “limb onset” ALS. If initial symptoms includes speech or swallowing difficulties, this is referred to as “bulbar onset” ALS and typically displays a more rapid progression.

PROGNOSIS

More than half of people with ALS live more than three years after diagnosis. Most people diagnosed with ALS have a life expectancy of three to five years, though many people can live longer (5 percent live 20 years or more). When breathing becomes difficult, due to muscle weakness, ventilation is required. Progression may stop for periods of time (“arrests”) or the person may even show temporary improvement.

TREATMENT

Riluzole, a drug approved in 1995, has shown to prolong life by several months in people with ALS. More recent studies show this drug slows progression during the early stages of the disease. Edaravone is another drug that has shown to slow the functional impact of ALS.

RESEARCH

Research continues, much of it funded by money raised through the Ice Bucket Challenge several years ago. There have

“FINALLY, RESEARCH IS BEING CONDUCTED ON ANTISENSE THERAPY, A TYPE OF RNA THERAPY THAT PREVENTS A MALFUNCTIONING PROTEIN FROM BEING MADE, SUBSEQUENTLY PREVENTING TOXICITY IN THE MOTOR NEURONS.”

ETIOLOGY

The cause of ALS is unknown. Research is ongoing to determine what genetic or environmental factors may be involved. For example, military veterans, particularly those deployed during the Gulf War, are twice as likely to develop ALS.

PATHOPHYSIOLOGY

Onset of ALS is often gradual and initial symptoms can vary. Progressive muscle weakness and paralysis occur and early symptoms may include stiffness,

muscle cramps and twitches, as well as uncontrollable periods of laughing or crying. Sensation and cognition are not affected. There is not a definitive test to diagnose ALS. It is imperative that a possible diagnosis is confirmed by an expert, as other

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been genetic discoveries, including the discovery of two novel ALS genes (NEK1 and C21orf2). Researchers are using stem cells from people with ALS as models to test treatments. Assistive technology continues to advance, particularly in communication for people with ALS. Finally, research is being conducted on antisense therapy, a type of RNA therapy that prevents a malfunctioning protein from being made, subsequently preventing toxicity in the motor neurons. In December 2016, the first antisense therapy (Spinraza) was approved for spinal muscular atrophy.

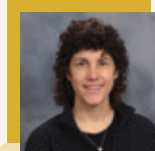
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<https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Amyotrophic-Lateral-Sclerosis-ALS-Fact-Sheet>

Lange is an occupational therapist with 30 years of experience and has been in private practice, Access to Independence, for over 10 years. She is a well-respected lecturer, both nationally and internationally, and has authored numerous texts, chapters and articles. She is the co-editor of "Seating and Wheeled Mobility: A Clinical Resource Guide;" editor of "Fundamentals in Assistive Technology" (Fourth Edition); NRRTS Continuing Education Curriculum coordinator and clinical editor of DIRECTIONS magazine. Michelle is on the teaching faculty of RESNA. Michelle is a member of the Clinician Task Force and is a certified ATP, certified SMS and is a Senior Disability Analyst of the ABDA.





POWER WHEELCHAIR ALTERNATIVE DRIVING METHODS

a decision-making hierarchy

WRITTEN BY: **MICHELLE L. LANGE**, OTR/L, ABDA, ATP/SMS
THIS CEU ARTICLE IS SPONSORED BY STEALTH PRODUCTS.

Power wheelchairs can provide functional mobility for many clients who are unable to efficiently use any type of manual wheelchair or power operated vehicle (scooter). The most common driving method is a joystick, typically mounted at the end of an armrest. However, not all power wheelchair users are able to operate a joystick. A wide variety of alternative proportional and non-proportional driving methods are available to match an individual's needs. This article will review many alternative driving methods using a decision making hierarchy to guide the team toward appropriate options to evaluate and trial.

A driving method should facilitate optimal driving control. If a client can drive the power wheelchair, but inefficiently, a different driving method may be indicated.

JOYSTICKS

Joysticks provide proportional control. Proportional (also called analog) driving methods provide full directional control in 360 degrees. Speed control is also built in: the further from center the joystick is deflected, the faster the wheelchair will move. Non-proportional (also called digital) driving methods are typically a combination of switches. Each switch represents a specific direction of movement, and speed is not generally controlled by the directional switch.

CONTINUED ON PAGE 32

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To take advantage of proportional, directional and speed control, the client must have adequate motor control to operate the joystick. Joystick control requires grading of the force and distance of movement. Without grading (balancing opposing muscle groups), the client may undershoot or overshoot the joystick handle. The client may extend and fully deflect the joystick, having difficulty “backing off” to execute a turn. Clients with increased muscle tone often have difficulty with grading.

Standard joysticks can be modified to better meet an individual’s needs. The joystick can be placed in a position that better meets the client’s need, such as in midline. The handle can be changed to accommodate a client’s hand position and grip. Finally, programming can optimize the performance of the joystick.

If a client has muscle weakness, active range of motion (travel) and force are diminished. In this case, **mini proportional joysticks** may be used, as travel and force requirements are significantly lower than those of a standard joystick. For example, a standard joystick requires approximately 250 grams of force versus a mini proportional joystick which typically requires between 10 and 50 grams of force. Mini proportional joysticks can be placed by a finger or thumb and are often used by the chin.

IF THE CLIENT DOES NOT HAVE CONTROLLED VERTICAL MOVEMENTS (THIS IS MORE DIFFICULT FOR CLIENTS WITH INCREASED MUSCLE TONE), A PROXIMITY ARRAY CAN BE PLACED UNDER THE SURFACE OF THE TRAY. PROXIMITY SWITCHES ARE CAPACITIVE SWITCHES AND ARE ACTIVATED BY A HAND ABOVE THE TRAY, BUT NOT BY THE TRAY ITSELF.

