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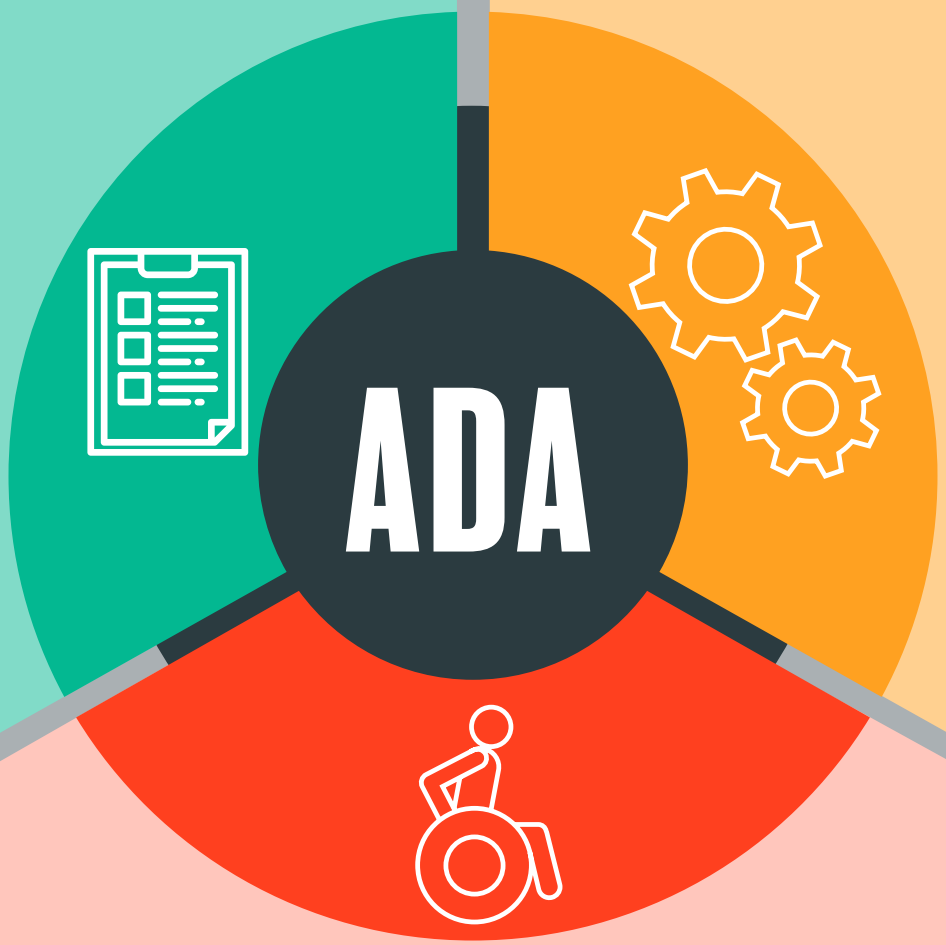

AMERICANS WITH DISABILITIES ACT 30TH ANNIVERSARY COMMENTARY

Page 40

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SO MUCH NEWS

Written by: **GERRY DICKERSON, ATP, CRTS®**

Once again, it is heartbreaking to begin my president's message with sad news.

On the morning of June 17, 2020, John Zona, a NRRTS past president, called to tell me that Patrick Meeker had died. Zona and his wife had a friendship, beyond their Complex Rehab Technology (CRT) relationship, with Meeker and his fiancée. Meeker was one of the nicest, warmest, friendliest and most genuine people you would ever meet. Anyone who knew him through his work at ROHO would agree. Most would also agree he quickly became your friend. This is another loss for all of us. In the prime of his life, 52, gone in a twinkling of an eye.

This president's message was due on June 22, so there was not enough time to properly remember Meeker in this issue. In my next president's message, we can do a tribute to him. So if you have stories, memories or laughs that you would like to share, please send them to me at gdcrts@gmail.com. We will do the best we can to include as many as possible. Space is limited, so we may not be able to get everyone included.

Happy Anniversary to the Americans with Disabilities Act (ADA)!

Wow, 30 years. Do you remember what you were doing 30 years ago?

The Hubble Space Telescope was launched. Nelson Mandela was freed from prison.

Desert Shield. The average income was around $28,000, and we were entering a significant recession.

This thing called the internet was beginning to invade our lives.

The ADA was, and remains, a significant milestone for individuals with disabilities.

As a temporarily able-bodied person, involved with the provision of mobility interventions, I always struggled with understanding the ADA and its benefit for the people I work with.

Access for all, as long as you did not walk in your home. If you did/do walk in your home but need a mobility device to access the outside world, there was, and still remains, a very good chance you would not have access to the benefits of the ADA. The in-the-home rule makes no sense. What good is the ADA if you are stuck at home and cannot participate in the outside world?

A narrow view I know, but I was fortunate to be on a Zoom meeting with our friend and fellow advocate, Jenny Siegle, just before I began writing this message. I asked her opinion of the ADA. Was it a good thing? Did she feel it met its promise? Her reply was perfect. "The ADA has meant a lot to a lot of people, but it still needs work." That is how I will view the ADA going forward. Like most things, it needs work.

The worst of the COVID-19 pandemic seems to be behind us, at least in most places. We are beginning to venture out into a "new normal." Nobody knows exactly what that is, or what it will look like, but it will be different for all us.

On behalf of myself, the NRRTS Board of Directors, and the amazing NRRTS staff, we wish you health and safety as we all emerge from this nightmare.

I'm writing this on Father's Day. A belated Happy Father's Day to all you dads! As I write this, I think of Patrick Meeker and his family. Our hearts sink thinking of how hard this Father's Day is for them. If you have a friend or a loved one you have not spoken to in a while, give them a call. Do not wait for the right time. Now is the right time. Life is so very fragile.

All the best in the "new normal,"

CONTACT THE AUTHOR
Gerry may be reached at GDCRTS@GMAIL.COM

Gerry Dickerson, ATP, CRTS®, is a 40-plus year veteran of the Durable Medical Equipment and Complex Rehab Technology industries. Dickerson, president of NRRTS, works for National Seating & Mobility in Plainview, New York. Dickerson is the recipient of the NRRTS Simon Margolis Fellow Award and is also a RESNA fellow. He has presented nationally at the RESNA Conference, ISS and the National CRT Conference and is a past board member of NCART.

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ACTIVISM IS NOT AN EASY ROAD

Written by: **ROSA WALSTON LATIMER**

Melanie Davis will head back to college this fall at the University of Nebraska Omaha with the goal of earning a degree in political science. The 30-year-old chose this course of study, because she aspires to be a leader in disability activism.

Degree, or not, Davis is already an influential activist and has no plans to slow down. "My instinct usually guides me," she said. "I believe I need to be at the table and in the room for everything possible to represent and advocate for people with disabilities."

> "I'VE ACCOMPLISHED SOMETHING THE WORLD TOLD ME I COULDN'T."

Diagnosed with cerebral palsy at age 2, Davis' "life on wheels" makes her especially capable of championing the needs of individuals with disabilities. "My approach to activism is realistic. It relates directly to my circumstances," Davis said. "I begin with my story and experiences and try to build a deeper discussion from there. I cannot access accessible features if my basic need of a wheelchair is not met." Her story was the featured in "Independence to Inclusion," a three-part documentary produced in 2014 by the Minnesota Twin Cities Public Television. (https://www.tpt.org/independence-to-inclusion/)

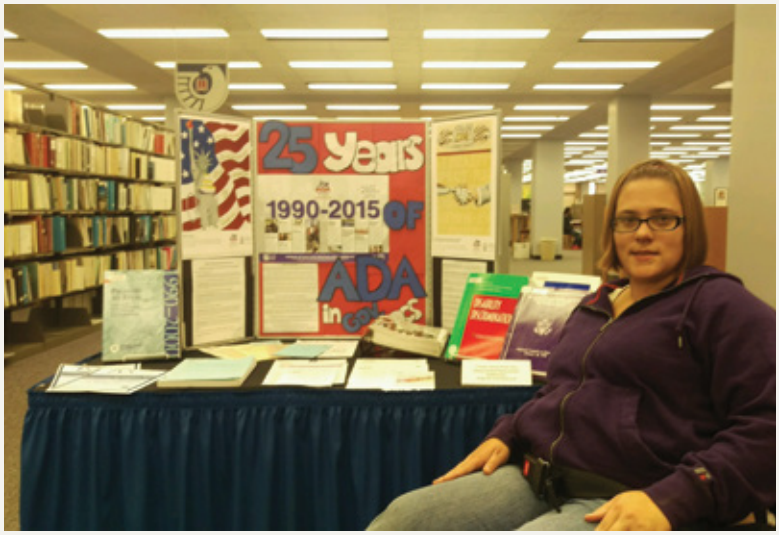
Throughout her life, Davis has experienced difficulties obtaining the equipment she needs and is currently using a loaner wheelchair. "My difficulty getting and maintaining equipment is not unique to my situation. We are slowly losing durable medical suppliers, and it is increasingly hard to get equipment and to maintain it," Davis said. "The process for me to get what I need needs to be reliable, consistent and easier to access. People do not go without tennis shoes, and for me, my wheelchair is my tennis shoes. This is absolutely not a political issue. Regardless of whether you are red or blue, surely you recognize a wheelchair is an essential item for me."

Earlier this year, while researching ways to get help obtaining her wheelchair, Davis found information about the 2020 Access2CRT advocacy summit. This annual conference, co-hosted by NRRTS and NCART, is held in Washington, D.C., and combines educational sessions and networking opportunities with Capitol Hill meetings with members of Congress and their health care staff. "The conference seemed like a perfect opportunity to get my message to legislators, and I made plans to attend," Davis said. "Unfortunately, because of COVID-19, the event was canceled, but I am hoping to attend next year."

In the meantime, Davis continues to take advantage of as many local events as possible to educate and advocate for the rights of people with disabilities. "I attended a one-day seminar at the University of Nebraska Omaha to learn more about the Fair Housing Act," Davis said. "It turned out I was the only participant who was not a realtor or property owner and the only person there with a disability. The event provided me a platform. I had the opportunity to share my personal experience finding accessible housing and helped dispel the general misconception that people with disabilities mostly live in HUD housing."

"My service dog, Chief, is a 6-year-old Weimaraner, and I volunteer with the local Weimaraner breed rescue group, Husker Weim Rescue Inc. I help with various fundraisers and take the lead at the regular PetSmart Adoption Days. (https://petsmartcharities.org/adopt-a-pet/adoption-events) I try to take every opportunity to help educate others about the responsibilities of owning a dog and the specific functions of a service dog for people with disabilities." Chief is a rescue dog trained by Davis to be her service dog. "Weimaraners are very smart, but Chief had many behavior problems and was not considered a good candidate for service dog responsibilities. I read every book I could find about dog training and took several classes. Chief helps with routine

Melanie Davis



Melanie Davis at special recognition of the anniversary of the Americans with Disabilities Act, Minnesota History Museum, St. Paul, Minnesota

daily tasks as well as in unexpected situations," Davis said. "He will find help if I become disoriented, and his presence helps me navigate street crossings as well as relieve my anxiety in stressful circumstances."

Davis is also involved with Canine Commons (https://caninecommons.com/), a group that builds indoor dog parks in the United States. Her role is as an advisor for the group's accessibility efforts. "I got involved with this group because, for the most part, outdoor dog parks aren't wheelchair accessible," Davis said. "In my experience, many cities have not been receptive to modifying existing parks. It is more positive, and efficient, to design accessible dog parks from the beginning rather than change something already in place. This is what Canine Commons does."

Davis has been a volunteer assistant at the Creighton University Rehabilitation Science Research Lab (https://spahp.creighton.edu/research/rehabilitation-science-research-laboratory), for the past three years. "I participate in physical therapy sessions with students in the Physical Therapy department as a subject for their lessons," Davis said. "I provide constructive feedback to the student groups to help them fine-tune their skills for future patients." While living in Minnesota before moving to Omaha, Davis served as a board member at SMILES Center for Independent Living in Mankato, Minnesota. (http://smilescil.org/) "This board position provided me with the opportunity to contribute the perspective of a young woman living with disabilities."

This month Davis begins work at the Munroe-Meyer Institute (MMI) University Center for Excellence in Developmental Disabilities (UCEDD) program in Omaha. (https://www.unmc.edu/mmi/center-grants/ucedd/index.html) The internship is a paid position that focuses on disability advocacy and leadership. "I have strong ties to the Munroe-Meyer Institute," Davis said. "They have many positive initiatives for those living with disabilities, especially on the inclusive side. Often a lack of awareness prevents us from treating others on an equal basis.

"We are losing dynamic leaders in the disability community. Ed Roberts, a pioneering leader of the disability rights movement, passed away in 1995. Pioneers such as those within Crip Camp need young blood to join the

Melanie Davis with a chameleon made of Legos™, Lauritzen Gardens, Omaha, Nebraska.

> "I GOT INVOLVED WITH THIS GROUP BECAUSE, FOR THE MOST PART, OUTDOOR DOG PARKS AREN'T WHEELCHAIR ACCESSIBLE"

CONTINUED ON PAGE 10

Melanie Davis and her service dog, Chief, representing Husker Weim Rescue, Inc. at Lincoln Canine Cognition and Human Interaction lab, University of Nebraska.

Melanie Davis helping with a Christmas gift wrapping fundraiser for Husker Weim Rescue Inc.

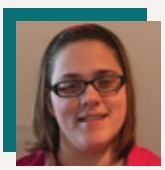
ACTIVISM IS NOT AN EASY ROAD
(CONTINUED FROM PAGE 9)

movement. We need strong disability advocates for the future. I intend to be a resource for those individuals and make a difference in their lives. I want disability rights to be as much a part of our national conversation about civil rights as Martin Luther King Jr. is."

"The Americans with Disabilities Act doesn't make us all equal. We shouldn't stop with that," Davis said. "We haven't even fully complied with the ADA, and it passed 30 years ago. Sidewalks still lack compliant curb cuts; many public buildings are not accessible. I believe those who are in a position to make a difference, such as architects and engineers, may not have a thorough understanding of the importance of universal design.

"Activism is not an easy road to choose, and my life hasn't been easy, but we all have difficulties. Some are hidden, and some are obvious," Davis said. "It is perfectly acceptable to talk about the challenges of having a disability. These discussions need to happen whenever possible."

CONTACT
Melanie may be reached at
MELANIE.DAVIS004@GMAIL.COM



Melanie Davis is a consumer activist who lives in Nebraska.

See page 41 for Davis' thoughts on the ADA.

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MEET BILL NOELTING: MUSICIAN, MARKETING EXPERT, AND PODCAST HOST

Written by: **DANETTE BAKER**

CUE THE JAZZ MUSIC.

Welcome to DIRECTIONS magazine and our profile of an industry leader.

CUE THE GUEST'S BIO.

Bill Noelting is the owner of Noelting Creative Productions in Nashville, Tennessee. He has been delivering marketing services, application development, video production and strategic planning support for more than 35 years, with a focus on Complex Rehab Technology (CRT). His consulting services have provided effective, successful and even remarkable outcomes for large and small companies. Pfizer Laboratories, Bristol-Myers, Eli Lilly, Vanderbilt University Medical Center, Diabetes Treatment Centers of America, HME Standards Association (board member) and National Seating & Mobility have benefited from Noelting's knowledge and experience.

Noelting is also a songwriter, performer and music producer for B&S Music. His collection of vintage and unique guitars is especially noteworthy.

Here's Bill Noelting.

If this introduction sounds familiar to you, it should. I wanted to give a shout out to Noelting's Talk Rehab podcast as an opener to my interview with him. Give him a listen. Undoubtedly, you'll recognize many of the individuals featured in the 17 podcasts produced to date, including CRT and durable medical equipment industry experts such as Mark Sullivan, Michelle Lange, Dr. Mark Schmeler and Weesie Walker.

Talk Rehab is one of Noelting's enterprises under Noelting Creative Productions. The organization is a mash-up of his personal and professional ventures: B&S Music; restaurant and entertainment podcast, He Said, She Said; full-service CRT marketing and consulting services; and a soon-to-launch resource management and discovery app, Decision Building.

CUE THE INTERVIEW.

YOU HAVE A BACHELOR'S DEGREE IN MUSIC AND EXPERIENCE IN PHARMACEUTICAL MARKETING. HOW DID YOU END UP WORKING IN THIS INDUSTRY?

I graduated from Indiana University School of Music in Bloomington, Indiana, with a degree in music theory and composition. From the time I was about 10 years old, I have been writing, performing and recording music. That's been the constant throughout my life; so, naturally, what I chose for a major. I was focused on being a concert clarinetist, but when I was a senior in high school, I got in a scuffle and lost the bottom of both front teeth to a soft drink bottle, which shot that career all to hell. After that, I pursued my second ideal job as a songwriter and musician. I did the rock 'n' roll road gig for a couple years, but it wasn't very lucrative. I quickly realized that, while I'm not a wealthy person, I was a really bad poor person, so that became an avocation rather than an actual vocation.

I began working for Ball Communications, doing marketing and product launches for the pharmaceutical industry. We had clients such as Pfizer Laboratories, Bristol-Myers and Eli Lilly. My responsibilities were broad. As computer technology entered the picture in the late '70s, I married technology and video, creating interactive product simulations and training tools. That eventually led to my first durable medical equipment customer, John Stevens' Surgical Supply House. Fast forward a few years, and I'm now a consultant with clients in seating and mobility. Through a friend, I met Mike Ballard and began to help National Seating & Mobility with what was supposed to be a training and education project. I later joined the company as chief information officer and vice president of marketing and worked there for 20 years. In 2017, I left and did nothing for a while before I established Noelting Creative Productions.

SO, YOU JUMPED IN WHEN THE INDUSTRY WAS JUST GETTING STARTED. WOULD YOU SHARE YOUR PERSPECTIVE?

There really wasn't a huge industry presence when I started — this would have been in the mid-'90s. There were no real national suppliers and very little organization around the industry. NRRTS was in the early stages, and there was no NCART. There was very little in the way of external marketing. Most marketing efforts were aimed toward rehab technology suppliers (RTS); they were our primary customer, not referral sources – occupational therapists and physical therapists (OTs and PTs) — or even end-users.

Every RTS was basically a stand-alone, community-based business, as they really are today. No one looked up and said, "Hey, I'm part of a national company." Instead, it was, "Hey, I'm a community-based branch office, and I know my therapists and my customers."

From the national organization perspective, we worked to give them the services and support they needed to be the best RTSs they could be. We handled the business side of being a supplier and let them do the work they love.

Today, you have two large national companies vying for mergers and acquisitions and market share. And you also have an organized industry with strong, cohesive support organizations, like NCART, NRRTS, United Spinal, MDA and others.

WHAT ARE THE POSITIVES AND NEGATIVES AS THE INDUSTRY HAS GROWN?

To me, it's a double-edged sword. One of the positives is the growth of Numotion and National Seating & Mobility and the clout they now bring to the legislation and reimbursement environment. The accessories bill is one example, and I believe the separate benefit category is going to be another because of the clout big companies can provide. That's one of the good things that happened that benefits everybody. All ships rise with the tide. These two companies also bring a new level of consistency and support for their RTSs, their referral sources and for the people who need mobility and independence.

The risk might be these large companies are more likely to lose focus than smaller independent suppliers since their ultimate business objectives might be a bit different than the smaller suppliers. Manufacturers are also stepping up their game with new products and technology.

CONTINUED ON PAGE 14

MEET BILL NOELTING
(CONTINUED FROM PAGE 13)

There's always room for improvement, but the provision of mobility seems to be serving the disabled community in a good way.

WHAT ARE SOME OF THE MILESTONES THAT HAVE MARKED YOUR CAREER?

Well, one of my greatest accomplishments was marrying my wife, Sandra, whom I love dearly. But in terms of professional achievements, I would have to say helping Mike and others round up this industry into something a little more cohesive. We actually created something pretty meaningful. I also think the work I did in software development in the pharmaceutical industry was quite satisfying, as was the work I did with National Seating & Mobility. And, the latest song I wrote, "Mexican Vampire Blues," a rock 'n' roll instrumental piece is pretty cool. So, I guess there are a number of things I consider accomplishments.

SO, LET'S CIRCLE BACK TO NOELTING CREATIVE PRODUCTIONS. WOULD YOU TELL US A LITTLE MORE ABOUT YOUR COMPANY?

As I mentioned, I'm doing marketing and consulting services and the Talk Rehab podcast for this industry. I also have B&S Music for songwriting and music production, and I also sold vintage guitars from my private collection under the B&S brand. Sandi and I have done He Said, She Said Restaurant Reviews for years as we travel.

I needed an entity to wrap all of this up, so I created Noelting Creative Productions as sort of a synthesis of all these activities. I'm not really sure how or why they all came about, I just sort of followed what I liked and what I was good at. I'm good at orchestration; I'm able to see a number of seemingly discreet things that don't make a lot of sense to other people and put them together in a well-orchestrated package. All of these things led me in one direction, and I suppose that's where I am now.

HOW DID YOU DEVELOP THE TALK REHAB PODCAST?

So, a couple of years ago, when National Seating & Mobility was on the block the last time and when Numotion sold again, I had a lot of people calling and private equity companies interested in learning more about this industry. I would set up calls and chat about the industry and answer questions about what an RTS is and the industry model and how it works. So, I did that for a couple of years, and then I decided I would start

a podcast talk show where I interview all kinds of industry people. My initial concept was to create a platform where somebody could learn about the industry and the people working in it. There are amazing people who spend their life doing things all day long that you couldn't even imagine so someone else can have independence and a better quality of life. That morphed into a broader concept where I could inform, educate, motivate, and hopefully, entertain not only industry newcomers, but everybody within the industry as well.

AND THE OTHER NOELTING CREATIVE PRODUCTIONS HOLDINGS? WHAT'S THEIR BACKSTORY?

Well, my wife and I love to travel, and we're foodies; so, as we travel and dine, we record episodes of cool places to eat, drink and hang out, each of us giving our reviews, so that's how we began He Said, She Said. With the whole coronavirus thing, we've leveraged that into a virtual café, which is currently a collection of the podcasts and cool curbside and take-out food.

The Decision Building application is especially interesting to me. It's a resource management and discovery application that I developed and recently converted to being smartphone ready. There's a demo of the app on the website. It's pretty cool, actually. By the way I'm looking for beta testers, if you're interested.

And, then there is my consulting and marketing services and music background.

LET'S TALK A LITTLE MORE ABOUT YOUR INTEREST IN MUSIC. WHAT'S YOUR GENRE? WHO ARE YOUR FAVORITE ARTISTS?

I will always turn on the jazz station and always listen to early mainstream jazz. I enjoy the likes of Charlie Parker, John Coltrane and Miles Davis. I'm also a Keith Richards guy from way back. I like listening to and playing rock 'n' roll. There's not really anybody these days who makes my socks go up and down, but I keep listening and hoping somebody will come along and do something really cool.

AND FOR YOUR CAREER IN THE INDUSTRY, WHO HAS HAD AN IMPACT ON YOUR WORK?

There are so many people from so many different directions. It would be hard for me to nail one down. John Coltrane's music always inspires me; John Stevens was my very first DME customer, so that made an impact. Jerry Velders, best software developer I ever met, friend and musician for over 50 years. Mike Ballard with whom I worked quite heavily for 20 years. Hymie, Weesie, all the RTSs, OTs and PTs that I've known throughout the years. All my friends and all of these amazing people in the DME and CRT industries. I'm fortunate to have had a lot of good role models and acquaintances in my life.

WITH NOELTING CREATIVE PRODUCTIONS BEING A RELATIVELY NEW VENTURE, WHAT GOALS ARE ON THE HORIZON?

Oh, I don't really have other goals on the horizon. I definitely see the need for value-based care models, a tweak on the seating and mobility delivery model and some bundled service models, and I'd like to have a hand in that somehow. I would like to help develop a new delivery model.

WHEN IT'S ALL SAID AND DONE, WHAT LEGACY WOULD YOU LIKE TO LEAVE FOR THE INDUSTRY?

I'd like for people to still be using some of the software that I helped create. And I'd like people to be listening to some of the music that I created. I would like to have made an impact on the lives of the people who provide and manufacture CRT and the lives of people who use wheelchairs. Mostly just be remembered for being interested.

CUE THE JAZZ MUSIC.

And that's all we have for this issue.

Bill Noelting has no doubt made a lasting impact on this industry by helping to establish its presence and value for the suppliers, manufacturers and end-users. It just goes to show when you follow your passion, work will follow. Thank you for allowing us to share your story.

CONTACT
Bill may be reached at BILL@NOELTING.COM

Bill Noelting offers marketing and consulting services for the CRT and DME industries. He established Noelting Creative Productions (www.noelting.com) in 2017. You can listen to Talk Rehab at www.noelting.com/talkrehab and He Said, She Said at www.hesaidshesaidrestaurantreviews.com/ and follow the podcasts on Facebook — Talk Rehab and HSSSRR. Noelting also has a new Facebook page in the works for B&S Music.

ASK FOR HELP AND KEEP LEARNING

Written by: **ROSA WALSTON LATIMER**

Meredith Linden was in her last year of high school with a solid plan for a future in special education when a diagnosis of rheumatoid arthritis required the teenager to participate in physical therapy. After two sessions, her condition improved, and she made a life-changing decision to pursue a career as a physical therapist. "I made that decision after I had already gotten into college to study special education," Linden said. "My mom was a special ed teacher for over 30 years. While growing up, I would go with her to her classroom and to our local recreational center, where she was responsible for programs for kids with special needs. I thought this was the work I wanted to do; however, after my experience in therapy, I could not ignore the strong feeling that physical therapy could be my career. It is a perfect fit! I can teach my patients and take on physical therapy (PT) students, and I work with individuals with special needs and disabilities. I applied to several schools that offered PT and, after I was accepted, made campus visits to decide where to go. I have never regretted my decision."

Linden chose Duquesne University in Pittsburgh, Pennsylvania, and received three degrees from the school: Bachelor of Science in Biology, Bachelor of Health Sciences and Doctor of Physical Therapy. Linden has also earned Assistive Technology Professional (ATP) and Seating and Mobility Specialist (SMS) certifications. She is currently a physical therapist supervisor in the Outpatient International Center for Spinal Cord Injury, Kennedy Krieger Institute in Baltimore, Maryland, and an ATPA credentialed clinical instructor. Linden also works in two seating clinics at Kennedy Krieger, one is for pediatric patients with developmental disabilities and the other for adults and children with spinal cord injuries.

WHAT ABOUT YOUR PARTICULAR EXPERIENCE IN PHYSICAL THERAPY CAUSED YOU TO MAKE THE CHANGE IN YOUR CAREER PLANS?

I had a great PT who thoroughly explained everything I was experiencing. She told me how the problems with my spine affected my postures and how that influenced other parts of my body. I found all of this to be fascinating, and I also improved a great deal physically. Beginning with this experience, I developed a keen interest in posture and how it affects so many other things. I had always been interested in science, but it took the personal experience for me to understand how much dysfunction in the body can completely change your function, and sometimes, small changes can make a big difference.

After I had completed my education, I began working in a spinal cord clinic. My very first patient had just sustained a spinal cord injury and was starting outpatient rehab. I was working with him when his power wheelchair was delivered. As I observed one of the other, more experienced therapists, I was fascinated with how the positioning components of the wheelchair influenced the patient's posture and how his posture directly influenced his function. This experience reminded me of how I felt when I was getting PT myself several years before. I also realized I had received the bare minimum education in college about seating and positioning. I knew if I was going to work with patients with spinal cord injuries, I needed a better understanding of the process and possibilities. It comes full circle. Posture affects everything, and the correct seating system can help complement that. I have never looked back! Now I have been doing seating and positioning for 11 years.

One of my favorite classes in college was organic chemistry, and most people hate it. The reason I loved it was because it was like solving a puzzle. In a way, that is the same approach I take when I do wheelchair positioning, especially if a patient has especially complex posture or spasticity. I like problem-solving to give them back whatever function possible.

RECENTLY, THERE ARE ADDITIONAL CHALLENGES TO TREATING YOUR PATIENTS. HOW HAS DEALING WITH THE COVID-19 PANDEMIC AFFECTED YOUR WORK?

Rather than seeing all patients in person, I am doing some in-person visits but primarily offering telehealth services. I thought I would have a

Mark and Meredith Linden

Meredith Linden (back, right) with colleagues and patients at an advocacy event in Washington, D.C.

hard time with this; however, I've learned there is a lot of value in using telehealth. I believe even if the pandemic ended tomorrow, our clinic would return to in person, but we would still offer some telehealth services. Some circumstances can be improved by the therapist actually seeing a patient use equipment in the home.

One of my patients with a spinal cord injury had a standing frame delivered to his home. We hadn't been to the house, and neither he nor his mother has suggested any concern with the equipment. During a recent telehealth visit, I asked the patient to get into the stander so I could be sure everything was appropriate for him. As it turns out, the patient didn't get into the standing frame when the company rep delivered it. Unfortunately, it was set in the shortest position, and this patient is 6' 3" tall. I was able to direct his mom on how to make adjustments. He looked fantastic in the adjusted standing frame and was, of course, much safer. Without telehealth services, this issue with this patient's standing frame may have continued, and he could have sustained an injury.

We are still doing in-person treatments in the seating clinics if the person meets specific criteria. However, with many of these patients, I am now doing a follow-up telehealth session to get a better home assessment. I believe this situation has helped me be more creative in how I'm treating patients. This newly discovered value of telehealth has surprised me and my co-workers. However, I really miss the personal interaction with my patients!

IT IS REFRESHING TO HEAR A BUOYANCY IN YOUR VOICE WHEN YOU TALK ABOUT YOUR WORK. WHAT KEEPS YOU ENGAGED?

The favorite thing about my work is, of course, the patients. Working in the Washington, D.C./Baltimore metro area, we see patients from

(l to r) Mark, Mark Jr., Aly and Meredith Linden, Cape Cod, Massachusetts.

a wide variety of backgrounds with many different stories and circumstances. Getting to know them and establishing a rapport with them is enjoyable, plus we know we can make a difference in their lives. I don't need a 'thank you' for doing my job, but when I receive affirmation I have helped a patient, it is very satisfying. The bond I have with my patients helps balance all of the paperwork and denials!

When I was growing up, my dad always told me he didn't care what I did as long as I enjoyed getting up in the morning and going to work. This work is challenging, and I feel a tremendous responsibility with my patients, but I do enjoy the work and love going to work each day.

CONTINUED ON PAGE 18

FAMILIES ARE KEY COLLABORATORS
(CONTINUED FROM PAGE 17)

TELL US ABOUT YOUR FAMILY AND WHAT YOU DO WHEN YOU AREN'T WORKING.

I am married and have two step-children, Mark Jr. and Aly. We spend a lot of fun times together, and we love playing board games. We also enjoy bike rides. I am particularly interested in long-distance riding. I try to do a 100- to 150-mile bike ride each year, but I don't compete. These are usually charity rides with friends that I do for fun. I enjoy participating in fundraising athletic events. The past few years, friends and I participated in the Swim Across America fundraiser for the Johns Hopkins Kimmel Cancer Center (https://www.swimacrossamerica.org/) and also completed the Seagull Century 100-mile bike ride to support Kennedy Krieger's hand-cycling race team.

I also have five nieces and nephews I am very close with, and all of my family goes to Cape Cod every summer. These times are very special to me. My grandparents lived on Cape Cod, and growing up, I spent summers there with them. Cape Cod is the one place where I can count on seeing my family all together. I love sharing this with my husband and step-children.

Eleven years ago, our social work department at Kennedy Krieger Institute announced the fund used to help patients and their families with various needs not covered by insurance, was depleted due to the poor economy. A friend and I organized a fundraiser, Dining for Dollars, to help raise money for this need-based fund. The first year the one-night event raised $1,800, and now we average approximately $10,000 each year. This event is near and dear to me! It has been wonderful to see the fund grow.

(l to r) Meredith Linden, Kaitlin Hagen, and Lauren White at Kennedy Krieger Institute Dining for Dollars fundraiser event.

Meredith's Puggle, Jackson, and her Great Dane, Maggie.

Meredith Linden (standing left) with the Seagull Century Kennedy Krieger Institute 100 miler team.

WHAT ADVICE WOULD YOU OFFER TO SOMEONE JUST BEGINNING ON THE CAREER PATH OF A PHYSICAL THERAPIST?

Remember you do not have to know everything. You need to be willing to look for answers, and you will succeed. Do not be afraid to ask for help. My favorite thing about Kennedy Krieger is the constant support for ongoing learning and growing professionally. I take advantage of this attitude, and after 12 years, I learn something new almost every day.

If you are open to learning and are willing to step back to realize what you do not know, you will be successful. Look for a place to work that strongly supports learning and growth. Do not let the paperwork get you down, focus on what you are doing for your patients, and you'll wake up every day looking forward to going to work.

CONTACT
Merideth may be reached at
LINDENM@KENNEDYKRIEGER.ORG

Meredith Linden, PT, DPT, ATP/SMS is a clinical specialist at the International Center for Spinal Cord Injury at Kennedy Krieger Institute in Baltimore. She received her Bachelor of Science and Bachelor of Health Sciences in 2006 and her Doctor of Physical Therapy in 2008 from Duquesne University in Pittsburgh. She specializes in treating clients with a variety of paralyzing neurological conditions and has specialized in seating and mobility for 10 years. Linden has been a certified ATP since 2011, and a certified SMS since 2015. Areas of interest including seating and mobility, serial casting, pediatrics and aquatic therapy.

DUCHENNE MUSCULAR DYSTROPHY

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

DEFINITION

Duchenne muscular dystrophy (DMD) is a rare genetic disease that primarily occurs in males. Progressive muscle degeneration and weakness occur due to changes in a protein called dystrophin, which keeps muscle cells intact. The disease primarily effects skeletal muscles.

ETIOLOGY

DMD is X-linked recessive and inherited from the mother. In about 25% of cases, the disease occurs spontaneously without any family history. A mutation in the dystrophin gene can be detected through genetic testing. Dystrophin is a protein that stabilizes and protects muscle fibers. Genetic mutations alter the function of dystrophin or prevent its production completely. Duchenne and Becker muscular dystrophies are sometimes classified as dystrophinopathies.