SOME CLIENTS HAVE VERY LITTLE CONTROL OF THEIR UPPER AND LOWER EXTREMITIES, BUT HAVE GOOD HEAD CONTROL. THIS INCLUDES MANY CLIENTS WITH A HIGH LEVEL SPINAL CORD INJURY, ALS, CEREBRAL PALSY, AND MULTIPLE SCLEROSIS.

FAIR UPPER EXTREMITY CONTROL

If the client is unable to use any type of joystick, but has fair upper extremity control, **switches can be placed on, or even under, the surface of a tray.** Clients with cerebral palsy, traumatic brain injury, multiple sclerosis, and muscular dystrophy often have fair upper extremity control. Any type of mechanical switch can be placed on the surface of a tray. Ideally, four switches provide control of forward, left, right, and reverse/*reset. If the client only needs to drive the power wheelchair, Reverse is selected. If the client needs to control other features using the directional switches, reset is selected. It is important to choose the switch size and force that best meet a client’s individual needs (see sidebar). The client must be able to move his or her hands horizontally and vertically to move up and over the switch surface. The switches will need to be secured to the tray (i.e. Velcro). If a full-sized tray is used, each switch must be unplugged when the tray is removed and re-plugged when the tray is placed on the wheelchair. Color coding the ends of the switch cables and the corresponding jacks on the switch interface box will improve the likelihood that the switches are connected correctly.

If the client does not have controlled vertical movements (this is more difficult for clients with increased muscle tone), **a proximity array** can be placed under the surface of the tray. Proximity switches are capacitive switches and are activated by a hand above the tray, but not by the tray itself. These switches capture larger movement and require no force. This array typically includes four switches for forward, left, right, reverse/*reset. The switches can be placed in the specific spacing and pattern that best match a client’s needs. If a solid color tray is used, the client cannot see the switches and a cue is required. Tactile cues placed above each switch location, such as loop Velcro, do not require the client to look down at the tray to determine where a switch is located. The activation distance can be adjusted and is an invisible “bubble” around the switch. If the activation area is too large, the switches may activate one another or be activated by the top of the client’s thighs. These switches may also be activated by anything conductive on the surface of the tray, such as a beverage or the family cat. The switches themselves must be protected

from moisture and are typically placed in a hollow tray with a cover. Smaller trays can be mounted on a swing-away mount for transfers. Larger trays must be removed, requiring the switches to be unplugged. The proximity array typically terminates in a single plug. A “pigtail” cable can be ordered so that the cable plugs and unplugs near the end of the tray, rather than at the wheelchair electronics – often hidden under a backpack behind the wheelchair.

GOOD FINE MOTOR CONTROL, LIMITED ACTIVATION TRAVEL AND FORCE

Clients with diagnoses such as ALS, spinal muscular atrophy, and muscular dystrophy may not be able to use any type of joystick. The large travel requirements of proximity switches (which cannot be placed close together) and the force of mechanical switches may exceed the client's



FIGURE 1: Switch-It Touch Drive 2

abilities. A proportional option is a **touch pad** (Switch-It, see Figure 1). This driving method uses the same technology as a smartphone screen. The client must have adequate movement of a finger or thumb to move within a 360-degree circle for full available directional control. The farther the finger or thumb moves from center, the faster the wheelchair moves.

A non-proportional option is to use a **fiberoptic switch array**. Fiberoptic switches capture very small movements and, as an electrical switch, require no force. A typical array contains four switches for forward, left, right and reverse/*reset. The switches can be placed in a pattern that matches the client's abilities and can be placed closely to one another. The client should be able to feel the tip of the fiberoptic switch or mount to determine location. The activation distance is a straight line from the end of the switch and is adjustable.



FIGURE 2: Stealth Products Fiberoptic Array in Hand Pad

This is matched to the client's available movement, which is typically quite small. Fiberoptics can be placed at the angle required by the client. Switches can be placed facing directly upwards in a tray or handpad (see Figure 2). A finger or thumb is then moved horizontally over the switch location. These switches can also be positioned parallel to the floor, allowing the fingers to be moved while curled over the edge of a handpad or tray in a flexed position. This latter position works well for many clients with significant weakness. The cables are fragile and

*RESET

Reset (sometimes called **Mode**) is an important power wheelchair function. Reset redefines what the forward, left and right directional switches control by changing the mode of operation of the wheelchair, providing control of reverse, speeds, power seating, IR transmission, mouse emulation, and interfaced external assistive technology devices.

need to be well-protected. Switches can be mounted in a tray, armtrough handpad or in a hollow gooseneck mount. It is critical to provide postural support of the forearm, wrist and hand to facilitate a very small movement.

GOOD HEAD CONTROL, LIMITED EXTREMITY CONTROL

Some clients have very little control of their upper and lower extremities, but have good head control. This includes many clients with a high level spinal cord injury, ALS, cerebral palsy, and multiple sclerosis. A proportional driving option is **Magitek**. This driving method uses a sensor, which is typically placed on a headband on top of the client's head. Head movement is translated into power wheelchair movement. Magitek is proportional. The client stops the wheelchair by returning to an upright and midline head position – the “neutral zone.” It is critical that the client can consistently return to this position. Very good head control is required.

Another option that is no longer commonly used is the **proportional head control** (RIM control). A posterior head pad is attached to a joystick behind the client's head. Moving the head rearward moves the power wheelchair forward. The client must sustain pressure against the back pad to sustain forward movement. This can lead to increased tone in some clients or require excessive muscle strength for others. Increased tone may impact the client's ability to stop. A reverse strategy is required. The **head array** can also be used with these clients, despite not providing proportional control. This is discussed below.