PATHOLOGY

Proximal muscles are affected first and experience progressive weakness and loss of muscle mass (atrophy). The condition then progresses to the distal limb muscles and finally the heart and respiratory muscles. Cardiomyopathy develops as the cardiac muscle weakens and then later enlarges.

Early signs and symptoms may include:

- Frequent falls.
- Difficulty getting up from the floor. Referred to as Gower's sign or maneuver — the child uses their hands to 'walk' up their body to stand.
- A waddling gait.
- Enlarged calf muscles, which can lead to toe walking. Pseudohypertrophy occurs, in which muscles become enlarged with deposits of fat and fibrous tissue.
- Muscle pain and stiffness.
- Learning disabilities.

As the disease progresses, the child will have difficulty walking, lose motor skills due to progressive weakness, and develop contractures and spinal asymmetries (lordosis and scoliosis). Eventually, breathing and heart problems, along with difficulty swallowing can occur.

PROGNOSIS

Life expectancy has increased due to medical advancements in cardiac and respiratory care, with survival into the early 30s being common.

INCIDENCE

DMD is the most common form of more than 30 types of muscular dystrophy and has a prevalence of 1 in in every 3,500 – 5,000 newborn males worldwide. Between 400 and 600 boys are born with this disease each year in the United States. The average age of diagnosis is five years and 90% of children require a wheelchair by age 15.

TREATMENT

While there is no current cure, some medications and therapies can manage symptoms and slow the disease. Three medications approved by the Food and Drug Administration are available for people with DMD – Eteplirsen (Exondys 51), Deflazacort (Emflaza, a corticosteroid), and Golodirsen (Vyondys 53). Corticosteriods are commonly used to delay progression, though prolonged use has other side effects including weight gain and weakened bones.

Becker muscular dystrophy is caused by a mutation on the same gene and has very similar signs and symptoms, yet differs in severity, age of onset and progression. In most cases, age of onset is later, and progression is slower.

CONTACT THE AUTHOR

Michelle may be reached at
MICHELLELANGE1@OUTLOOK.COM

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Michelle Lange is an occupational therapist with over 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 NRRTS DIRECTIONS magazine. Lange is a RESNA Fellow and member of the Clinician Task Force. She is a certified ATP, certified SMS and is a senior disability analyst of the ABDA.

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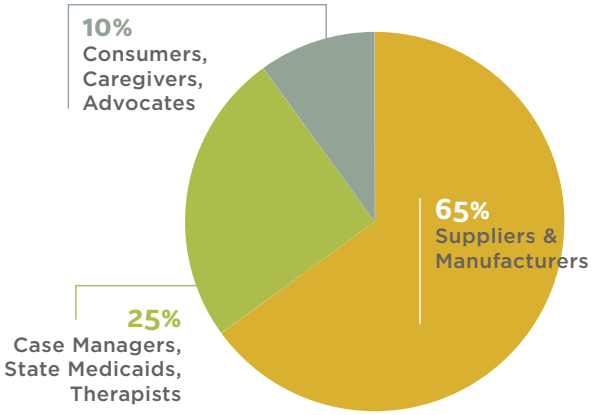

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MALA AARONSON: OPEN TO NEW POSSIBILITIES

Written by: **ROSA WALSTON LATIMER**

"I am a spiritual person and believe everything happens for a reason," Mala Aaronson said. "This is true throughout my personal and professional journey. I find peace in knowing a greater power directs my path. As long as I am open to opportunity, I believe I am cared for." Acknowledging she has experienced "hills and valleys," Aaronson is acutely aware that, at pivotal moments in her life, she is presented opportunities or information to guide her course. "This is usually something I don't seek," Aaronson said. "I try always to be open to these new possibilities."

Aaronson's approach to life has guided her career for more than 35 years. "Whether you are a believer or not in faith, it is difficult not to recognize the direct connection between challenging situations that turned into blessings and directed my path from the time I was 16 years old until today," Aaronson said. A passion for training and showing horses filled life throughout her childhood and teenage years. "Working with horses was my sport, my focus, my serenity," Aaronson said. "If I wasn't in school, I was at the horse barn. It was always my plan to continue training or teaching as a career.

The summer before Aaronson's senior year of high school, a couple of hours after qualifying for national equestrian finals, she and her horse were in a freak jumping accident. Aaronson broke her back, but, miraculously, she suffered no paralysis. "I realized because of the injuries from that fall, working with horses wasn't going to be my future," Aaronson said. "After graduation, I went to college because that was the thing to do, but I had no idea what my future would be."

During Aaronson's freshman year at college, her boyfriend was driving up to visit her and was involved in a tragic automobile accident. "Bruce suffered a severe brain injury and was in a coma for about nine months," Aaronson said. "For a while, I stayed in school and spent as much time visiting him in the hospital as I could. Then, I decided to take time off from school and support him in his rehabilitation. As difficult as this time was for both of us, I found myself appreciating the work of Bruce's therapists and nurses and decided I would go to nursing school."

Very soon after making this decision, Aaronson met a woman in a social setting who was director of nursing at a rehabilitation facility specifically for young adults with brain injuries. Aaronson expressed her plans for attending nursing school. The nurse told Aaronson it would be a good idea to know, before starting nursing school, whether she would enjoy taking care of someone she didn't love and invited Aaronson to tour the rehabilitation facility. "I was familiar with physical therapy but was not familiar with occupational therapy," Aaronson said. "At the end of the tour, I was fascinated. The nurse offered me a job as a nurse aide, and I accepted immediately. That is when my love for occupational therapy was born. I was accepted into the OT program at Boston University and received my degree in 1985."

The majority of her time as an occupational therapist, Aaronson has been a Registrant of NRRTS serving the organization as a review chair, board member and member of the ad hoc task committee for the ATP test validation. She was also was a principal author of the seating and mobility certification exam. Aaronson is a member of RESNA. She is currently a Certified Rehab Technology Supplier® (CRTS®) with National Seating & Mobility and is a member of the company's Product Advisory Council. She is also an adjunct professor of seating and mobility in the Doctor of Physical Therapy program at Northeastern University in Boston, Massachusetts. "Teaching and sharing information is important to me," Aaronson

Mala Aaronson with Noah.

said. "I enjoy helping these new physical therapists gain awareness and some understanding of the seating and mobility aspect of treating their patients."

After earning her degree, Aaronson worked seven years with a neurological population of children and adults with brain injuries at New England Sinai Hospital. "I was immediately drawn to seating and mobility, although there wasn't much commercially available at that time," Aaronson said. "During my first year or so at Sinai, 'custom seating' meant making friends with the maintenance guys, and after hours, using their tools and wood to make wheelchair backs and seats. I wasn't aware there were more options available, so I did much of my own fabrication." Aaronson discovered a wheelchair supplier who had a physical therapist, Susan Hallenborg, on staff, and she came to New England Sinai to help start a wheelchair clinic. "Susan became my long-time mentor and has been a very positive influence on my career."

As much as Aaronson enjoyed her work at the hospital, she decided to move to the seating and mobility industry and transitioned with a small custom seating company, and then, eventually, a larger supplier called Atlantic Rehab, which was acquired by National Seating & Mobility. "I have a wide variety of clientele and am involved with custom seating for clients of all ages and disabilities," Aaronson said. "My youngest client was 4 months old, and my oldest client was 104 years. I've pretty much touched all of the populations we serve in our industry. The diversity of my clientele keeps me interested and challenged." Aaronson treasures the long-term relationships she often develops with her clients and their families. "I've known some of my clients since they were just a year or two old. I've watched them grow and could be an effective part of their mobility, social and cognitive development," Aaronson said. "This continuity of care is

Mala Aaronson getting cozy with Shimbi and Callie.

The Aaronson family: (l to r) Jeremy, Corina, Mala and Jay.

beneficial to the clients and for me as I am better able to understand an individual's needs and personal circumstances."

After 25 years as an Occupational Therapist, Aaronson experienced a personal connection with a client on a deeper level than ever before, or since. The situation would again bear witness to her faith and belief that everything happens for a reason. "About 10 years ago, I developed a strong interest in early intervention and worked with some physical therapists that specialized in this. These therapists were contracted with the state to treat children with special needs who were in

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MALA AARONSON
(CONTINUED FROM PAGE 23)

medical foster homes," Aaronson said. "When I would go to the home for the evaluation, instead of talking about things such as range of motion and spasticity, I would learn through my hands what the child needed as opposed to doing a typical mat evaluation. I made this type of visit several times a month. I love children and thought they were all adorable, but I never wanted to take one home."

One particular visit to the medical foster home was very different. "I went into the home to do an evaluation as I had done many times before," Aaronson said. "They introduced me to this adorable little boy named Noah. I sat on the floor with him in my lap, and when I looked into that sweet face, I felt an immediate, strong bond with this 9 month-old boy." Aaronson said. "The feeling was emotionally overwhelming. I had never experienced this before. Ever."

Aaronson completed her evaluation and wrote up an order for a supportive seating system for the child. Noah had been admitted to the hospital as a "shaken baby" when he was 3 months old and had suffered a brain injury. There was also evidence of previous abuse. "I left the foster home, got into my car and burst into tears," Aaronson said. "I didn't understand why I was affected so strongly by this baby or what these feelings were. I knew this baby had captured my heart, and I was committed to caring for him on a deeper level than I had ever felt about a client. Without question, I believed this experience was placed in my path for a reason."

During the next few months, Aaronson continued to help with Noah's treatment as she would her other clients, but the personal bond grew stronger. Soon, as improbable as it seemed to her, who was 50 years old, she was certain she wanted to adopt Noah. Almost 1 ½ years later, Aaronson and her husband completed all of the training, paperwork and other requirements, and the adoption was approved. The couple was preparing a room to bring the boy home. "At that point in this experience, we realized adopting Noah was not the path we would travel," Aaronson said.

Noah continued to live in the foster home, and Aaronson continued to spend time with him. Eventually, the Massachusetts Department of Children and Families was successful in finding another family for him. "I am beyond blessed to have had such a loving, open and secure adoption for Noah," Aaronson said. "When you are adopting a child who is almost 3 years old who has developed a

The Propel DR team and special patients in the Dominican Republic.

bond with someone else, whether it be a foster parent or biological parent, it can be very threatening to continue to have that person in their life. The adopted parents want to and need to develop their parental bond with the child. From the beginning, Noah's adoptive family has honored my relationship with him. His family is very active and takes several vacations a year that are not always enjoyable for Noah. So, he gets to spend time in the room we prepared for him in our home with all of his special needs equipment."

Aaronson emerged on the other side of this complex situation, realizing that the experience, as a whole, was a blessing for everyone involved. "Noah is now 8 years old. I am so very grateful I was open to the possibilities of having this relationship with him," Aaronson said.

Aaronson and her husband, Jay, have been married 27 years and have a daughter, Corina, 24 years old, and a son, Jeremy, 21 years old. "Jay has always been incredibly supportive of my career, and when our children were young, he always stepped in with family responsibilities when I was traveling," Aaronson said. "Corina has just completed her DPT education and graduated from Northeastern University. She is very interested in pediatric physical therapy and excited about her future. Jeremy just completed his junior year at the University of Massachusetts Amherst and is a great student. He is passionate about his membership in the Student Force of the Amherst Fire Department. Jeremy has endured tough training drills and devotes many hours each week to help keep the community safe. I am so proud of both of them!" The family loves to be outdoors and enjoys biking, hiking

Mala Aaronson with her dad, Ralph, and brother, Dave.

Mala Aaronson with her mother, Sharlene.

and kayaking. "Whenever possible, I'm on a beach at the ocean," Aaronson said. "I usually have the dogs, Shimbi and Callie, with me. My soul rests at the sea. That is where I find my peace." Aaronson takes the opportunity of being outdoors to enjoy another hobby, photography, and when confined to the indoors, she enjoys refinishing furniture.

"About five years ago, a situation became available to me that allowed my participation in the mission work of some of my NSM (National Seating & Mobility) colleagues and Mission Emanuel in the Dominican Republic," Aaronson said. She is part of a team known as Propel DR (https://www.propeldr.com/) that travels to that country each October to work in a temporary clinic to distribute wheelchairs as well as educate local health care suppliers. "This experience has had a tremendous impact on me personally and professionally," Aaronson said. "During the week we hold the clinic, you have children with needs, and you work with what you have to meet those needs. None of the equipment is specifically designed for the children we are trying to help. We have to be creative! Yet, our efforts will make a huge difference for the child and their families. Many parents have carried their disabled child over their shoulders for the child's entire life. The work I've done on these trips has taught me to let go of perfection. I am also more appreciative of what we are capable of doing for our clients in the United States." Propel DR has also helped raise awareness in the Dominican Republic of the availability of assistive technology. Now, to some extent, funding is available in the country's health care coverage for custom wheelchairs.

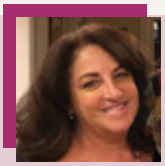
For many years, Aaronson has personally sponsored a girl who lives with her family in Brazil. "I connected with her through the Christian Children's Fund when she was 3 years old," Aaronson said. "She is now 16 years old and an excellent high school student. We correspond regularly, and I hope to support her college education."

Aaronson's propensity to help others doesn't stop with her clients and children in the Dominican Republic and Brazil. Her ongoing commitment to Project Thrive! (https://projectthrivelocal2global.org/), a small animal sanctuary in Colorado for neglected, abused and abandoned farm animals, pays for the feed and medical care of a goat and a sheep. These responsibilities outside of her work and immediate family are especially meaningful to her. "I try to remember we can always do something to help, even if it seems small," Aaronson said. "Life moves so fast. We never know when our kindness will make a difference in another's circumstances."

During a career that covers over three decades, Aaronson has experienced many changes in the industry. At the same time, many things are the same. "As ATPs, there is always much demand for our time. It seems as though we are always in a race to finish paperwork and get technology to the client as soon as possible," Aaronson said. "I've learned it is important to take the time to see each of our clients as a whole person. Take into account the client's surroundings, self-perception and goals – not just their position in a wheelchair or their mobility needs. We are often in a rush and lose sight of who they were before their disability or how they hope the world sees them. After considering all of these dynamics, we are then equipped to advocate for what is best for the client and to think outside the confines of funding restrictions."

CONTACT

Mala may be reached at
MAARONSON@NSM-SEATING.COM



Mala Aaronson ATP, CRTS® is a NRRTS Registrant who works for National Seating & Mobility in Natick, MA. She has been a Registrant since 1994.

CRT AND COVID-19

Written by: **DON CLAYBACK, EXECUTIVE DIRECTOR OF NCART**

While most COVID-19 policy changes and clarifications have been received, the challenges of evaluating, recommending, assembling, fitting, training and maintaining Complex Rehab Technology (CRT) continue. Operational, financial and safety issues present major hurdles for CRT suppliers as they work to supply timely and professional services to the children and adults with disabilities who depend on CRT.

On the plus side, the dedication and commitment of the clinicians, suppliers, manufacturers and others involved in the CRT provision process has been evident across the country. It is this dedication and the ability to be flexible and creative that will be the foundation for providing quality products and services to people with disabilities in the months ahead.

CRT MANUAL WHEELCHAIR ACCESSORIES

As we know, there was a big win for CRT access last December when Congress passed legislation to do two things: (a) provide an exemption from the Medicare Competitive Bidding Program (CBP) for CRT manual wheelchairs and accessories; and (b) provide an 18-month suspension of Medicare inappropriately applying CBP payment rates to CRT manual wheelchair accessories from Jan. 1, 2020, to June 30, 2021.

While it took some time, the July 1 Medicare Fee Schedules reflected these new payment rates and suppliers are able to use the KU modifier when billing CRT manual wheelchair accessories for dates of service July 1 and after. For previous claims submitted from Jan. 1 to June 30, suppliers can resubmit for retroactive payment adjustments through a streamlined resubmission process. Additional details and instructions can be found at https://www.cms.gov/Center/Provider-Type/Durable-Medical-Equipment-DME-Center.

MEDICARE COVERAGE OF POWER SEAT ELEVATION AND STANDING SYSTEMS

Members of the ITEM Coalition (a national organization of consumer, disability and clinician groups) have been meeting with the Centers for Medicare and Medicaid Services (CMS) over the past 18 months to establish Medicare coverage of power seat elevation systems and power standing systems used with CRT power wheelchairs. Unfortunately, these systems are currently classified by Medicare as non-covered.

ITEM workgroups developed a formal "Request for Reconsideration of the National Coverage Determination for Mobility Assistive Equipment" that will be submitted to CMS as the next step in this initiative. The request presents the basis and evidence to support the coverage of these items as a Medicare benefit and will require a formal review and decision by CMS. The objective of this work is to get Medicare beneficiaries the same coverage of this specialized equipment as others with disabilities already have through many Medicaid and commercial insurance plans across the country.

REMOTE SERVICES OPTIONS

There is no doubt that appropriate and effective use of telehealth and other remote services can

play an important role in maintaining needed access to CRT. While not applicable to all situations, these options can be used for needed evaluations and consultations and reduce the need for in-person encounters. During the COVID-19 pandemic, Medicare and many Medicaid and commercial insurance plans permitted the use of telehealth (clinician based) and other remote services (CRT provider based).

NCART published its "COVID-19 Advisory — Use of Remote Technology Required During Pandemic to Protect People with Disabilities Access to Needed Complex Rehab Technology." This outlines the basis and application of telehealth and other remote services in relation to CRT. It also includes a decision tree developed by the Clinician Task Force to provide clinical guidance on the triaging of CRT clients when using remote technology. You can obtain a copy at www.ncart.us.

A consortium of CRT stakeholder organizations has been formed and will be working on making the current availability of telehealth and other remote services permanent options after the current Public Health Emergency expires.

STATE CRT LEGISLATION

Over the years, passing legislation at the state level has been an important component of establishing recognition that CRT represents specialized equipment and requires focused safeguards and policies. Seven states already have passed CRT related legislation: Colorado, Connecticut, Illinois, Oklahoma, Tennessee, Washington and Wisconsin. The good news is that new CRT legislation has been introduced in the state of Michigan in the form of Senate Bill SB855. Passage of this bill will provide benefits to both Medicaid recipients with disabilities and to the Medicaid program.

You can get more information on the bill and how to help with passage at www.protectcrt.org. Should you wish to pursue CRT legislation in your state, please contact NCART as we have a variety of strategies and tools that will assist in that effort.

NATIONAL CRT AWARENESS WEEK

The close of the Americans with Disabilities Act 30 Year Anniversary Campaign at the end of July will roll right into our annual National CRT Awareness Week, which will be Aug. 10-14. This initiative is designed to create opportunities for suppliers, manufacturers, clinicians and consumers to collectively share and promote with policymakers the importance of CRT access and the need for supporting regulations and policies. It will include a grassroots advocacy event for Congress to highlight the issues and needed solutions. Be sure your organization takes part in the August activities.

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CRT AND COVID-19
(CONTINUED FROM PAGE 27)

NCART MEMBERSHIP

During these challenging times it is critical to have an effective national CRT industry association. If your organization provides or manufactures CRT and is not yet an NCART member, please join to support our important work. We are exclusively focused on CRT advocacy at the federal and state levels and have a proven record of leading and collaborating with others to protect access and secure needed policy changes. More NCART members are needed to keep up the good fight. Check out the membership area at www.ncart.us for details or please contact us to set up a conversation.

LOOKING AHEAD

It is hard to predict the future, but we know CRT access challenges will continue. The COVID-19 pandemic will have a major impact on federal and state budgets that government officials will need to address. And the new protocols and challenges will necessitate renewed advocacy, creativity and collaboration.

The CRT access issues ahead include: (a) continued limited access to evaluation and deliveries due to closure of schools, facilities, workshops and health concerns; (b) higher operating costs and lower productivity for suppliers; (c) potential state Medicaid budget cuts; and (d) decreased CRT manufacturer and supplier revenue as we move through the summer and fall.

The needed solutions include: (a) increased federal support to avoid state Medicaid program cuts; (b) additional CRT/DME Supplier Relief Fund payments; (c) expansion and permanency of Medicare, Medicaid and commercial payer policies allowing telehealth for physical/occupational

therapists and remote services for CRT suppliers; (d) making permanent the "temporary" Medicare CRT manual wheelchair accessory payment policy; (e) a one-year delay in the upcoming Medicare Competitive Bidding Program; and (f) Medicare coverage of power seat elevation and standing.

NCART and the other dedicated industry organizations are here for you and will continue to work hard to ensure people with disabilities have timely access to CRT and the needed supporting services. If you have not already done so, get signed up to receive CRT Alerts at www.access2crt.org. This will ensure you receive timely updates on issues and actions that impact the availability and provision of CRT.

CONTACT THE AUTHOR
Don may be reached at
DCLAYBACK@NCART.US

Don Clayback is executive director of NCART. NCART is national organization of Complex Rehab Technology (CRT) suppliers 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. Clayback has more than 30 years of experience in the CRT and Home Medical Equipment industries as a supplier, consultant and advocate. He is actively involved in industry issues and a frequent speaker at state and national conferences.

ENTER THE RESNA UNIVERSE

Written by: **MARY ELLEN BUNING, PHD, OT, ATP/SMS, RESNA FELLOW**
PRESIDENT, RESNA

The RESNA conference has been an annual event for going on 40 years. This year, the COVID-19 pandemic nearly upset our plans. But thanks to our volunteer leadership and supporters, RESNA 2020 will take place virtually on Sept. 23–24.

With the theme "Enter the RESNA Universe," the virtual experience will reflect on 40 years of RESNA conference history, love of technology and deep belief in human potential. Many Assistive Technology Professionals (ATPs) remember their first RESNA conference fondly, as a time when they discovered other like-minded professionals engaged whole-heartedly in making the world a better and more inclusive place through technology. At RESNA, it didn't – and still doesn't - matter whether your interest is wheelchairs, communication, computer access, job accommodations or any other assistive technology – you belong. It's no accident that for many years, RESNA's conference logo paid homage to the television show "Star Trek," with its takeoff of the Starfleet Federation insignia. Like the voyagers on the Starship Enterprise, RESNA members were – and are today – a part of something bigger.

It's that spirit of discovery and limitless potential that we hope to capture on Sept. 23–24, along with having some fun. RESNA 2020 will include:

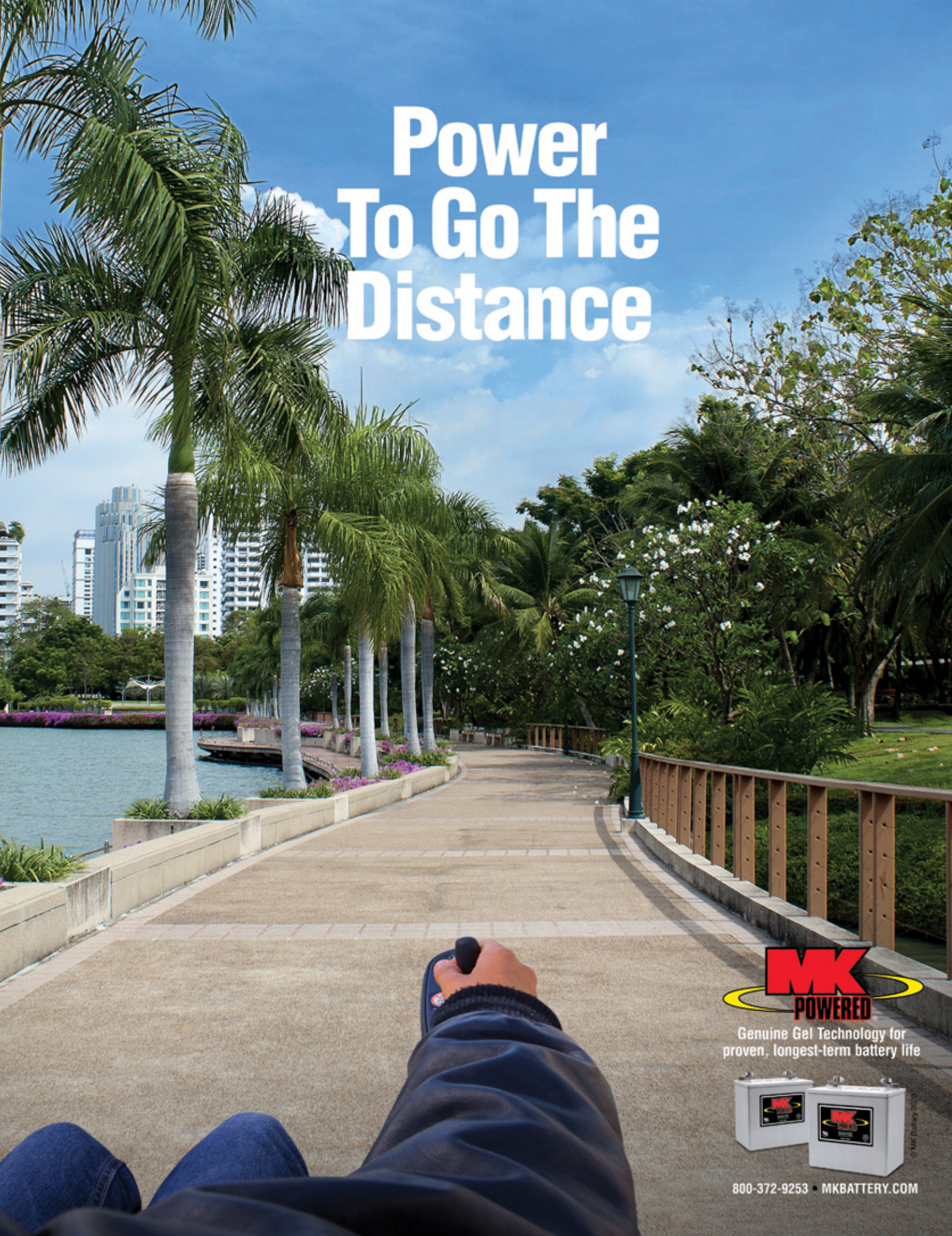
- Keynote lectures from prominent assistive technology thinkers and leaders.
- 20 continuing education sessions on a wide range of assistive technology topics, available live and on-demand.
- Interactive scientific paper platform sessions and poster hall.
- The Student Design Challenge and Student Scientific Paper Competition.
- Virtual exhibit hall, with the ability to offer product demonstrations and one-on-one meetings.
- Opportunities to meet, network and exchange information with other like-minded professionals.

Plus, there's one decided advantage of attending RESNA 2020. If you've ever been to the RESNA annual conference, you know from experience there is usually several competing sessions at once. Realizing you can only be in one place at one time can make for some agonizing decisions. With the virtual experience, you can have it all. Registered conference attendees can experience every session on demand after its initial debut – and receive CE credit, too. This time we can say with certainty that you can earn 2.2 CE – because you can attend all the sessions if you want. If, before clicking on the recording link, you say to yourself "beam me up, Scotty" – be assured you won't be the only one.

Please join us on this initial voyage into the RESNA Universe, and (apologies for the one last Star Trek reference), "boldly go where no assistive technology pro has gone before." Visit www.resna.org to learn more.

CONTACT THE AUTHOR
Mary Ellen may be reached at
ME_BUNING@MAC.COM

Mary Ellen Buning is an occupational therapist with a specialty in assistive technology. She is an experienced educator and presenter and has a strong commitment to the use of the internet and telecommunications to improve practice, conduct survey research and disseminate research findings. She is particularly interested in wheelchair transportation safety for those who must sit in wheelchairs during motor vehicle travel. She holds a master's degree in occupational therapy from the University of Colorado, and a PhD in rehabilitation science from the University of Pittsburgh. Buning is a recipient of the RESNA Fellow Award, the organization's highest honor, in recognition of her service to RESNA and the field of rehabilitation engineering and assistive technology.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STAYING THE COURSE: SERVING CLIENTS WITH COMPLEX NEEDS DURING COVID-19

Written by: **AMBER WARD, MS, OTR/L, BCPR, ATP/SMS, FAOTA**

NAVIGATING UNCHARTED WATERS

The impact of the COVID-19 pandemic is far-reaching, touching nearly every aspect of our professional and personal lives. The pandemic has also carved out unprecedented challenges across health care systems, legislative and regulatory bodies, and national and state economies. Users and other stakeholders of Complex Rehab Technology (CRT) have also been directly impacted. Despite the challenges clinicians, suppliers, manufacturers, supporting agencies and advocates continue to respond. In collaboration with industry partners, the Clinician Task Force (CTF) is forging ahead and navigating these uncharted waters based on its mission-driven work: to ensure individuals with complex needs have access to the CRT equipment and supporting services they need. The aim of this article is to highlight CTF's role in co-hosting a series of CRT industry COVID-19 webinars and publishing a CRT Decision Tree to help clinicians and suppliers navigate challenges in the current environment.

CRT INDUSTRY COVID-19 WEBINAR SERIES

The CTF, NCART, NRRTS and U.S. Rehab launched a series of CRT industry COVID-19 webinars in April and May. The webinars provided a forum for sharing up-to-date regulatory information and solutions to address CRT issues posed by the COVID-19 pandemic as well as state and federal responses. Panels of experts shared CRT developments in regulatory changes, documentation requirements and updates in advocacy efforts, including the expansion of therapists using telehealth-based technologies in service provision. Webinar attendees posed specific questions to obtain guidance and answers from the organizational leaders. Additionally, attendees were encouraged to share information and resources provided in handouts accompanying the webinars. On April 16, 2020, CTF's Executive Director Cathy Carver introduced an up-to-date CRT Decision Tree to webinar attendees and outlined how this tool can guide clinicians and suppliers in CRT service provision within the COVID-19 environment.

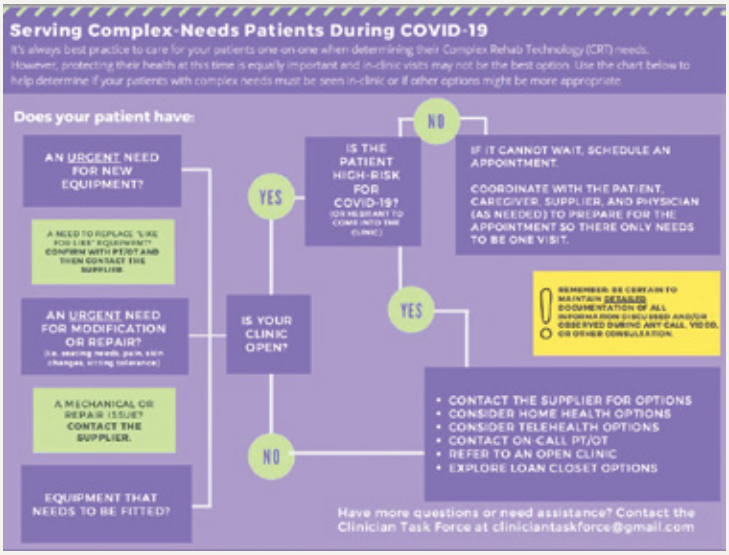

Figure 1: CRT Decision Tree published by the Clinician Task Force.

CRT DECISION TREE

The CRT Decision Tree was published based on the collaborative efforts of CTF members serving on a COVID-19 work group. The tool's purpose is to provide clinical guidance to clinicians and suppliers when considering an individual patient's needs and facilitating discussions to make the most appropriate decisions on a case-by-case basis. The CRT Decision Tree can help clinicians and suppliers to determine if patients with complex needs must been seen in clinic or if other service options would be more appropriate, such as telehealth. Figure 1 includes the CRT Decision Tree, which offers a visual diagram outlining three specific scenarios. The tool prompts clinicians to respond to three questions:

1. Does the patient have an urgent need for new equipment?
2. Does the patient have an urgent need for modification or repair?
3. Does the patient have equipment that needs to be fitted?

"AS WE EMERGE FROM THE CHALLENGES POSED BY THIS PANDEMIC, WE WILL "STAY THE COURSE" AND REMAIN COMMITTED TO MEETING THE NEEDS AND GOALS OF THOSE WE SERVE."

Depending on the responses to these questions, and whether a clinic is open, clinicians should consider whether patients may be high-risk for COVID-19 or may be hesitant to come into the clinic. The CRT Decision Tree provides clinicians with options to consider in such circumstances. Such options include communicating with the supplier, considering home health options, considering telehealth appointments, contacting an on-call therapist, referring to an open clinic, exploring loan closet options, and deferring an appointment to a later time.

If a patient is not considered high-risk for COVID-19 and is willing to attend visits at an open clinic, scheduled appointments may proceed. However, clinicians may need to coordinate communication with the patient, caregiver, supplier and physician, as needed, to prepare for only one visit based on certain circumstances. The tool also reminds clinicians to maintain detailed documentation of all information discussed and/or observed during any call, video and or other consultation.

STAYING THE COURSE

Though regulatory and legislative environments continue to evolve due to the COVID-19 pandemic, the CTF and other industry partners remain committed to providing high quality services and optimally configured equipment that supports users' goals and needs. Clinicians and suppliers must consider patients and caregivers' concerns and evaluation options during the COVID-19 situation.

Additionally, we must continue our trajectory in advocating to legislative policymakers and regulatory leaders. We must engage in pivotal conversations to steer policymakers toward improved access to CRT equipment and supporting services. Team members must continue to effectively communicate while creatively problem-solving for the best possible solutions. If telehealth-based services by physical and occupational therapists are to expand, additional research is needed to determine its effectiveness and benefits particularly during a public health emergency. Furthermore, CRT stakeholders must stay abreast of the latest information regarding federal and state legislation as well as directives from regulatory agencies, including the Centers for Medicare and Medicaid Services, state-based Medicaid programs, and commercial payers.

To conclude, the CRT Decision Tree can assist clinicians and suppliers in weighing the risks and resources by considering a patient's needs on an individual basis during this pandemic. The resource is intended to facilitate coordinated care and communication among CRT team members. The CRT Decision Tree is readily available for download through the COVID-19 tab on the CTF's website: ctf.org. Recordings of the CRT industry COVID-19 webinars and accompanying handouts are also available through the websites of NRRTS, NCART and U.S. Rehab. As we emerge from the challenges posed by this pandemic, we will "stay the course" and remain committed to meeting the needs and goals of those we serve.