FAIR HEAD CONTROL, LIMITED EXTREMITY CONTROL

If a client has only fair head control, the **head array** is a possible driving method. Clients with fair head control, yet limited extremity control, have diagnoses such as cerebral palsy, traumatic brain



FIGURE 3: Stealth Products i-Drive Head Array

injury and high level spinal cord injury. Various manufacturers offer a head array. Three to five proximity switches are placed in a head support, often a tri-pad configuration, though various styles can be used. When the client moves their head rearward toward the posterior pad, the power wheelchair moves forward. Turning the head toward the left and

HOW DO I KNOW WHICH SWITCH TO USE AND WHERE TO PLACE IT?

An optimal switch placement is where the client has small, isolated, repeatable and sustained ability to activate and release a switch. Switches vary in size and force requirements. Any combination of switch types at any body sites at which the client has this control can be used.

right lateral pads moves the wheelchair in the corresponding direction. If the client can maintain contact with the rear pad while activating a side pad, a more subtle turn (diagonal) occurs. This can be useful in making course corrections while driving down a long hallway. A reverse strategy is required.

Newer head array options have become available in the last few years and offer novel features. The *Permobil Total Control Head Array* allows a combination of mechanical and proximity switches to be used. Sometimes when a client attempts to activate a side pad for turns, they may lose contact with the proximity switch in the rear pad to continue forward movement. The rear pad contains two proximity switches to better capture these diagonals.

The *Switch It Dual Pro Head Array* also allows mechanical and proximity switches to be combined – one of each switch type is placed in each pad. This head array has three operational modes. In the first option, the head array functions using proximity switches only. In the second option, the head array functions using mechanical switches only. If the client exerts increased force against the switch, the speed of the wheelchair will subsequently increase. In the third option, both switches are active. The proximities are very sensitive and so the wheelchair will respond quickly to head movements. The mechanical switches then allow increased speed in response to increased activation force. The speed for each switch/direction can be changed on the rear of the head array. Clients with abnormal muscle tone may experience an increase in tone if attempting to increase activation force and may then have difficulty stopping as a result. Clients with muscle weakness or decreased endurance may fatigue if using this head array in the second or third operational modes.

SOME CLIENTS WITH MULTIPLE SCLEROSIS, TRAUMATIC BRAIN INJURY, SPINAL CORD INJURY OR CEREBRAL PALSY MAY HAVE LIMITED ABILITY TO USE A HEAD ARRAY OR SIP 'N PUFF. A HYBRID DRIVING METHOD COMBINES THESE INTO A SIP 'N PUFF HEAD ARRAY. ANY PUFF IS FORWARD, ANY SIP IS REVERSE, AND THE HEAD ARRAY LATERAL PADS ARE USED FOR LEFT AND RIGHT DIRECTIONAL CONTROL.

Adaptive Switch Labs has a newer head array called the *ATOM*. This head array has several unique features. First, a “user switch” can be connected directly to the head array to turn this driving method on and off (signaled by a double beep). This allows the client to rest on the head pads without driving, changing modes, or powering off the wheelchair. If the user switch is held down for a longer amount of time (signaled by a long beep), a directional command from the Head Array can now send a wireless signal to an external assistive technology device, such as a speech generating device. This eliminates the need for an interfacing component and cable. Finally, auditory feedback can be turned on to provide an auditory cue each time a proximity switch is activated.

The *Stealth Products i-Drive Head Array* also allows mechanical and proximity switches to be combined (see Figure 3). Typically, a driving method is programmed through the specific power wheelchair manufacturer’s electronics. The i-Drive line of driving methods includes additional programming to further customize the driving experience and meet an individual’s needs. Each switch function is assigned using i-Drive programming. Stealth Products offers a wide variety of head supports and any of these can be used as a head array, allowing optimal head support and driving to be combined.

GOOD ORAL MOTOR CONTROL, LIMITED HEAD OR EXTREMITY CONTROL

If a client has good oral motor control but limited motor control elsewhere, **Sip ‘n Puff** pneumatic control is an appropriate driving method to explore. Clients with a high level spinal cord injury who lack the head movement to use a head array, may be able to use Sip ‘n Puff. This driving method requires good intra-oral pressure control, which requires good lip closure and a competent soft palate. Without a competent soft palate, air escapes out of the nose. People with ALS lose the competency of the soft palate. Sip ‘n Puff typically use four pressure controls: hard puff (forward), soft puff (right), hard sip (reverse) and soft sip (left). Various strategies for changing speed are available and vary by power wheelchair base electronics. Latch is used to sustain forward movement without sustaining a hard puff and is typically turned on by a second hard puff and turned off with a hard sip. Consider a fiberoptic “kill switch” if the client will use latch so that the wheelchair will stop if the straw moves away from the client’s mouth. Two pressure control (Q-Logic) is also available: two puffs (forward), one puff (right), two sips (reverse) and one sip (left). This may be helpful for clients who are having difficulty discerning between hard and soft pneumatic commands. A newer option is stage control on the Stealth Products i-Drive. Stage 1 only controls forward and reverse and is not latched. A softer puff moves the chair forward slowly (i.e. creeping up to a table). Stage 2 (entered via a hard puff) provides standard four pressure control with a latch option.

PARTIAL ORAL MOTOR CONTROL, PARTIAL HEAD CONTROL

Some clients with multiple sclerosis, traumatic brain injury, spinal cord injury or cerebral palsy may have limited ability to use a head array or Sip ‘n Puff. A hybrid driving method combines these into a **Sip ‘n Puff Head Array**. Any puff is forward, any sip is reverse, and the head array lateral pads are used for left and right directional control. This may be appropriate for a client who cannot discern between hard and

soft pneumatic commands, but has some head movement. This driving method is available from several manufacturers.