CONTACT THE AUTHOR

Amber may be reached at
AMBER.WARD@ATRIUMHEALTH.ORG

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Amber Ward has been a treating occupational therapist for 25-plus years; 10 years in inpatient rehabilitation and 15-plus years as full time occupational therapy coordinator with persons with amyotrophic lateral sclerosis (ALS) and muscular dystrophies. She has treated a wide variety of patients of all ages and functional levels. She currently is an adjunct professor at the occupational therapy assistant and Master of Occupational Therapy programs at Cabarrus College of Health Sciences in addition to working in the clinic. She received the RESNA Assistive Technology Professional (ATP) certification in 2004, the Seating and Wheeled Mobility (SWB) certification in 2014, and became board certified in physical rehabilitation in 2010 by the American Occupational Therapy Association. She runs the seating clinic at the Neurosciences Institute Neurology in Charlotte, North Carolina. She is involved with multiple research projects and is the author of two peer-reviewed journal articles about power wheelchairs with persons with ALS.

SOLUTIONS FOR CHILDREN WITH SPECIAL TRANSPORTATION NEEDS

Written by: **MISSY BRYAN, OTD, OTR/L, ATP, CPST**

CLINICAL PERSPECTIVE - CEU ARTICLE

Safe transportation is essential to many of the meaningful activities of daily life. People leave home to learn, work, play, participate in health care and meet daily needs. All children need access to safe transportation, but for children with special health care needs, finding the right solution can be a challenge. The good news is that there are many solutions available. This article aims to provide Assistive Technology Professionals (ATPs) with the resources needed to pursue further learning and build competence in meeting the transportation needs of all children.

Motor vehicle crashes are a leading cause of injury death in the United States (CDC, 2018). Far beyond the rate of deaths, many more people are injured each year in motor vehicle crashes. Thankfully, we know that using appropriate child safety restraints and positioning children in the rear seat works synergistically to provide children with the best protection in a crash (Durbin, Chen, Smith, Elliott, & Winston, 2005).

BEST PRACTICE

For most children, a commercial child safety seat is sufficient to meet transportation needs. Best practice is to keep infants and young children rear-facing as long as possible, until the height or weight limit of the seat is exceeded (Durbin, 2011). The harness of a rear-facing seat should be positioned at or below the child's shoulders. Once a rear-facing seat no longer fits the child, the child should transition to a forward-facing seat with a five-point harness. The harness of a forward-facing seat should be positioned at or above the child's shoulders. There are several commercially available seats with a harness that accommodate children up to 65 pounds. After a five-point harness is outgrown, children should use a belt-positioning booster seat to ensure that the vehicle lap and shoulder belt fits across the strong bony structures of the body. Once a child is able to sit on the vehicle seat with the pelvis against the vehicle seat back, feet on the floor of the vehicle, and the vehicle lap and shoulder belt across the pelvis, sternum and clavicle, the child can transition to the vehicle lap and shoulder belt only. This usually happens at a height of 4 feet 9 inches. Children should remain in the rear seats of the vehicle until reaching the age of 13 years old. Child safety seats should not be installed in the front seat or near any airbag, as the airbag can cause injury or death to a child.

> "CHILDREN WITH VERY LITTLE HEAD CONTROL MAY REQUIRE ADDITIONAL SUPPORT AND / OR A SECOND ADULT TO RIDE IN THE VEHICLE TO PROVIDE CONSTANT OBSERVATION AND ASSIST WITH REPOSITIONING WHEN NEEDED."

Though most children can be safely transported using conventional child safety seats, some children require specialized solutions. Children who have muscle weakness or abnormal muscle tone, like those with cerebral palsy, spina bifida or spinal muscular atrophy, may require individualized positioning and support to prevent discomfort or destructive posture during travel. Some children continue to require additional postural support after they grow beyond the height and weight limits of commercial child safety seats. Others may require unique positioning solutions because of wearing casts or other medical restrictions. Children with very little head control may require additional support and/or a second adult to ride in the vehicle to provide constant observation and assist with repositioning when needed.

Some children do not have the safety awareness and maturity to sit in a commercial child safety seat and may unbuckle or climb out of even a well-fitting and adjusted five-point harness. Children with autism spectrum disorder are often resistant to sitting within the child safety seat for the duration of travel. Many of these children escape the seat, engage in aggressive or self-injurious behavior, or attempt to escape from the vehicle during travel. This affects not only the safety of the child but distracts the driver and endangers others in the vehicle and those on the road (Yonkman, Lawler, Talty, O'Neil, & Bull, 2013). While behavioral strategies should be implemented first to

encourage safe travel behaviors, some children require specialized environmental interventions to be able to travel safely.

TRANSPORTATION SOLUTIONS

The author has no affiliation with any product manufacturers and does not endorse any particular products. The seats, products and options that are described in this article are not meant to be inclusive of all available options but are intended to demonstrate the variety of transportation solutions that are available. Descriptions in this article are an introduction to the range of solutions but are not intended to be a substitute for manufacturer instructions, uses and specifications. Anyone wishing to provide durable medical equipment for transportation should pursue the full education and training described later in this article.

LARGE MEDICAL SEATS

Large medical seats are child safety seats with an integrated five-point harness intended to be used as the primary restraint during transportation. Large medical seats have higher height and weight limits than commercial options, with some seats and harnesses extending up to 130 pounds and 66 inches. Large medical seats are generally installed with the vehicle seatbelt and a top tether. It is essential that the top be tethered because the seats are large and heavy and may tip forward in a crash if not secured. Some large medical seats have options for additional postural support. The Spirit Plus by Inspired by Drive https://bit.ly/2OHh2Tp has adjustable, swing-away lateral trunk and thigh supports and a swing-away medial thigh support. The Roosevelt (see Figure 1) by Merritt Manufacturing https://bit.ly/2WGrUp2 has a scoliosis kit option, with padding to fill in gaps between the child and the seat and a harness that is individually adjustable on each side. It is crucial to follow the manufacturer's instructions on adding this additional padding, as placing anything between the child and a child safety seat typically is not allowed. Another unique option of the Roosevelt is an EZ-Up Cap, which fits on the child's head and velcros to the back of the seat to provide head support. Several large medical seats offer a waterproof incontinence cover that can be removed for cleaning without having to rethread the harness. Seat depth extensions are available on some seats and can be used to accommodate a child's size or growth. Some large medical seats offer a seat wedge or tilt bar to provide limited tilting of the seat to help children maintain an upright trunk and head position.

Large medical seats can also be helpful for children who have not yet developed the maturity and safety awareness to transition to a belt-positioning booster seat. For some children, continuing the use of a five-point harness helps the child remain in a safe position throughout the duration of travel. For children who elope from a five-point harness, some seats have anti-escape features that can be helpful. Child locks on vehicle doors should always be engaged to prevent opening the door while the vehicle is moving or getting out of the vehicle before the caregiver is prepared.

Prior to considering an environmental modification through anti-escape features, families should try the less invasive strategy of behavioral intervention. One example is using a first/then strategy with visual cues. When getting in the vehicle, show the child a picture of themselves sitting correctly in their child safety seat with harness or lap and shoulder belt in place. Say "First, sit in your seat like this. Then,

FIGURE 1 Roosevelt

CHILD LOCKS ON VEHICLE DOORS SHOULD ALWAYS BE ENGAGED TO PREVENT OPENING THE DOOR WHILE THE VEHICLE IS MOVING OR GETTING OUT OF THE VEHICLE BEFORE THE CAREGIVER IS PREPARED.

FIGURE 2 Buckle guard

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you may have ..." a preferred item or activity. Some children enjoy specific music, a favorite toy or even an electronic device. Use a highly preferred item that can be provided only when in the vehicle so that riding in the seat correctly is consistently reinforced. If the child gets out of the seat, the driver should pull over and remove the preferred item until the child is back in position and buckled correctly. It may be helpful for the caregiver to plan many short trips over a brief period of time solely for the purpose of teaching proper seat use so that the positive behavior is reinforced without disrupting actual family plans. Consider a child's reason for elopement from the seat, as that may provide clues to help a child stay seated. For example, if a child is overly sensitive to sound, wearing noise cancelling headphones or playing preferred music may improve tolerance to staying seated in the child safety seat. If these methods do not work, then consider a seat with anti-escape features.

The Roosevelt by Merritt Manufacturing has a buckle guard option (see Figure 2) that allows the caregiver to unbuckle the harness but prevents the child from accessing the buckle. It also offers a chest clip guard (see Figure 3), which has a lock to prevent the child from unbuckling the chest clip and a strap that goes behind the child's neck to prevent pulling the chest clip down and out of place. There is an A-lok cover option that restricts the child's access to the harness tensioning system but allows the caregiver access using a tool. This is helpful for children who loosen the harness to climb out.

It is crucial to discuss the safety concerns that are inherent in using anti-escape options with caregivers. Every feature that makes it more difficult for a child to escape also increases the difficulty for an adult assisting the child in getting out of the seat in an emergency and on an everyday basis. Parents should create emergency plans when using these seat options, such as keeping a webbing cutter on their key ring or in the vehicle at all times. It may also be helpful to post a sign with instructions on how to safely assist the child out of the seat and care for the child once out of the vehicle. The instructions should indicate if a child is able to understand or use verbal communication and whether the child needs physical contact (i.e., hand holding) to maintain safety once out of the vehicle. These instructions should be placed where they are visible to anyone who approaches the child in the seat but should not interfere with any portion of the harness or vehicle seat belt. Car seats should never be altered in a way that is not indicated by manufacturer instructions to prevent a child from escaping, as this increases risk to the child and could interfere with the function of the seat.

FIGURE 3 Chest clip guard

MEDICAL BELT-POSITIONING BOOSTER SEATS

Medical belt-positioning booster seats serve the same purpose as commercial belt-positioning boosters. The intent is to ensure that the vehicle lap and shoulder belt contacts the child across the strong bony structures of the body to protect the organs and soft structures in a crash. Unlike commercial belt-positioning boosters, medical booster seats have harnesses to provide postural support. Unlike a forward-facing seat with five-point harness, the harness in a booster is not intended to be the restraint in a motor vehicle crash. Medical booster seats are generally installed in the vehicle using the lower anchors and top tether. The child is positioned in the seat with the harness providing postural support. The vehicle lap and shoulder belt goes across the child to provide safety in a crash. It is crucial that a caregiver understands the functioning of each of these three systems so that they use the seat and seat belt correctly.

The Convaid Carrot 3 Child Restraint https://bit.ly/2DXlqeK (see Figure 4) is a medical belt-positioning booster seat that fits heights between 37 and 60 inches and weight from 30 to 108 pounds. It is a modular system that can grow with the child. There are a variety of positioning supports available. One unique feature of this seat is that it has a free angle recline (see Figure 5). If the seat is installed in a vehicle seat that reclines, the seat to back angle of the Carrot 3 Child Restraint can be changed to match it. This seat also offers the option of an under seat wedge, which allows a rear tilt in space position to be attained. The harness has a padded anterior support that can provide distribution of support across a large portion of the abdomen and lower chest. This seat can be especially helpful for a child whose head falls forward in an upright sitting position, as the reclined position allows gravity to assist the child with keeping the head back and in the head support. Do not confuse the Carrot 3 Child Restraint (technically a belt-positioning booster seat) with the Convaid Carrot 3 Booster seat (also a belt-positioning booster), which is made for much larger adolescents and adults. The Carrot 3 Booster provides free angle recline, a positioning harness and low sides for transfers, but accommodates individuals between 79 and 165 pounds and 54 and 67 inches.

The Churchill by Merritt Manufacturing https://bit.ly/39dG2ep is a belt positioning booster designed for larger children, accommodating weights between 65 and 175 pounds and heights between 48 and 72 inches. It has a low profile flat booster base and provides the child with postural support through thigh harnesses and a Velcro vest or through a five-point harness. It is possible to use the Merritt Manufacturing chest clip guard and buckle guard on the five-point harness, but the vehicle lap and shoulder belt must still go over the child and buckle for restraint in a crash. If the child unbuckles the seat belt, this option will not provide a safe solution.

The Recaro Monza Nova 2 Reha https://bit.ly/3fOAQA5 by Thomashilfen offers a swivel feature that can decrease caregiver strain and effort when transferring the child into and out of the seat. Parents have reported concern with risk of injury to themselves or their child during vehicle transfers (Falkmer & Gregersen, 2002). The seat offers moderate support through a postural support harness. It also offers a crash tested foam tray table that can be used during travel.

SAFETY VESTS

Safety vests provide an alternative method of securing a child who elopes from a commercial child safety seat or who cannot be transported in a sitting position. EZ-ON Products https://bit.ly/39gW0Eo makes a variety of vests for differing transportation needs. For children who escape from a commercial child safety seat, the 103Z vest can be used on a school bus or in a family vehicle with a bench seat or captain's seat. In order to use this vest in a family vehicle, the family must have two heavy duty anchors installed in the floor of the vehicle behind the seat so that the floor mount can be used to secure the vest. The 103Z vest has a rear zipper closure that prevents the child from removing the vest. Though these vests are more economical than a medical car seat, they require vehicle modification for use in a family vehicle, which may limit the number of vehicles in which the child can ride. If the family vehicle does not have a bench seat or captain's seat, the 303Z vest can be considered, but the vehicle seat belt must be used over the child's pelvis. If the child unbuckles the seatbelt, this vest is not a safe option.

The 101M2 and M203 vests allow a child to be transported while lying in supine. This may be necessary for children who are wearing casts that limit hip flexion or who cannot sit for other medical reasons. These vests can be used in a family vehicle.

CAR BEDS

Car beds are used for infants born prematurely or with a birth weight that is too low for a commercial rear-facing infant seat or who are unable to medically tolerate the reclined position of a rear-facing infant seat. Infants with osteogenesis imperfecta, apnea, Pierre Robin sequence, myelomeningocele, omphalocele, hydrocephalus or casts may not tolerate a typical car seat position. Prior to discharge from the hospital, infants at risk should undergo a car seat challenge to ensure they can tolerate sitting in the seat. Car beds allow infants to be transported supine, prone or sidelying with physician orders. Car beds may take up more than one rear seat position in the vehicle. Once large enough or medically stable, the infant can transition into a commercial rear-facing infant seat.

USING WHEELCHAIR AS A SEAT IN A VEHICLE

It is generally safer to transfer a child from the wheelchair into a child safety seat or vehicle seat for transportation. However, there are situations that make the transfer difficult, painful or unsafe for the child or caregiver, especially as children grow into adolescence. In these situations, the child may remain in the wheelchair in a wheelchair compatible vehicle during transport. Basic concepts of using a wheelchair as a seat in a vehicle are: 1) use equipment that is compatible with transportation; 2) secure the wheelchair to the vehicle; and 3) use a vehicle lap and shoulder belt to secure the rider (University of

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Michigan Transportation Research Institute, 2018). In-depth discussion of transportation in a wheelchair is beyond the scope of this article, but detailed information is available at https://bit.ly/32D5B7u.

TRAINING AND RESOURCES

Assistive technology suppliers and therapists must pursue training to develop competence in addressing transportation needs of children. Fortunately, the training is standardized and is available across the nation. Also, because the number of specialized products is relatively small (in comparison with seating and wheeled mobility products), it is reasonable that a single provider can be familiar with most or all available products. While assistive technology suppliers and therapists are masters of modification, modifying child safety seats is not recommended. Child safety seats and transportation vests are developed and tested to meet FMVSS 213 (National Highway Traffic Safety Administration [NHTSA], 2011), the safety standards for child passenger safety. They must be used according to the product manufacturer's instructions, as well as the vehicle manufacturer's instructions. Variance from these uses may impact the performance of the product in a motor vehicle crash.

The first step in provision of transportation safety solutions is to become a Child Passenger Safety Technician (CPST). This standardized national certification course by NHTSA provides didactic and hands-on training on best practice for child passenger safety. The three- to four-day course is focused on commercial child safety seats and emphasizes basic concepts that are applied to all child safety seats. CPST certification lasts for two years and can be renewed through continuing education, community education, and seat checkoffs on each of the different types of seats. Information about the CPST course can be found at https://bit.ly/3jlzu1X.

CPSTs help families with selection of appropriate seat types for their children. They assist with proper installation and use of child safety seats and seat belts. The role of a CPST is very important because 46% of car seats are not installed or used properly (Greenwell, 2015). Common misuses are incorrect positioning of the harness, chest clip out of position or not used, loose installation, loose harness and incorrect seat belt placement. A 2009 study by O'Neil, Yonkman, Talty and Bull found a 73% restraint misuse among children with special healt care needs. CPSTs are trained to recognize misuses and guide caregivers to implement best practice.

Once certified, CPSTs are eligible to take the Safe Travel for All Children course through the Automotive Safety Program at the Indiana University School of Medicine. This is a day and a half course that covers medical and developmental conditions that impact child passenger safety and specialized restraint systems. It includes classroom lectures and hands-on exercises with many of the available specialized restraint systems. Information on Safe Travel for All Children courses is available at https://bit.ly/2OE2CmW.