MOTOR CONTROL AT FOUR BODY SITES

When no other driving method meets a client’s needs, individual mechanical and/or electrical switches can be placed at whatever location the person has control. This strategy may apply to some clients with cerebral palsy, traumatic brain injury, ALS, spinal muscular atrophy and muscular dystrophy. If **four switch sites** can be identified, these can then be used for forward, left, right, and reverse/★reset. Stealth Products i-Drive and Switch-It Cool Cube interfaces allow any mechanical and electrical switches to be combined. The strongest switch site should be used for forward, as this requires the most contact. The weakest switch site can be used for reset, as this switch activation is not timed or sustained.

Movement can be quite limited in clients with diagnoses such as cerebral palsy, traumatic brain injury, ALS and spinal muscular atrophy. In these cases, only three, two or even one switch site may be identified for driving control. Full directional control is still possible.

MOTOR CONTROL AT THREE BODY SITES

If only **three switch sites** can be identified, these can be assigned forward, left and right directional control. Reverse or ★reset can be added later if another switch site can be developed. Another option is to use standby. If no switch is activated for a programmable amount of time, the power wheelchair enters standby mode. The mode of operation of the

POWER WHEELCHAIR ALTERNATIVE...
(CONTINUED FROM PAGE 35)

wheelchair now depends on which directional switch is next activated. For example, if the forward switch is activated, the power wheelchair enters driving mode. A left switch activation may select power seating control. Many power wheelchairs have such a small turning radius (particularly midwheel drive configuration) that reverse is not as critical as it once was. Many new drivers begin with only three directions of control and reverse is provided after the driver develops more competence.

MOTOR CONTROL AT TWO BODY SITES

Two switches can be used to emulate four directions and even *reset.

Two switch control (available on Q-Logic electronics) requires very specific momentary and sustained switch activations to drive. If the first switch is activated twice and sustained, the wheelchair will go forward. If the first switch is activated once and sustained, the wheelchair will turn left. If the second switch is activated twice and sustained, the wheelchair will go rearward. If the second switch is activated once and sustained, the wheelchair will turn right. If the client activates the first switch twice momentarily, a *reset command is executed.

Another two switch option that may be more intuitive for some clients is

the **i-Drive Link** feature. When both switches are activated, the power wheelchair goes forward. If only the first switch is activated, the wheelchair turns left. If only the second switch is activated, the wheelchair turns right. If the client activates the first switch twice momentarily, a *reset command is executed. Any mechanical or electrical switches can be combined.

Adaptive Switch Labs offers a **two switch fiberoptic array** that works like the i-Drive Link. If both fiberoptic switches are covered/activated, the wheelchair moves forward. If only the left fiberoptic switch is activated, the wheelchair turns left, and if only the second fiberoptic switch is activated, the wheelchair turns right.

A final two switch option is the Adaptive Switch Labs **Single Switch Scanner** with Dual Switch Step Scan. Although the product name says “single switch,” two switches are required. The client must use a scanner. The first switch moves through the available directions with each momentary switch activation – forward, left, reverse, right. When the desired direction is highlighted, the client activates the second switch with a sustained activation for as long as travel is required in that direction. The client must be able to visually monitor the display. This driving method uses a similar strategy to two switch scanning on speech generating devices.

MOTOR CONTROL AT ONE BODY SITE

Rarely, the power mobility evaluation team can only identify one potential switch site that the client has control over. It is possible to use this one switch to provide full directional control, as well as control of *reset. This is called **single switch scanning**. The first switch activation begins a scan of the available directions – forward, right, reverse and left. A second switch activation moves the power wheelchair in the highlighted direction for the duration of time switch contact is sustained. Reset can also be scanned, allowing control of other features such as power seating. This can be a very tedious means of driving and so each power wheelchair manufacturer’s electronics include strategies to increase efficiency. For example, the pattern of the scan can be changed so that reverse is only scanned every other rotation, as this direction is needed less frequently. Additional directions can be scanned – instead of only four directions, the diagonals in between can also be scanned, for a total of eight directions. The speed of the scan can be increased as the client builds competency. Scanning is typically shown on the power wheelchair display, although Adaptive Switch Labs offers an external display that may be easier to see, particularly outdoors. The MK 6i electronics require an external display at this time.

DRIVING A POWER WHEELCHAIR REQUIRES SPECIFIC SENSORY, COGNITIVE AND MOTOR SKILLS. IF A CLIENT HAS ADEQUATE VISION AND MOBILITY CONCEPTS, THE PRIMARY BARRIER TO POWER WHEELCHAIR USE IS THE DRIVING METHOD. WITH SUCH A WIDE VARIETY OF DRIVING METHODS AVAILABLE, WE SHOULD BE ABLE TO IDENTIFY A METHOD TO MATCH A CLIENT’S INDIVIDUAL ABILITIES. THIS MAY REQUIRE PROBLEM SOLVING AND PERSISTENCE, BUT IT IS WORTH IT!

CONCLUSION

Driving a power wheelchair requires specific sensory, cognitive, and motor skills. If a client has adequate vision and mobility concepts, the primary barrier to power wheelchair use is the driving method. With such a wide variety of driving methods available, we should be able to identify a method to match a client's individual abilities. This may require problem solving and persistence, but it is worth it!

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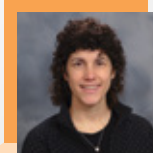
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Kelly Waugh, PT, MAPT, ATP

TUESDAY, APRIL 17, 2018

7 – 8 PM EASTERN TIME

Trends in Funding Policy and How It Impacts Access to CRT

Rita Stanley

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WEDNESDAY, APRIL 18, 2018

11 AM – 12 NOON EASTERN TIME

Seating – Using the Science of Materials to Compare Wheelchair Cushions

W. Darren Hammond, PT, MPT, CWS

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THURSDAY, APRIL 19, 2018

7 – 8 PM EASTERN TIME

Custom Molding – Stepping Outside the Molding Box

Lindsey Veety, PT, DPT, ATP/SMS

TUESDAY, MAY 8, 2018

7 – 8 PM EASTERN TIME

Ethics in the Trenches

Michele Gunn, ATP/CRTS®

THURSDAY, MAY 10, 2018

7 – 8 PM EASTERN TIME

Leaving on a Jet Plane—Hope I See My Chair Again!