Once an assistive technology professional or therapist has completed these courses, they are ready to begin providing services to children and families. Service provision should include a team assessment by an occupational and physical therapist or supplier. At least one member of the team should be a CPST and have completed the Safe Travel for All Children course. The evaluation should explore the child and caregivers' prior transportation experiences, concerns, needs and goals. The therapist should do a thorough assessment of the child's physical skills, safety awareness, communication and behavioral regulation. The team should assess the vehicle and the child's current child safety system. Once goals are established, the therapist and supplier should provide a hands-on trial of possible interventions. This allows the team to verify the product that best meets the child and caregiver needs and confirm compatibility with the vehicle. Once the recommended device has been obtained, the entire team should reconvene for fitting and child and caregiver education on positioning, installation, and use. It is crucial for the caregiver to get direct practice with installing the seat correctly, so they can repeat installation at a later time, if needed. Caregiver education should be a primary goal of each step of this process to minimize misuse.

Once the family has the seat, the team should establish a plan for follow up and follow along. Because misuse of child safety seats is known to be high, the team members should check on seat use during future contacts with the client. The caregiver needs to know who to contact if the seat is not functioning as intended. It is very common for straps to get twisted over time so that the harness becomes very difficult to use correctly. Seat covers get worn and postural supports may loosen over time and need adjustment. Generally, child safety seats expire after six years. Establishing a clear plan for follow up will increase the likelihood that repairs and changes are made when needed.

CONCLUSION

Transportation is an aspect of a child's routine that can be easily overlooked, but the ramifications of not addressing a child's transportation safety needs are very high. Families who do not

FIGURE 4 Convaid Carrot 3 Child Restraint

FIGURE 5 Free angle recline on Convaid Carrot 3 Child Restraint (Note that in a vehicle, the safety seat back must rest flush against the vehicle seat back.)

feel they can safely transport their child may limit their own travel and that of their child, which can result in occupational deprivation for the entire family. There are a variety of transportation solutions available. Suppliers and therapists can gain thorough knowledge of these solutions by pursuing CPST certification and taking the Safe Travel for All Children course. Equipping assistive technology teams with competence in solutions for transportation can improve safety and comfort and prevent postural asymmetries. Above all, equipping families with safe transportation solutions enables them to get out of the house and live the lives they find meaningful.

CONTACT THE AUTHOR

Missy may be reached at MISSY.BRYAN@BELMONT.EDU

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RESOURCES:

Become a Child Passenger Safety Technician - https://cert.safekids.org/

Take the Safe Travel for All Children Course - https://preventinjury.pediatrics.iu.edu/training/safe-travel-for-all-children/

Transportation in a Wheelchair - http://wc-transportation-safety.umtri.umich.edu/ridesafe-brochure

Missy Bryan, OTD, OTR/L, ATP, CPST is an assistant professor of occupational therapy at Belmont University and occupational therapist Level IV at Monroe Carell Jr. Children's Hospital at Vanderbilt. She has over 20 years of experience in pediatric outpatient and home health settings. Her current practice is in an outpatient seating and mobility clinic and special needs transportation clinic. She teaches courses in assistive technology.

ADA


AMERICANS WITH DISABILITIES ACT 30TH ANNIVERSARY COMMENTARY

REFLECTIONS OF THE AMERICANS WITH DISABILITIES ACT

Written by: **MELANIE DAVIS**

The Americans with Disabilities Act has afforded me many opportunities that many before me did not have the opportunity to benefit from. I have the right to access city parks, city sidewalks without barriers, public buildings and equal opportunity to employment. I was fortunate to not have to experience the discrimination that generations before me endured, as I was not quite 5 years old when the ADA was passed into law. My life has not been without struggle. I feel as though we lack greatly in enforcement of the various standards of the ADA as well as an understanding of what the ADA actually covers. I do not go a day without finding an access barrier before me.

It is a common misconception that the ADA covers housing. I currently live in an apartment with a handicap accessible bathroom with an additional bathroom without accessible features. So, I pay rent for two bathrooms while only having the benefit of one. Additionally, my kitchen and laundry facilities are not to the standards of the ADA. I have the right to modify, at my cost. I believe that this could be a great addition, but the ADA currently doesn't have much more than a mention about housing. I've inquired about an automatic door at the lobby entrance of my loft community, and the management company informed me that would be at my cost as well, even if I weren't the only beneficiary. We have done a great disservice to the disabled community by omitting this area of society.

All too often city sidewalks and other areas of city property are not meeting the current standards of the ADA. This creates a great barrier for people of all disabilities. We must continue to push forward in the area of enforcement. City and state governments must be held accountable for ensuring their sidewalks are compliant with the ADA. All too often, I see curb ramps taken out during reconstruction, sidewalks being partially repaired, which doesn't clear the barriers, and/or new curb cuts being designed with cross-slope. Ensuring accountability comes in the form of empowering the disabled community to feel comfortable speaking up, foremost. Secondly, our government officials need to become more efficient at noticing their pitfalls to create a more inclusive community.

We have great strides to make in the area of employment. I believe many are discouraged from working due to various restrictions within the social services system. The majority of people with disabilities are not employed. Most are well qualified for the positions they apply for but are not given the opportunity. It is hard to prove discrimination in the hiring process, but one with a disability is left to question if their status is the reasoning behind their lack of employment. I also believe attaining support for career choices an individual may make can be difficult. Oftentimes people with disabilities are not new to having peers, family members, employment agencies or prospective employers from telling them where they feel they would be a good fit versus respecting their thoughts and honoring their passion.

I have often felt that when I voice my concerns regarding access that I am "rocking the boat." So many are used to the status quo, and this makes seeing equality difficult. We must continue to strive for a more equal world in which all individuals are given access. The passage of the Americans with Disabilities Act was only the beginning.

CONTACT THE AUTHOR
Melanie may be reached at MELANIE.DAVIS004@GMAIL.COM

See story about Davis on page 8

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ADA

Written by: **SUZANNE JARDINE STRUB**

In the 1970s, years before the Americans with Disabilities Act, children with disabilities were not placed in regular classes but instead were placed in special education. They were segregated in classrooms elsewhere in the building or schooled in separate facilities; in some instances in Quonset huts. As an appointed member of the Governor of Maryland's Task Force, I traveled the western part of the state gathering information to bring back to the governor as to the conditions in which children with disabilities were being educated. I saw firsthand in the western most out reaches of the state Quonset huts being used as classrooms with snow all around. Upon visiting the elementary school my own son attended, I saw another part of the building where special education class was held. This area was segregated from the rest of the school. The students were of varying ages and ability levels – all in the same classroom.

All over the country, children with all degrees and types of disabilities were lumped together in special classrooms. In my experience if it was thought a student was borderline between attending school in regular classes and special education classes, that student would be tested by the school and the results of that test would determine if they were placed in regular or special ed classes. My husband and I feared the school system testing could be distorted to meet certain quotas. In other words, if nine students were needed in special education classes for the school to be allocated an extra teacher, and there were only 8 students, but one of the students being tested was borderline ... well, I am sure you understand where my thought process is headed. We were never asked by the school to have our child, who is orthopedically handicapped, tested and never would have allowed testing by the school system. I would advise any parent to have their child tested privately by an independent testing facility. Once a child is "labeled," it is almost impossible to shake it.

Our child attended regular classes. It never came up but I made it very clear in general conversation I would not stand for him being anywhere else. We had him tested outside the school system, so we had the results handy if needed. I made the school principal aware of the testing. Although our child was attending regular classes, I found myself more and more outraged when I saw all those children who could be in the regular classroom instead segregated and all lumped together in one educational level no matter what their abilities. In addition they were not enjoying the socialization with the larger school population. In my mind, I questioned why each of them was not receiving lessons geared to individual abilities and allowed to progress at his or her individual pace rather than all moving at the same pace and receiving lessons at the same level (This was before the diverse types of classes we have today where students are placed according to ability.)

I joined a group of citizens who, like me, believed children with disabilities should have the same opportunities to reach their highest potential as everyone else and furthermore should be mainstreamed into their schools. I was there representing children born with spina bifida. It was a diverse mix of people and interest. You could say we were an umbrella group representing many organizations with an unfailing determination and a win-win spirit.

We bombarded Members of Congress with requests to be heard. Our efforts paid off. We obtained joint appointments with the legislative aides for Sens. Edward Kennedy and Jacob Javits, who were on the Health, Education and Welfare Committee. Thus began our "lobbying" efforts on behalf of children with disabilities. Eventually representatives were going to be allowed to testify before a Congressional Committee. Members of the group that had forged the way were not necessarily the ones who testified before the committee. Representatives from many organizations were present, and several would speak. My husband, president of the local Spina Bifida Association of the Greater Capitol Area, and I had been asked to co-author testimony that would be read into the record by the president of the Spina Bifida Association of America. We spend many nights at the table pouring over just how to present with heartfelt emotion how parents of these shunned children felt and yet at the same time presenting facts and figures in a more professional manner. Fortunately in the chamber the day our testimony was delivered were people with name recognition and clout: Muriel Humphrey, wife of Sen. Hubert Humphrey, and David Hartman of Good Morning America. Our main issue, other than having the children mainstreamed, was our objection to the school system testing and then labeling children. We gained an attentive audience and were able to get our points across.

Eventually we were scheduled to appear before the committee. That was a long day on Capitol Hill with many emotional commentaries. One of which came from a young man who had been labeled "retarded" (his words not mine) and placed in special education classes. He had a halting way of speaking that would lead some people to think he did suffer from mental challenges but he was far from being "retarded." Due to his school placement he was challenged in reaching his highest potential and missed out

on socialization with others his age. He continued his story and told of his struggles to achieve his goals of college and ridding himself of the label he had been stigmatized with most of his life. He was adamantly opposed to labeling and made a strong impression on the committee as well as everyone in the chamber. There were not many dry eyes in that room when he came to the end of his testimony by telling us he had just graduated college and finally achieved his long-desired goal.

Our goal had also been achieved. Children with disabilities would no longer be totally segregated within school buildings or in separate facilities. They would be mainstreamed into the school system along with the other children in their community. Where necessary there would be in-class assistants trained to assist the children. The socialization and communication skills of the child would be addressed, and if needed, the child would receive therapy to bring them up to a standard suitable for class. The Education for All Handicapped Children Act was enacted by the United States Congress in 1975. In 1990, it was renamed Individuals with Disabilities Education Act (IDEA). This act required all public schools accepting federal funds to provide equal access to education and one free meal a day for children with physical and mental disabilities. Public schools were required to evaluate children with disabilities and create an educational plan with parent input that would emulate as closely as possible the educational experience of non-disabled students, according to Wikipedia. Now every opportunity would be given to children with disabilities to reach their highest potential.

CONTACT THE AUTHOR
Suzanne may be reached at
SJSTRUB@YAHOO.COM

THE ADA- HOW IT HAS HELPED AMERICANS WITH DISABILITIES AND WHERE IMPROVEMENTS COULD/SHOULD BE MADE

Written by: **KELLY NAROWSKI**

Title I (Employment) – When comparing titles, there are FAR more Title I complaints than II and III put together. This includes individuals with disabilities filing complaints with the Equal Employment Opportunity Commission as well as private lawsuits.

The Americans with Disabilities Act (ADA) does not specify bed height regulations — or any regulations for beds — in ADA-compliant hotel rooms. This is a major barrier for many people with mobility impairments. The next time the U.S. Access Board updates the ADA guidelines, hotel beds should be addressed.

Public transportation (falls under Title II) also needs to be improved in many areas of the country.

Housing – While the ADA does not pertain to housing, finding accessible housing remains a very significant challenge for many individuals with mobility-related disabilities. I would like to see legislation, something like the U.K. has, mandating newly constructed homes have at least one accessible entrance compliant with ADA regulations.

Also not pertaining to the ADA, education related to disability as a category of human variation is part of inclusion. In my opinion, disability should be added to diversity training in government organizations, the private sector and in post-secondary education. Education would ideally include disability-related legislation such as the landmark ADA.

The good: In my view, Titles II and III have drastically improved the lives of Americans with disabilities. Regarding access, these titles have made an enormous impact. Having lived in Europe for three years, I appreciate Title III the most.

Here's the link to an article I wrote about my perspective on how life-enhancing Title III is: https://pushliving.com/living-abroad-an-american-wheelchair-users-perspective/

CONTACT THE AUTHOR
Kelly may be reached at KELLY@KELLYNAROWSKI.COM

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ADA

Written by: **ANDREW DAVIS**

Before the Americans with Disabilities Act (ADA), when we went on family trips finding accessible bathrooms was a major concern. We would stop and my Dad would go inside a hotel, service station or restaurant and check out the accessibility. If it was accessible, then he would get my wheelchair out and the two of us would go inside to the bathroom; otherwise we would continue on down the highway to another stop until an accessible bathroom was found. The same problem with finding accessible restaurants. After the ADA, all buildings that receive federal funds had to be adapted to include an accessible bathroom. All new construction was required to be architecturally barrier free.

Before the ADA, movie theatres were not wheelchair accessible. The theatres insisted on me transferring to a regular aisle theatre seat and then the usher would remove my wheelchair so it wouldn't block the aisle. The concern was always in case of fire I had no way to escape until, and if, my chair was brought back to me. My parents or whoever I was with would follow the usher to see where my wheelchair was being taken so it could be found quickly. Today theatres have vacant spaces next to rows of seats for wheelchair users to park while remaining in their wheelchairs.

Before the ADA, there were no curb cut downs. I had to have someone help me get onto the sidewalk. After the ADA, there are curb cut downs, and I don't need assistance getting onto the sidewalk.

Before the ADA, there were no designated parking spaces. I had to find places to park so I could take up two spaces to have room to get my wheelchair out, and then when I returned to my car have room to get my wheelchair back in my car. As I drive a regular car with my chair behind the driver's seat, I need room on that side of the car to open the door wide enough to get my chair in. Today, after the ADA, there are designated parking spaces for people using wheelchairs who drive or are passengers in automobiles or vans. However citizens who do not have any physical handicap abuse those spaces. I decided to do something about it, and with the help of my state representative was successful in lobbying Georgia Congress to make changes to the way the handicap permits were approved by physicians and how they were prepared. After the bill passed, the regulations to be approved for a permit were made more stringent and the placards themselves are no longer on thin paper that expiration dates and names could be easily changed. They are now laminated and the expiration dates are printed by computer and large enough for passing patrols to see. Many times today, I still have some instances of people parking so close to my car that I cannot get in and have to have someone back my car out (into traffic lane) so I have room to get my door open wide enough to put my chair into my car.

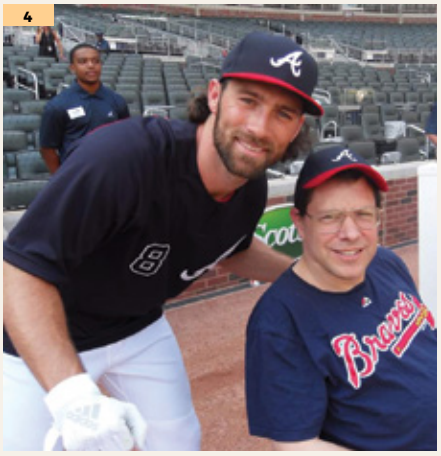
Before the ADA, there were no automatic door openers. It was very difficult to open doors and position my chair in the doorway to hold it open so I could get inside the building or restroom. I usually had to have help. Now after the ADA, with the automatic door openers, I can enter buildings and restrooms with ease and without help.

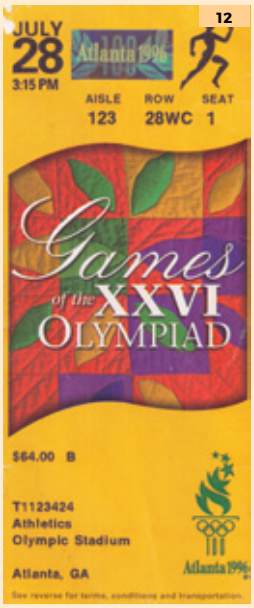
Before the ADA, hotel rooms did not have roll-in showers or tubs with tub chairs and bathroom doors were not always wide enough for my wheelchair to get through. In some instances there wasn't enough room between the dresser and end of the bed to get to the side of the bed. When I traveled with my parents, they would go inside the hotel and check out the accessibility of the room before we unloaded the car. After the ADA, hotel rooms and bathrooms are for the most part accessible.

Before the ADA, subways only had STAIRS from the street level down to the train level. When we lived in the Washington, D.C., area the Metro was being built. It came to my mother's attention that there would be no consideration given for people using wheelchairs, walkers or baby strollers to get down to the train level. She joined with a group of citizens and began their mission to insure that all citizens had access to the Metro transportation. They came up against some heavy opposition. First Lady of the United States Lady Bird Johnson sponsored Beautify America and had billboards removed from highways among other things. Since elevators had not been in the original plans and would have to be retro fitted it created an architectural feature the First Lady did not find attractive. She was not in favor of sidewalk "boxes" housing entrances to elevators down to the Metro. The "boxes" looked something like telephone booths. However, the argument that ALL citizens should have access to public transportation prevailed and the elevators with their "boxes" were installed. Today, after the ADA, there is easy access to subway systems throughout the country.

CONTACT THE AUTHOR

Andrew may be reached at ADAVIS@NRRTS.ORG





Andrew 1 – Welcoming consumers to CELA | **Andrew 2** – Ziplining | **Andrew 3** - Board walk access to the beach at Cumberland Island was NOT wheelchair accessible.
Andrew 4 - Making sure getting on the field is accessible for autographs during the Braves pre-game batting practice. I served as a member of the Braves Accessibility Advisory Committee.
Andrew 5 – Explaining bills to legislative aids. | **Andrew 6 -12** Atlanta Olympics 1996

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ADA

Written by: **JENNY SIEGLE**

I was paralyzed in 1983 when I was 9 months old with transverse myelitis. I was only 7 years old when the Americans with Disabilities (ADA) Act was signed into law in 1990. I don't really remember what life was like before then, but I am very grateful for the access and rights I have been able to experience. I do feel like there is still a lot more work to be done though.

I'm a very active person, so being able to access buildings independently is very important to me. However, I do live in Denver, and there are a lot of historic buildings downtown that do not have to be ADA compliant. It is a similar situation in our mountain towns. I can't get into a lot of those buildings on my own either because they are not accessible. Thankfully, I can use my manual wheelchair; but on the other hand, that also means I need help and can't be independent.

I enjoy going to sporting events and concerts as well. I like knowing that I will be able to purchase accessible seats and be able to see the event that I am attending. The only bad thing is seats are often sold to people who are not disabled and do not need them. This is an issue I am seeing more and more of and feel like it really needs to be addressed.

Traveling is one of my favorite things to do and it is a wonderful feeling to be able to stay in a hotel that has a roll-in shower and a sink that I can access in the bathroom. It isn't always a perfect set up, but at least I know that in most cases, the basics should be covered. If I do encounter problems, I like to use that as an opportunity to educate others.

The one section of the ADA Act I am most grateful for is employers are prohibited from discriminating against qualified individuals with disabilities. I basically work two full-time jobs, and I love every minute of it. I'm a producer for a regional sports network, and I'm an editor for the Colorado Rockies baseball team. I love going to work every day knowing I will be able to pay for my home and my van on my own. Not only am I a woman working in a male-dominated field, but I'm also a woman in a wheelchair!

CONTACT THE AUTHOR

Jenny may be reached at JENNY_SIEGLE@YAHOO.COM


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Jenny 1 - Jenny as a child

Jenny 2 - Jenny in Chicago

Jenny 3 - Jenny in Chicago

Jenny 4 - Fantasy Football Hour hosts and me

Jenny 5 - This is when I went to Disney World for my friend's bachelorette party. The bride to be is in the white tank top!

Jenny 6 - Working a Rockies game last summer.

Jenny 7 – Jenny in her office

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ADA

Written by: **KAY KOCH**

When Atlanta was awarded the 1996 summer Olympics, local groups and the spinal cord injury hospital in the Atlanta area created committees to get the 1996 summer Paralympics held in Atlanta. Atlanta's mass transit system MARTA was in early compliance with the ADA and was a factor along with many other things to get Atlanta selected for the Paralympic Games.

The Paralympic torch was lit from the eternal flame that burns at the tomb of Martin Luther King Jr. in Atlanta before it was flown to the White House to begin the relay back to Atlanta. The torch relay went through four states and over 1,000 hands on its way to Atlanta.

The following are photos taken the day it arrived back in Atlanta. I was able to run in part of the torch relay about 10 miles outside of the city.

CONTACT THE AUTHOR
Kay may be reached at
KKOTRCHOA@YAHOO.COM

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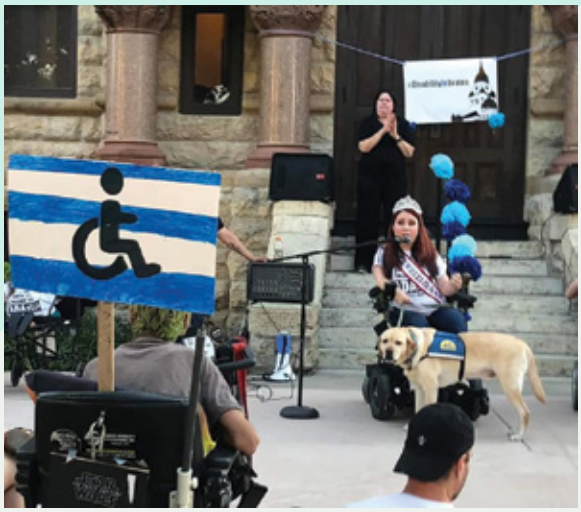
Kay 1 - Atlanta- The 22-acre Centennial Olympic Park was created as a meeting and gathering space for the 1996 Olympics and Paralympics, and pre COVID-19 times was one of the most visited and photographed area of the city in downtown. The Fountain of the Rings is an accessible and safe water feature open to the public. All people are encouraged (pre COVID -19) to enter the fountain.
I took this photo a few summers ago, when walking in the park one day with friends and marveled that it really was being enjoyed by all the visitors
Kay 2-5 - 1996 Paralympic torch run and rally



ADA

Written by: **LAUREN TAYLOR**

Without the ADA, I would not be able to have a voice much less even be considered a human being. It has been one of the biggest steppingstones to equality that our community has ever experienced. We still have a lot of work to do, but look at how far we've come!

CONTACT THE AUTHOR
Lauren may be reached at MWTX2019@GMAIL.COM

ADA AT 30 - HOW HAVE THINGS CHANGED?

Written by: **RICK HAYDEN - EXECUTIVE DIRECTOR, UNITED SPINAL ASSOCIATION**

In 1976 I was injured in a motorcycle accident that resulted in a T-8 spinal cord injury. This new world of disability way back then was certainly challenging, and not just due to the lack of physical access to most buildings, but also the attitudinal barriers toward our community. We were not considered equal to "normal people" so there was no need for inclusion. When the ADA was signed in 1990, it provided a roadmap that over the years would open many of the doors that had been previously closed. Physical access to buildings, access to educational opportunities, employment opportunities that extended beyond benchwork electronics and accounting as well as a chance to educate the public and show that we were indeed of equal status.

What still needs to happen?

Here we are 30 years later, and things have moved far slower than most of us may have expected. Though we have greater physical access and access to personal opportunities, there has been adequate time to have resolved this issue in total and put it to rest. Access to education at the college/university level is quite open though public schools continue to struggle with providing equal access to programs.

The unemployment rate for a person with a physical disability is more than double that of their able body counterpart. I ask myself all the time, why is that. I believe the two factors that contribute to this problem are a lack of knowledge and fear. A lack of knowledge on disabilities and disability etiquette. Fear that they may ask the "wrong" question during an interview and that reasonable accommodations might be cost prohibitive.

So how do we fix this? By educating Human Resource departments on disability etiquette and dispelling the myth that reasonable accommodations come at a high cost is certainly a solid first step.

It's not all one-sided. The disability community has to take responsibility for recognizing what their particular needs are and how to insert that information into the interview, preferably toward the beginning of the interview, which can reduce some of the tension and allow for an interview based on the person's ability to do the job. Our chapter, Spinal Network, provides workshops for individuals to work through the process of recognizing what their needs are in the workplace.

There are many organizations and agencies out there, each working toward this common goal. If we would like to speed up the process, we should look at strategic collaboration.

CONTACT THE AUTHOR
Rick may be reached at
RICK@SPINAL-NETWORK.ORG

EMERSON ROSE

FROM #PREEMIESTRONG TO POWER WHEELCHAIR DRIVING PRESCHOOLER

Written by: **ANGIE KIGER, M.ED., CTRS, ATP/SMS**

NRRTS thanks Sunrise Medical for sponsoring this article.

Emerson, or "Emmy" (see Figure 1) as her friends and family call her, entered the world quite a bit earlier than her parents expected at just 29-weeks gestational age and weighing 1.8 pounds. Since that September day in 2016, Emmy has been proving she is #PreemieStrong by challenging people's expectations of her and motivating her multidisciplinary team to not only push Emmy, but also themselves as professionals. Over the past 3 ½ years, Emmy has grown into a spunky preschooler with a magnificent smile that draws people to her. The journey to get Emmy to where she is today would not have been possible without the support of her parents, Andrew and Megan (see Figure 6), big sister Aubree (see Figure 4), or her dedicated team of professionals. We invite you to join us as we look back over twists and turns of the path that led Emmy from being a micro-preemie to a power wheelchair driving preschooler!

THE EARLY DAYS

Emmy spent her first 147 days of life in the neonatal intensive care unit (NICU) of a local hospital in the Tampa Bay Area of Florida. During her time in the NICU, Emmy's primary goals were to grow and get stronger. Emmy experienced many of the common medical issues that arise when babies are born early including neurological, respiratory, pulmonary, and gastrointestinal. Throughout her stay in the NICU, she was followed by a team of medical professionals from a variety of specialty areas including occupational and physical therapy. While she was in the NICU, her family began referring to her as being #PreemieStrong when posting updates for loved ones on social media.

> "OVER THE PAST 3 ½ YEARS, EMMY HAS GROWN INTO A SPUNKY PRESCHOOLER WITH A MAGNIFICENT SMILE THAT DRAWS PEOPLE TO HER."

Emmy was finally discharged from the NICU in February 2017 and within a month of being home she hit another milestone, having officially gained 10 pounds since birth. Her first few months at home were busy with follow-up appointments, adjusting to a new routine, starting both physical and speech therapies, and enjoying being home with her parents and sister.

FIGURE 1 Emmy on her first day of life holding hands with her mother.

FIGURE 2 Emmy at 14 months on the day her Voyage was delivered.

In August 2017, at the age of 11 months, Emmy was evaluated for her first piece of Complex Rehab Technology (CRT) in an outpatient seating clinic with a team of professionals that included a physical (PT) and occupational therapist (OT) - Angela Stone, MS,OTR/L, ATP (see Figure 6), and Rick Capps, CCRT, ATP, from Custom Mobility Inc. Based on that evaluation, her team decided Emmy would benefit from an adaptive early intervention stroller with a seating system that provided her with support to maintain optimal posture. Approximately three months later, Emmy received her personal ZIPPIE Voyage® with advanced seating (see Figure 2).

Right before Emmy's first birthday, she was once again seen by Stone for an evaluation, but this time it was through outpatient OT services. Stone has remained her primary outpatient OT ever since.

CHANCE MEETINGS THROUGH CONTINUING EDUCATION

In early 2016, over a year before Emmy was born, Stone attended a full day continuing education seminar on power mobility taught by Angie Kiger, M.Ed., CTRS, ATP/SMS clinical strategy and education manager for Sunrise Medical, hosted by Custom Mobility Inc. in Largo, Florida. As someone who spent the first 12 years of her career working at a pediatric hospital in Washington, D.C., and leading an assistive technology team at that facility, Kiger has a passion for pediatric power mobility and developed a power mobility training program. Throughout the course, Kiger and Stone discussed their experiences with power mobility and young children. Kiger provided general thoughts on implementing a power mobility program at a facility and for young children.

The following January, Stone attended another seminar Kiger taught at Custom Mobility Inc. on pediatric seating and wheeled mobility. One of the topics covered during the class was the impact of vision on seating and mobility with an emphasis on cortical visual impairment (also known as cerebral visual impairment or CVI). During one of the breaks, Kiger and Stone caught up on programs at Stone's facility and talked in-depth about CVI.

FIGURE 3 Emmy in July 2018 at 22 months during power training with therapist, Nicole Schmitt..

FIGURE 4 Emmy shopping with her big sister Aubree in her new power chair.

PEAKS, VALLEYS, AND PLATEAUS LEAD TO A NEW PATH

With Emmy's significant medical history as a preemie and associated global deficits in gross motor, fine motor and self-care skills; she received extensive therapeutic intervention on an outpatient basis including occupational, physical and speech therapies twice a week for about a year and a half. In addition, Emmy continued to be followed by multiple specialty clinics include physical medicine, pulmonology, genetics, gastroenterology, neurosurgery, and ophthalmology. During this time Emmy was diagnosed with spastic quadriplegic cerebral palsy and CVI.

Then in early Spring 2018, Emmy's PT program was transitioned to Nicole Schmitt, PT, DPT, PCS (Figure 6). Emmy's goals at that time (established by previous physical therapists) included rolling, prop sitting and maintaining quadruped. Schmitt and Stone collaborated frequently on treatment plan ideas for Emmy. Both clinicians noted that Emmy's progress toward achieving the developmental goals involving motor skills was slow. However, Emmy demonstrated strong social and cognitive skills, despite her significant motor impairments and limitations.

Less than a month later, while participating in an advanced continuing education class regarding the importance of mobility to learning and overall development, ideas began to spark in the minds of both Schmitt and Stone, altering their treatment plans for Emmy. The seminar

> "EMMY CONTINUED TO BE FOLLOWED BY MULTIPLE SPECIALTY CLINICS INCLUDE PHYSICAL MEDICINE, PULMONOLOGY, GENETICS, GASTROENTEROLOGY, NEUROSURGERY AND OPHTHALMOLOGY."

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EMERSON ROSE
(CONTINUED FROM PAGE 51)

proposed early power mobility as a treatment option to stimulate other domains of development, such as language, social-emotional skills and cognition. Additionally, there was evidence to support power mobility as a modality to improve CVI and independent function. Given Emmy's slow progress in motor skills and great potential in social-emotional and cognitive skills, Schmitt and Stone began to explore adding power wheelchair training to her plan of care.

The first step was to propose their idea of incorporating power mobility into Emmy's treatment plan to her family and her physiatrist. All parties agreed Emmy was an appropriate candidate for a power mobility trial. Her mother, Megan, admits even though she agreed to the idea and trusted her daughter's treatment team, she was skeptical when the idea was first presented to her. Megan reports that both she and Emmy's father are "realists," and they had accepted Emmy would likely need a wheelchair for mobility. But they had never imagined Emmy could learn to drive a power wheelchair at such a young age, much less, enhance her other developmental areas by driving a power wheelchair.

Stone reached out to Capps at Custom Mobility Inc. for assistance with securing a loaner power wheelchair. The first time Emmy experienced driving a power wheelchair (with assistance from therapists), she lit up with excitement and joy.

SCHOOL OF POWER MOBILITY

By summer 2018, Emmy's team had secured a loaner power wheelchair from Custom Mobility Inc. to utilize with Emmy during her outpatient OT and PT sessions (see Figure 3). Stone and Schmitt were ready to implement a power wheelchair training protocol with Emmy to facilitate her learning how to drive the power wheelchair, and also create a formalized way to document her mastery of skills to help justify the provision of Emmy's own power wheelchair to her insurance company when the time was right. Recalling the information Stone had learned in the two continuing education courses she took taught by Kiger specifically related to power mobility training and CVI, she decided to reach out to Kiger to brainstorm ideas. In addition, Emmy's therapy team connected with her visual specialist to discuss potential modifications to the training program and driving method to best set her up for success.

During their first phone discussion about Emmy, Kiger asked Stone to provide a complete description of Emmy's history and status not just related to OT or power mobility, but all her developmental areas. The areas that particularly drew Kiger's attention were Emmy's motor, cognitive, sensory (hearing and vision), social, and communication (expression and comprehension) skills. As Stone

"MEGAN REPORTS THAT BOTH SHE AND EMMY'S FATHER ARE "REALISTS," AND THEY HAD ACCEPTED EMMY WOULD LIKELY NEED A WHEELCHAIR FOR MOBILITY."

painted a picture of Emmy's abilities, Kiger began to develop a mental picture including recommendations for specific equipment to try, adaptations to the equipment, training environment set-up, skills to focus on while not in the power wheelchair, activities to engage in to motivate Emmy and help develop the baseline skills, as well as recommendations for communication during the sessions. Although Emmy was having difficulty with some of her fine motor skills, Stone reported that she believed Emmy had emerging skills necessary to utilize a proportional joystick and believed she would eventually be able to drive with one. Based on all that information, Kiger and Stone agreed Emmy would benefit from trying non-proportional proximity switches for driving. By making this change to the driving method, Emmy's team could work on more basic skills, not only related to motor skills, but also cognition and comprehension of controlling the movements of the power wheelchair. In addition, Kiger suggested specific environmental modifications and communication strategies.

Emmy continued to train with her team throughout the summer. In early October 2018, Kiger had the opportunity to meet Emmy and her mother in person during one of Emmy's outpatient therapy appointments. Kiger observed Emmy driving the trial wheelchair with her therapists and afterwards discussed her impressions and suggested next steps. It was clear during the observation that Emmy was

FIGURE 5 Angela Stone (L) and Nicole Schmitt (R) with Emmy driving at a park in Florida.

FIGURE 6 Emmy with her team — (from left) Angela Stone, therapist; Andrew, her dad; Nicole Schmitt, therapist; and Megan, her mom.

motivated to drive a power wheelchair and had developed numerous skills over the past few months to allow her to do so more independently.

In November 2018 at the age of 26 months old, Emmy was re-evaluated for a power wheelchair with her therapists and Capps from Custom Mobility Inc. By that time, Emmy presented with the appropriate skills and needs to justify funding for a power wheelchair. Emmy's personal Pearl Pink ZIPPIE ZM-310® power wheelchair with tilt was delivered in February 2019.