Jessica Presperin Pedersen, OTD, MBA, OTR/L, ATP/

TUESDAY, JUNE 5, 2018

7 – 8 PM EASTERN TIME

You Can't Make This Stuff Up!

Lauren Rosen, PT, MPT, MSMS, ATP/SMS

WEDNESDAY, JUNE 6, 2018**11 AM – 12 NOON EASTERN TIME**

Maintaining Independence: Tips to Keep the Wheelchairs Rolling!

Tim Robinson, ATP/SMS, RRTS®

THURSDAY, JUNE 7, 2018**7 – 8 PM EASTERN TIME**

Pediatric Stander Selection for Fun and FUNction!

Katherine Clark, MOT, OTR/L, ATP and Erin Pope, PT, MPT

WEDNESDAY, JULY 11, 2018**11 AM – 12 NOON EASTERN TIME**

Wheelchair Supports:
Pull, Push, Hold and Fix

Amber Ward, MS, OTR/L, BCPR, ATP/SMS

WEDNESDAY, JULY 18, 2018**11 AM – 12 NOON EASTERN TIME**

What Happens When You Sit?
Explaining Seated
Buttocks Deformation

Sharon Eve Sonenblum, PhD

WEDNESDAY, JULY 25, 2018**11 AM – 12 NOON EASTERN TIME**

Pivot, Shift, Slide or Lift: How Transfer Techniques Impact Wheelchair and Seating Equipment Selection

Angie Kiger, M.Ed., CTRS, ATP/SMS

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TUESDAY, AUGUST 14, 2018**7 – 8 PM EASTERN TIME**

The Mat Assessment: Where to Begin?

Barbara Crume, PT, ATP

TUESDAY, SEPTEMBER 11, 2018**7 – 8 PM EASTERN TIME**

Integration of Mobile Devices with Advanced Powered Wheelchair Electronics

Emma Smith, MScOT, ATP/SMS

THURSDAY, SEPTEMBER 13, 2018**7 – 8 PM EASTERN TIME**

Cortical Visual Impairment (CVI) and How It Can Deter Power Mobility

Kihmberly Hymore, MOT, OTR/L, ATP

TUESDAY, OCTOBER 16, 2018**7 – 8 PM EASTERN TIME**

The Benefits of Dynamic Seating for Individuals With Abnormal Tone Patterns

Jill Sparacio, OTR/L, ATP/SMS, ABDA

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I'm an Advocate, You're an Advocate —
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Weesie Walker, ATP/SMS, NRRTS

Executive Director

TUESDAY, NOVEMBER 6, 2018**7 – 8 PM EASTERN TIME**

Posterior Pelvic Tilt: Causes, Challenges, and Seating Interventions

Becky Breau, MS, OTR/L, ATP

WEDNESDAY, NOVEMBER 7, 2018**11 AM – 12 NOON EASTERN TIME**

Car Seats and Vehicular Transport for Children with Special Needs

Amber Yampolsky, PT, ATP, CPST and

Erin Baker, PT, ATP, CPST

THURSDAY, NOVEMBER 8, 2018**7 – 8 PM EASTERN TIME**

Wheelchair Seating Clinics: Strategies and Methodologies for Success

Theresa Berner, MOT, OTR/L, ATP

TUESDAY, DECEMBER 4, 2018**7 – 8 PM EASTERN TIME**

Pushing for Success

Andrina Sabet, PT, ATP

WEDNESDAY, DECEMBER 5, 2018**11 AM – 12 NOON EASTERN TIME**

Providing Power Mobility Training for Children with Multiple Severe Disabilities

Lisa K. Kenyon, PT, DPT, PhD, PCS

THURSDAY, DECEMBER 6, 2018**7 – 8 PM EASTERN TIME**

Seating Considerations for Clients with Spinal Cord Injury

Jill Monger, MS, PT, ATP

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SEATED STABILITY FOR SWITCHED POWER WHEELCHAIR USERS

Written by: **JAN FURUMASU**, PT, ATP

Assistive technology is the key to unlocking a person's potential and compensating for disability. Seating and wheelchair mobility can empower children and adults with disabilities to be recognized as individuals of value and to build the self-confidence necessary to interact positively with the world at large. Powered mobility using switches can open up an entire world and potential to actively participate and interact.

Jose is a 19-year-old young man with significant physical disabilities because of Lesch-Nyhan syndrome. Lesch-Nyhan syndrome (LNS), also known as Nyhan syndrome and juvenile gout, is a rare inherited disorder caused by a deficiency of an enzyme leading to over-production of uric acid. LNS affects about one in 380,000 live births.

Uric acid increases in all body fluids, resulting in severe gout and kidney problems. Neurological signs include poor muscle control and moderate intellectual disability. These complications usually appear in the first year of life. Beginning in the second year of life, a particularly striking feature of LNS is self-mutilating behaviors, characterized by lip and finger biting. Neurological symptoms include facial grimacing, involuntary writhing, and repetitive movements of the arms and legs like those seen in clients with Huntington's disease. Infants who had previously been able to sit upright typically lose this ability. Initially, muscles have low tone, (hypotonia) which makes holding the head in an upright position difficult. Affected infants may fail to reach developmental milestones such as crawling, sitting, or walking (developmental delay). Eventually, most children with Lesch-Nyhan syndrome experience abnormally increased muscle tone (hypertonia) and muscle rigidity (spasticity). Deep tendon reflexes are also increased (hyperreflexia). Cognitive impairment may occur and is typically moderate, though some clients have normal cognitive function. Accurate evaluation of intelligence may be difficult because of poorly articulated speech (dysarthria).