EXPLORING THE WORLD AS A PRE-SCHOOLER

After turning 3 years old in September 2019, Emmy began attending a preschool speech/language group where she receives outpatient therapy services. Emmy's entire team was excited she was able to join the group as the first member to be non-verbal and use an augmentative and alternative communication device for communication. She continues to improve her driving skills by using her ZM-310 in the community and therapy (see Figure 5). As with any preschooler, Emmy needs supervision while out and about.

The path to getting Emmy where she is today has been far from smooth or easy. Along the way, she encountered some obstacles, including acute respiratory and gastrointestinal illnesses, which resulted in hospital admissions, difficulties with insurance coverage, additional comorbidities related to her premature birth, etc. However, Emmy has continued to live up to the phrase used to describe her when she was just a couple of days old … #PreemieStrong (see Figure 6)!

CONTACT THE AUTHORS

Angie may be reached at ANGIE.KIGER@SUNMED.COM

Angie Kiger is the Clinical Strategy and Education Manager for Sunrise Medical. She earned a Master of Education in Assistive Technology from George Mason University and a certificate in assistive technology from California State University at Northridge. Angie is an Assistive Technology Professional (ATP), Seating and Mobility Specialist (SMS), and a Certified Therapeutic Recreation Specialist (CTRS). Angie has worked with infants, children and adults in both inpatient and outpatient settings. She has served as an adjunct instructor at George Mason University and presented at numerous conferences in United States and abroad.

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September 8, 2020 at 7 pm EST

Seat Cushion Shape for Control of Neuromotor Issues

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Jean Anne Zollars, PT, DPT, MA

September 9, 2020 at 11 am EST

Power Wheelchair Configuration Considerations for Evaluation and Skill Training

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Jennith Bernstein, PT, DPT, ATP/SMS

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NRRTS is accredited by the International Association for Continuing Education and Training (IACET). NRRTS complies with the ANSI/IACET Standard, which is recognized internationally as a standard of excellence in instructional practices. As a result of this accreditation, NRRTS is authorized to issue the IACET CEU.

INSURERS HINDER INNOVATION – ARE YOU GUILTY TOO?

Written by: **CLAUDIA AMORTEGUI, PRESIDENT, THE ORION CONSULTING GROUP, INC.**

I have been in this industry for a very long time. As most of you know I started my career at one of the Medicare contractors fresh out of graduate school and ready to conquer the world. I would have to say that as my first job, it was not the sexiest place to work, but as I have told many, I was baptized by fire into learning and understanding. The training wasn't the most thorough, but one of the manufacturer's local managers was smart enough to send products to our office just so my colleagues and I could learn. This certainly intrigued me and opened a whole new world for the next steps of my career.

For those of you who have been doing this for quite some time, you will remember "the good ole days." Medtrade was a big-selling show, and it seemed like new technology was constantly being introduced. I remember when the Quickie Revolution came out, and that was a huge WOW moment for me. There have been more of these moments throughout the years, but certainly not like other industries. The easiest example is our cell phones. There were those big bag phones, flip phones, the Blackberry, and of course the iPhone (and even that continues to change). So how is it phone innovation is constant but for wheelchairs it is more of a struggle? In my opinion, there are two key reasons: insurance is not involved, and it's simply a "cash" product.

In our world, whether its our current manufacturers or anyone who is trying to become more involved in Complex Rehab Technology (CRT), they have some major hurdles to get over, and in many cases, it's just not feasible.

The phone manufacturers can concentrate on their direct customers. Wheelchair manufacturers not only need to worry about the end-user but also insurance policies, insurance codes, ordering physicians and therapists, caregivers, facility employees, and most importantly, insurance allowables.

I am certain anyone looking to create advancements in CRT products has the end-user at the top of any and every idea. Sadly, because of everything involved, the feasibility of the idea can easily be chipped away. What's even worse, is many of us have allowed it to happen without any direct knowledge of what we were doing.

In the past, I have written articles asking, "Why are you not screaming?" Upgrades easily come to mind. Still to this day, this topic has just sat with no movement and the people we are trying to help are the ones who get hurt.

Let's go back to the topic of cell phones. What if someone told you that you had to get the flip phone because it would meet your needs to make and receive a phone call? It doesn't matter if a smartphone made life easier, and possibly safer. I know many of you

> "CRT SHOULD NOT BE A FLIP PHONE; AND WE SHOULD NOT ALLOW INSURERS TO MAKE IT ONE."

would be screaming saying, "That's ridiculous, I'm paying for it." So, what's the difference? Is it too hard to fight? Does it take too much time? Is it just not worth the headache? If this is the case, why should anyone try to innovate?

Who does everyone expect to pay for such improvements?

In most all other industries prices for products tend to go up. In our industry, the allowables have tended to go down especially when you consider what all is included in the insurance payment – ATP assessment time, delivery, set-up, and insurance filing, just to name a few. So, where has this gotten us? More importantly, what have end-users missed out on?

Are you OK with all of this?

As much as I hate to say it, I have heard people say to me … "It's not worth the fight … It's too complicated … I'm not going to show them this product because their insurance won't cover it …. The margins just aren't there …"

At this moment, some of you may be throwing this article across the room. My point is not to anger people as I know if you are reading this article, you care. We just need to advance from where we seem to be stuck. Just like you would not accept a flip phone, end-users should not be limited to what just meets their needs – especially when technology can make things so much better. Like anyone, end-users should be able to have a safer and better life within their wheelchair.

Think LUCI, Ability Drive, SmartDrive – these are some of the innovations that CRT has gained but imagine what has been missed. Even worse, think how many people may lose out on such needed products in their life simply due to their funding source. In some cases, we cannot say items are not covered, but the allowable makes it prohibitive for many. SmartDrive is a great example of a code that was created way before such technology was developed. Therefore, the allowable is based on equipment made at least 20 years ago.

Insurance will always be a battle, but we need to fight and not lay low. We also need to give the customers the choice. If they do not know about something, how are we providing choice, and how are we helping them? What if someone did not give you all the options available when buying a phone, a computer or even a car? No matter the situation, all of us want to make informed decisions. Family, friends or others may offer financial help if they can. We should not limit choice. Plus, how can an end-user, family member or even clinician fight for things when they do not know what technology is or could be available; or if they think something is free? Meanwhile a provider or even a manufacturer absorbs the cost.

By fighting we have a chance in improving the reimbursement issues, which in turn allow for innovation. By fighting, I mean talking, educating, listening and, yes, even some screaming. The insurers expect us to simply accept their policy and pricing changes – that is easy to think, when things are quiet. I have heard them say in the past ... we aren't hearing anyone complain.

This has been a time in our country where we see the importance of our voices. More voices allow us to be heard even in our small CRT industry. I always see and/or hear the same small number of people being involved. If you are one of those people, bring other people to the fight; if you are not, what have you done for the people you are trying to help? Yes, we may lose many of the battles, but that does not give us the right to give up. It's not just about you, it's about the end-user.

CRT should not be a flip phone; and we should not allow insurers to make it one.

CONTACT THE AUTHOR

Claudia may be reached at
INFO@ORIONREIMBURSEMENT.COM

Claudia 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 rehabilitation 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 Technology.

WE HAVE MORE WORK TO DO

Written by: **WEESIE WALKER, ATP/SMS, EXECUTIVE DIRECTOR OF NRRTS**

CELEBRATING 30 YEARS OF AMERICANS WITH DISABILITIES ACT (ADA)

In 1990, the Americans with Disabilities Act became law, which prohibits discrimination against individuals with disabilities to ensure equal access and opportunities in public accommodations, employment, transportation, state and local government services and telecommunications. This act is divided into five titles that relate to different areas.

TITLE 1 (EMPLOYMENT)

Employers are required to provide reasonable accommodations to qualified applicants or employees.

TITLE II (STATE AND LOCAL GOVERNMENT)

Clarification of the Rehabilitation Act of 1973 by detailing standards for the operation of public transit systems, including commuter and intercity rail services. This title is regulated and enforced by the Department of Justice.

TITLE III (PUBLIC ACCOMMODATIONS)

Prohibits private places of public accommodation from discriminating against individuals with disabilities. Some examples are hotels, restaurants, retail merchants, medical offices, golf courses, private schools, day care centers, sports stadiums, movie theaters, etc. This is the minimum standard for alterations and new construction of facilities. Also covered in this section is the requirement for effective communication for persons with vision, hearing and speech disabilities.

TITLE IV (TELECOMMUNICATIONS)

Requires telephone and internet suppliers to offer relay services that allow individuals with hearing and speech disabilities to communicate. All federal funded public service announcements must be closed-captioned. This title is regulated by the Federal Communication Commission.

TITLE V (MISCELLANEOUS PROVISIONS)

Variety of provisions relating to the ADA as a whole and its impact on insurance providers and benefits, including prohibition against retaliation and coercion, etc. A list of certain conditions that are not to be considered as disabilities is also included here.

There is much to celebrate in this landmark legislation. But there are still barriers holding people back from normal, routine activities.

"Let the shameful walls of exclusion finally come tumbling down"
President George H.W. Bush
July 26, 1990
During the signing the ADA

Until Congress passes legislation to create a Separate Benefit Category for Complex Rehab Technology that will update current policy, Medicare only recognizes the medical necessity for "in the home" use. (https://www.medicare.gov/coverage/wheelchairs-scooters)

Take a moment to contact your Members of Congress and ask them to support HR 2408 CRT Separate Benefit Category Bill. This bill provides coverage of CRT items based on a person's specific need "For basic and instrumental activities of daily living that include, but are not limited to, moving from place to place; transferring; maintaining or changing body position; caring for one's self (such as toileting, bathing, dressing, eating housekeeping and household management); acquiring necessities, goods and services; engaging in education, employment and economic life; or using transportation."

Visit http://www.access2crt.org/federal-issues#/4/ to send an email to your Member of Congress.

CONTACT THE AUTHOR
Weesie may be reached at WWALKER@NRRTS.ORG

Weesie Walker, ATP/SMS, is the executive director of NRRTS. She has more than 25 years of experience as a Complex Rehab Technology supplier. She has served on the NRRTS and GAMES board of directors and the Professional Standards Board of RESNA. Throughout her career, Walker has worked to advocate for professional suppliers and the consumers they serve. She has presented at the Canadian Seating Symposium, RESNA Conference, AOTA Conference, Medtrade, ISS and the NSM Symposium. Walker is a NRRTS Fellow.

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2180 Stein Dr Ste 106
Chattanooga, TN 37421-7247
Telephone: 423-464-1669
Registration Date: 04/29/2020

Austin Gutierrez, RRTS®
Mobility Professionals
12 Rancho Circle
Lake Forest, CA 92630
Telephone: 949-672-8989
Registration Date: 06/17/2020

Bernard Opp, RRTS®
Organziation: PrairieHeart Mobility
30333 Saskatchewan Dr
Regina, SK S4T1H5
Telephone: 306-584-8456
Registration Date: 05/20/2020

Charles Santiago, ATP, RRTS®
Ability Medical Supply
1923 W Copans Rd
Pompano Beach, FL 33064
Telephone: 954-955-0837
Registration Date: 05/20/2020

Daniel Harrison, RRTS®
Health Aid of Ohio
5230 Hauserman Rd
Parma, OH 44130-1224
Telephone: 216-678-2712
Registration Date: 05/21/2020

Daniel Glazer, ATP, RRTS®
Ocean Home Health LLC
1000 Airport Rd Ste 101
Lakewood, NJ 08701-5960
Telephone: 732-567-9318
Registration Date: 05/21/2020

Danny Ward, ATP, CRTS®
National Seating & Mobility, Inc.
502 Earth City Plaza
Earth City, MO 63045
Telephone: 833-386-9235
Registration Date: 06/04/2020

Donald Wrye, RRTS®
1st America Home Medical Equipment, L.P.
428 Northside Dr
Valdosta, GA 31602-1802
Telephone: 229-242-3433
Registration Date: 06/04/2020

Eric Gilbert, RRTS®
Health Aid of Ohio
5230 Hauserman Rd
Parma, OH 44130-1224
Telephone: 216-252-3900
Registration Date: 05/11/2020

Fernando Castillo, ATP, RRTS®
Patients Choice LLC
625 W University Drive, Ste A
Arlington, IL 60004
Telephone: 888-311-0202
Registration Date: 06/23/2020

Foster W Davis, ATP, RRTS®
National Seating & Mobility, Inc.
3417 Oakcliff Rd, Ste 106
Doraville, GA 30340-3004
Telephone: 770-452-1450
Registration Date: 05/27/2020

Gabriel DeNigris, ATP, CRTS®
Health Aid of Ohio
5230 Hauserman Rd
Parma, OH 44130
Telephone: 216-252-3900
Registration Date: 06/12/2020

Jeremy Kilgore, RRTS®
National Seating & Mobility, Inc.
306 E 5th Ave
Columbus, OH 43201
Telephone: 614-294-5585
Registration Date: 05/27/2020

Joe Lopez, RRTS®
Mobility Solutions, Inc.
1001 East Cooley Dr, Ste 104
Colton, CA 92324
Telephone: 909-824-2185
Registration Date: 06/18/2020

Jonathan Jesme, RRTS®
National Seating & Mobility, Inc.
4980 E University Ave Ste 114
Fresno, CA 93727-1659
Telephone: 559-231-6830
Registration Date: 05/05/2020

Pedro Ovando, RRTS®
Mobility Professionals
12 Rancho Circle
Lake Forest, CA 92630
Telephone: 844-865-2814
Registration Date: 06/18/2020

Richard Cooper, RRTS®
National Seating & Mobility, Inc.
2300 Valley View Ln, Ste 205
Farmers Branch, TX 75234-5704
Telephone: 972-206-7345
Registration Date: 05/11/2020

Teresa Glass-Owens, ATP, CRTS®
Freedom in Mobility
1315 Fletcher St NW Ste B
Huntsville, AL 35801
Telephone: 256-517-4404
Registration Date: 05/20/2020

Vincent Handrick, ATP, CRTS®
Valley Seating and Mobility
2330 W Broadway Rd, Ste 103
Mesa, AZ 85202-1886
Telephone: 480-844-0100
Registration Date: 06/15/2020

William Johnson, RRTS®
Health Aid of Ohio
5320 Hauserman Rd
Parma, OH 44130
Telephone: 216-252-3900
Registration Date: 05/13/2020

Zach Gural, ATP, CRTS®
National Seating & Mobility, Inc.
11 Freedom Way Unit A3
Niantic, CT06357-1041
Telephone: 860-739-3444
Registration Date: 06/11/2020

FORMER NRRTS REGISTRANTS

The NRRTS Board determined RRTS® and CRTS® should know who has maintained his/her registration in NRRTS, and who has not.
NAMES INCLUDED ARE FROM APRIL 29, 2020 THROUGH JUNE 26, 2020.

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

Brian Leitner, ATP
Oak Creek, WI

Joseph F. Perrault, ATP
Albany, NY

Louis Chiappelli, III
St. Marys, PA

Lee Kerns
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Eric Newell, ATP
Portland, OR

Giles Kaarto, ATP
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Daryl Bullard
Yakima, WA

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National Seating & Mobility, Inc.
Earth City, MO

Gabriel DeNigris, ATP, CRTS®
Health Aid of Ohio
Parma, OH

Teresa Glass-Owens, ATP, CRTS®
Freedom in Mobility
Huntsville, AL

Vincent Handrick, ATP, CRTS®
Valley Seating and Mobility
Mesa, AZ

Zach Gural, ATP, CRTS®
National Seating & Mobility, Inc.
Niantic, CT

RENEWED NRRTS REGISTRANTS

The following individuals renewed their registry with NRRTS between april 29, 2020 through June 26, 2020.

PLEASE NOTE **IF YOU RENEWED AFTER JUNE 26,** YOUR NAME WILL APPEAR IN A FUTURE ISSUE OF DIRECTIONS.
IF YOU RENEWED PRIOR TO APRIL 29, YOUR NAME IS IN A PREVIOUS ISSUE OF DIRECTIONS.

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

Alicia Truebenbach, ATP/SMS, CRTS®
Andres V. Ferreira, ATP, CRTS®
Ann Rodrigue, ATP, CRTS®
Benjamin Paull, RRTS®
Bill McGuinniss, ATP, CRTS®
Bobbi Mackedanz, COTA/L, ATP/SMS, CRTS®
Brent Manning, ATP, CRTS®
Brian McGuire, ATP, CRTS®
Brian Littlefield, ATP, CRTS®
Carl A. Mulberry, ATP, CRTS®
Cary Marsh, ATP, CRTS®
Cassi Jo Richardson, ATP, CRTS®
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Chris Thompson, ATP, CRTS®
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Christopher Ford, ATP, CRTS®
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David Bechtel, RRTS®
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Douglas Dulin, ATP, CRTS®
Douglas Praytor, ATP, CRTS®
Eddie Lee Shelton, ATP, CRTS®
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Matthew Tarrant, ATP, CRTS®
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Steven Shipley, ATP, CRTS®
Terry L. Bergman, ATP, CRTS®
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