Jose's sister reports there are different levels of involvement, and that Jose never demonstrated self-harming or self-mutilating behavior, even as a child. Whereas her nephew, who also has Lesch-Nyhan, is more cognitively involved and does demonstrate self-mutilating behaviors. Jose is not as involved, is cognitively age appropriate, and has never demonstrated those self-harming behaviors, allowing him to use a power wheelchair safely.

Jose is unable to sit upright secondary to extensor posturing and dystonia. His speech is dysarthric, but understandable. He has completed high school with the assistance of a one-on-one aide. He will be followed medically through California Children's Services (CCS) until age 21. Last year, Jose was hospitalized several times as he has chronic problems with kidney stones due to his high uric acid levels. Currently, Jose is doing well. He likes to play video games.

Jose postures in extension demonstrates dystonic type movement in his extremities. The extensor posturing is seen in conjunction with hip adduction and extension of

his hips, trunk and neck. He wears splints on his arms to provide stability and to reduce the dystonic type movement. Per his mother and sister, when not in his wheelchair, Jose sits comfortably in bed or on the sofa with his trunk reclined and wearing his arm splints for stability. He can play Xbox in bed using a standard controller with his right thumb if his hands and the controller are underneath a pillow to control the extraneous movement of his arms.

Jose was seen initially at the Center for Applied Rehabilitation Technology (CART) at Rancho Los Amigos National Rehabilitation Center by an occupational therapist, speech language pathologist and physical therapist. His primary goal was to try a power wheelchair. Stability in the seated posture is critical to ensure consistent, accurate access. Jose needed to sit as upright as possible with adequate stability to control a power wheelchair. In his current Kids Rock manual wheelchair, Jose sat in thoracic kyphosis and a posterior pelvic tilt with his hips sliding out of the seat. The flexibility of his legs, especially of his hip flexion and abduction, was assessed in supine. During the mat evaluation, we found Jose had significant extensor tone in his hip muscles. When his hips were flexed to 100 degrees, the persistent extensor tone and spasticity in his muscles around his pelvis relaxed. Sitting upright in his manual wheelchair, his hips are currently flexed less than 90 degrees. This leads to Jose sliding out into a posterior pelvic tilt and a windswept posture from his extensor spasticity. As a result, his seat-to-back angle was closed (the seat was wedged up past 90 degrees) to prevent his posterior pelvic tilt and extensor thrusting.

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When Jose was in a stable position, his thumb control was accurate for pushing down and coming off a switch, however he did not have the fine motor control needed to operate a small mini proportional joystick. Prior to his next appointment, we contacted the manufacturer's representative and the equipment supplier who worked with this young man at the CCS Medical Treatment Unit (MTU). We requested a non-proportional switch system to allow directional control using low force mechanical switches to drive the power wheelchair. At the time of the next evaluation, we had an Invacare Spree power wheelchair with Ultralight switches (Adaptive Switch Labs) ready and mocked-up with the required seating. A Comfort Company cushion was modified by adding a foam wedge in the front to increase the hip flexion angle to approximately 100 degrees. A foam abductor, which was positioned between his thighs, limited adduction and, subsequently hip extension. Foam wedges were also used as lateral thigh supports to keep his pelvis midline and stable. To assist in limiting extension, his knees were flexed to 90 degrees with his feet stabilized in shoe holders. Jose has poor head control and, if his neck can extend, his total body extension increases. Supporting his head in a forward or neutral position reduced extensor thrusting. A wide chest strap (Bodypoint universal strap) provided input to his chest to prevent arching or extension of his trunk (see Picture 1). Jose uses splints on his arms to maintain elbow extension, providing stability. Both arms were positioned on top of the laptray and further stabilized with a belt (see Picture 2). The laptray was short enough that he could wrap his fingers along the edge to stabilize his hand to use his right thumb optimally. He was able to use his right thumb to activate three switches and could have easily used a fourth, if needed. The three switches were placed around his thumb to allow easy, consistent, and accurate access (see Picture 3).

CONTINUED ON PAGE 42

SEATED STABILITY FOR SWITCHED POWER... (CONTINUED FROM PAGE 41)

Jose immediately understood the directional representation of the switches and could move the power wheelchair forward, right and left. Outside, he was able to use the power wheelchair to follow his sister, maneuver the power wheelchair along a wall, turn a corner, negotiate obstacles, and drive along a curving sidewalk (see Picture 4). He demonstrated good cognitive skills and physical endurance, driving the power wheelchair for 45 minutes with verbal cues and close standby assist. No hands-on assistance was needed, and he demonstrated good judgment with just verbal cues. He needed close standby assistance to go through a doorway, but demonstrated good judgment by requesting to change to indoor speed for this task.

Jose and his family live a distance from our program – more than one and one-half hours. Further practice at the local MTU was recommended as a result. The manufacturer's representative brought the same demonstration power wheelchair to the MTU for further trial and practice using the present Ultralight switches on the lap tray. Recommendations were also made for seating to optimize the stability of his body to access the switches for control of driving, as well as a power tilt-in-space for pressure relief and repositioning his body in space. The equipment supplier will work with the MTU therapists to recommend a definitive system once he received additional training. His mother and sister were pleased and pleasantly surprised at how well he did. They took pictures and video to show the therapists and supplier.

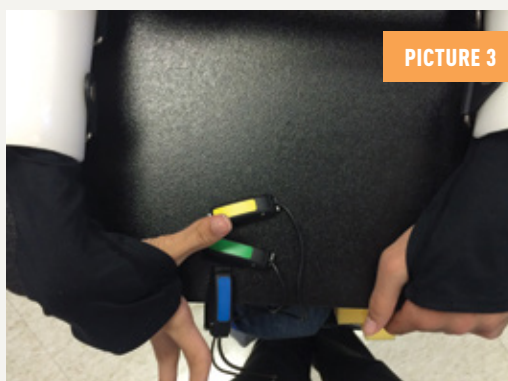
In populations with extraneous movement disorders, providing seated stability is critical to ensure energy efficient, accurate, and consistent access to switch controls. By providing consistent access, Jose was able to become independently mobile for the first time in his life, and the power wheelchair will hopefully open doors and opportunities for more life experiences.



PICTURE 1



PICTURE 2



PICTURE 3

PICTURE 1: Lateral view sitting with his hip, trunk and head in flexion to control his extensor thrusting

PICTURE 2: Arms are in splints and strapped down to the lap tray with his fingers wrapped around the edge for stability to prevent extraneous movement

PICTURE 3: Switch access using his right thumb

PICTURE 4: Demonstrating good control and safety judgment driving the wheelchair using switches with his right thumb



PICTURE 4

Jan Furumasu, BS PT, ATP is a physical therapist who has worked at Rancho Los Amigos National Rehabilitation Center since 1979. She is currently an instructor working in the Seating Center and the Center for Applied Rehabilitation Technology (CART), evaluating seating, mobility and assistive technology needs. She is also a consultant for the pediatric inpatient service and the adult spinal injury pressure ulcer management service. Since 1990, she has worked on three nationally funded research projects investigating cognitive readiness for powered mobility in young children—most recently a grant on custom wheelchair configuration, funded by the Department of Defense. She has published and presented extensively in areas including pediatric powered mobility, seating, mobility, gait and patients with muscle diseases. Furumasu was the recipient of the Excellence in Clinical Teaching Award in 1994 and the Amistad, Lifetime Achievement award at Rancho Los Amigos National Rehabilitation Center in 2008.

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MY CLIENT IS 60 YEARS OLD, WHY AM I USING A PEDIATRIC CODE?

Written by: **CLAUDIA AMORTEGUI**

It seems like lately I keep being questioned about the proper coding of specific manual wheelchair orders. I am not certain why there is a sudden increase, as these rules have not changed for more than 10 years.

The Medicare policy clearly states that if a manual wheelchair has a seat width and/or depth of 14 inches or less, it is considered a pediatric size wheelchair “and is billed with codes E1231 – E1238 or E1229” – the pediatric defined codes. As odd as it may sound, Medicare does not consider the end-users age for the coding of manual wheelchair bases, they only look at the seat size. This is the reason you may bill a pediatric manual wheelchair code for a 25, 55 or even 85-year-old client.

On the flip side, you may have a 14-year old that you will bill the same wheelchair but using the adult code, K0001 – K0009 or E1161. Again, the coding is not based on age it is determined by the wheelchair seat size. Therefore, if this client receives a 16 x 16 manual wheelchair, it will be coded as an adult code. Keep in mind, it only takes one dimension – width or depth – to be 14 inches or less, to be coded as a pediatric manual wheelchair.

Remember, that as a provider you must bill what you provide. Specific documentation, such as the delivery ticket, manufacturer invoice and even clinical documentation would support what is being billed.

The next question becomes, “Well, it’s not on the PDAC listing as a pediatric code so I cannot bill it, right?” As mind-boggling as this may sound, the Medicare Manual Wheelchair LCD (policy) does not require manual wheelchairs to be officially code verified by the PDAC. Providers are required to either use the PDAC code verification list or if not listed, use their knowledge of the policy coding guidelines to bill the appropriate code.

Therefore, if a manual wheelchair is code verified as a K0005 on the PDAC list but you are providing a 14 x 16, you will then convert it to the appropriate pediatric code (i.e. E1235) – even if PDAC does not show the equivalent pediatric code. I know this may sound a bit crazy, but I promise it is true.

The same scenario above applies to the reverse situation. If a manual wheelchair base is coded on the PDAC list as E1236 but you are providing a 16 x 16 then you must convert it to the appropriate adult code (i.e. K0005), even if the adult code is not listed on the PDAC list. I know that as providers you feel more comfortable when the code is on the list, but it truly is not required by Medicare

for reimbursement and you simply must follow the policy requirements.

Some of you may now be thinking that I made a typo in the above examples. How could both codes E1235 and E1236 be equivalent to a K0005 adult code? Realize that the pediatric manual wheelchair code definitions are not equal to the adult code definitions. The pediatric codes differ in regard to the frame type: folding, rigid, tilt-in-space and if it has seating or not. Therefore, a K0005 could equate to four different pediatric codes, with two codes being the most common: E1235 (rigid) and E1236 (folding).

If the story simply ended here, it would be great; however, there is another headache you must address. As you know Medicare places each code in a specific pricing category to determine if the item is a rental or up-front purchase. Most of the adult manual wheelchair codes are capped rentals, including the adult manual tilt-in-space. However, the K0005 ultra-lightweight code is considered inexpensive and routinely purchased, which allows it to be purchased up-front. Unfortunately, the equivalent pediatric codes are capped rentals. Meaning, you could have the exact same chair, with the exception of size and the larger size will be a purchase versus the smaller size being a rental. I wish I could tell you something to change this, but there is no way around the rule.

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AS ODD AS IT MAY SOUND, MEDICARE DOES NOT CONSIDER THE END-USERS AGE FOR THE CODING OF MANUAL WHEELCHAIR BASES, THEY ONLY LOOK AT THE SEAT SIZE.

The pricing issue is likely a reason why people want to "force" a specific code, but you simply cannot change this requirement. Again, you must bill what you provide, and then the code defines how you will be reimbursed.

This is a non-issue when it comes to power wheelchairs as those codes do require PDAC code verification, therefore it will be based on the actual model of power wheelchair provided.

As we all should know by now, common sense should be ignored when it comes to Medicare policy, especially with codes and allowables.

CONTACT THE AUTHOR

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Amortegui has a Master of Business Administration and more than 20 years of experience in the DMEPOS industry. Her experience comes from having worked on all sides of the industry, including the DMEPOS Medicare contractor, supplier, manufacturer and consultant. For many of these years Amortegui has focused on the rehab side of the industry. Her work has allowed her to understand the different nuances of complex rehab versus standard DME. This rare combination of industry experiences enables Amortegui and her team at The Orion Group to assist ATPs, referrals, reimbursement staff and funding sources in understanding the reimbursement process as it relates to complex rehab.



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Tim Robinson, ATP/SMS, CRTS®
National Seating & Mobility, Inc.
Grand Prairie, TX

Kevin Ross-Jenkinson, ATP, CRTS®
National Seating & Mobility, Inc.
Warwick, RI

Malachi Slice, ATP, CRTS®
National Seating & Mobility, Inc.
Doraville, GA

Rodger Smith, ATP, CRTS®
Medical Department Store
Venice, FL

Justin Thompson, ATP, CRTS®
HME Specialists
Albuquerque, NM

Peter R. Webb, ATP, CRTS®
Home Care Supply
Long Island City, NY

Margaret Whitworth, ATP, CRTS®
National Seating & Mobility, Inc.
Oklahoma City, OK

CURRENT NRRTS REGISTRANTS

The NRRTS board determined RRTS® and CRTS® should know who has maintained his/her registration in NRRTS, and who has not. The following individuals elected to maintain his/her registration in NRRTS.

NAMES INCLUDED ARE FROM NOV. 7, 2017, THROUGH JAN. 25, 2018.

(Please note if you renewed after Jan. 25, your name will not be listed until the next issue of DIRECTIONS.)

FOR AN UP-TO-DATE VERIFICATION ON REGISTRANTS, VISIT WWW.NRRTS.ORG, UPDATED DAILY.

Mala Aaronson, OTR/L, ATP, CRTS® Natick MA
Cyglenda Abbott, ATP, CRTS® Dunbar WV
Lydia Aceves, ATP, CRTS® Stockton CA
Alisa K Adams, ATP, CRTS® Jonesboro GA
Tracey Ashley, RRTS® Doraville GA
Jeff Auter, ATP, CRTS® Wauwatosa WI
Michael Barner, ATP, CRTS® Ann Arbor MI
William Bryan Beck, ATP, CRTS® Norcross GA
James Chad Bennett, ATP, CRTS® Doraville GA
Ralph M. Booker, ATP, CRTS® Pittsburgh PA
Curtis Boyer, ATP, CRTS® Montgomeryville PA
Roger J. Boylan, ATP, CRTS® Saginaw MI
Stephen W. Brevton, ATP, CRTS® Grand Prairie TX
Kenneth Bridge, ATP/SMS, CRTS® Mesa AZ
Carey Britton, ATP/SMS, CRTS® Pompano Beach FL
Benjamin Douglas Burton, ATP, CRTS® LaVergne TN
David Butcher, ATP, CRTS® Houston TX
David Charette, RRTS® Warwick RI
Michael Neil Coffinan, ATP, CRTS® Grand Prairie TX
Matthew Edward Convery, ATP, CRTS® Alexandria VA
Shannon Lee Cook, ATP, CRTS® Huntsville AL
Alicia Correa, RN, BSN, ATP, CRTS® San Antonio TX
Tony Cresta, ATP, CRTS® Tampa FL
Mike L. Daniels, ATP, CRTS® Valdosta GA
Gerald Dickerson, ATP, CRTS® Plainview NY
Phyllis L. Edwards, ATP, CRTS® Norfolk VA
Bob Fitzgerald, ATP, CRTS® Hudson NH
Michael Fitzhenry, RRTS® Bridgeview IL
Charles B. Fontenot, ATP, CRTS® Baton Rouge LA

Christian R. Galletta, ATP, CRTS® Bridgeview IL
Andrew Gilberti, ATP, CRTS® Charleston SC
Gary Gnal, ATP, CRTS® Owings Mills
Kenneth H. Goff, ATP, CRTS® Valdosta GA
Luis Gonzalez, ATP, CRTS® Doral FL
Raymond E. Gorneault, ATP, CRTS® Newington CT
Robbi Haase, ATP, CRTS® St. Paul MN
Rullie Hallman, ATP, CRTS® Atlanta GA
Denise Harmon, ATP, CRTS® Lombard IL
Mark Hawkins, ATP, CRTS® Santa Rosa CA
David W. Hayes, ATP, CRTS® Norcross
Tommy Wade Holley, ATP, CRTS® Woodbury GA
Stephen M. Iannazzo, ATP, CRTS® Newington CT
Rafael Ibarra, ATP, CRTS® Atlanta GA
Vann Johnson, ATP, CRTS® San Diego CA
Benjamin Jones, RRTS® Anaheim CA
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Donald V. Maulucci, ATP, CRTS® West Seneca NY
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Allen McNiece, ATP, CRTS® Martinez CA
Lester Miller, ATP, CRTS® Memphis TN
Russell L. Montoya, ATP, CRTS® Franklin TN

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Richard Ray Ottman, ATP, CRTS® Louisville KY
John Paull, ATP, CRTS® Chicopee MA
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Robert J. Shimko, ATP, CRTS® Port Charlotte FL
Jeffrey W. Shinn, ATP, CRTS® Chesapeake VA
Malachi Slice, ATP, CRTS® Doraville GA
Angela Smith, ATP, CRTS® Eugene OR
Wayne C. Smith, ATP, CRTS® Roseburg OR
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