NOTES FROM THE FIELD

Tom Simon Celebrates Career That Fills His Soul

WRITTEN BY: Barbara Hazelendon

Tom Simon as a helicopter crew chief in the U.S. Marine Corps.

Tom Simon's first day with Numotion — Aug. 21, 2015.

The warm afternoon sunshine danced across the summer camp's pool. Pool time is a summer camp tradition, and these 8- to17-year-old campers were eager to immerse themselves in the sparkling water. At the Muscular Dystrophy Association Summer Camp, each young camper partners with a volunteer camp counselor.

For over 30 years, one week at a time, Tom Simon, ATP, CRTS, QRP, has supported hundreds of youngsters, each experiencing MDA summer camp in their own way. Some young campers are ambulatory while others roll into the pool via their wheelchairs.

Over the years, Simon, president-elect of iNRRTS, the International Registry of Rehabilitation Technology Suppliers, has gotten up close and personal with the world of wheelchairs. He realizes that a properly configured wheelchair can help foster more confidence, independence and a better quality of life.

That growing wheelchair knowledge base set the stage for Simon's rewarding career in Complex Rehab Technology. His six-year U.S. Marine Corps stint as a helicopter mechanic prepared him for mechanical work. In 1988, Simon joined the retailer and MDA Telethon fundraiser Service Merchandise.

In 1993, Simon's energizing telethon experiences spurred him to become an MDA summer camp counselor. "It was a way to give back. It was something that could fill my soul up by helping people. And I loved working with the kids at summer camp," he remarked.

In summer 2003, Simon's chat with MDA leaders opened the door to a life-changing career. He was searching for healthcare opportunities, and an MDA team member mentioned a position at Majors Medical, a CRT provider.

During Simon's initial employment interview, he was asked what set him apart from "the guy on the street." He offered a memorable response. "For the past 10 years, I've been working with children with muscular dystrophy. Most of them have wheelchairs, and I've learned a lot about wheelchairs. The man on the street probably doesn't know anything about wheelchairs. That's what makes me different."

Naturally, Simon got the job.

Life-Changing Numotion Work

In 2015, Simon joined Numotion, a national CRT provider, and went to work in their Dallas, Texas branch office. Today, in addition to being a CRT supplier for Numotion, Simon serves on a multidisciplinary team at two area ALS and neuromuscular disease clinics. "They have a physical therapist, an occupational therapist and a speech therapist. A doctor, a neurologist, a nurse, a dietitian and a counselor are also team members." Simon is the indispensable "equipment guy."

Two Clients' Lives Transformed

During Simon's CRT career, he has helped "thousands" of clients improve their quality of life.

Heath's story

Heath, one of Simon's clients, has lived with ALS since his teens (a rare occurrence). Over the years, Simon and Heath have periodically connected at the ALS clinic, where Heath always declined a wheelchair. As his balance and gait worsened, though, Heath realized a wheelchair could help ensure his safety.

By then, however, Heath couldn't use his arms or control his foot movements. "We knew he had to go to chin drive. Eventually, we made it so he was driving with his lips. Your lips are kind of like pincers, like your fingers, right? We set that up for him. Immediately, because he was so intelligent, he was able to pick up the skill to be able to do it," Simon said.

As a Raytheon design engineer, Heath could keep working from home with his lip-driven joystick. "That was almost five years ago when I set that up for him, and he's still working today, using that same system," Simon said. "This allowed him to keep his house. It allowed him to send his kids to college. It allowed him to be gainfully employed. It just allowed him to maintain his dignity; that's the way I like to look at it.

"He's an amazing human, and he's my friend."

Dania's story

Simon was able to help 11-year-old Dania resolve a frustrating wheelchair-related issue. This young lady, affected by a rare form of muscular dystrophy, was having some equipment challenges. A case manager contacted Simon, who met with Dania's mother.

"Her daughter is just simply darling ... She's in a manual wheelchair. She has a power chair, but she doesn't like to use it. It's too big. Dania's really good at using her manual wheelchair, but it had gotten a little bit too small for her. At that age, kids grow. It's just what they do.

"We were able to get Dania's manual wheelchair widened a little bit, and we readjusted her smart drive. Dania was so excited to get a chair that fit her again. (She could push the chair) around, work with her friends and have fun with them.

"Dania also needed a standing frame. Standing is such good therapy, and she hadn't been able to do that because her standing frame was very old.

"It's really such a simple thing to be able to grow a wheelchair one inch to make it fit. With a standing frame, someone can realize the importance of standing," Simon remarked.

Simon's Greatest Reward

"The thing I find most rewarding is that I create a mobility device that gives people their independence back again. I create a device that people can sit on, drive, tilt, recline and elevate.

"They can actually operate their computer. They can operate their TV, their front door, and their phone from this mobility device. When you have ALS, and it progresses, you lose a lot of the ability to move your body.

"The mobility device that I design, deliver and set up for them gives them all of that freedom back ... That's probably the greatest gift I get from working as an assistive technology professional," Simon remarked.

How Clients Inspire Him

Simon admires his ALS clients' courage and resilience. "They inspire me every day. They have been given a terminal diagnosis. We all know we're going to die. You know, that's part of life.

"These clients, the majority of my clients, have been given the diagnosis of ALS. The doctor says two to five years. Some live six months. I've had one client live 20 years with it. No doctor can give them a linear timeline on what's going to happen when.

"With ALS, you go to sleep ... You could do things. Next morning, you wake up. You try to get out of bed. All of a sudden, you can't do it anymore. Now you have to go through all of the grief all over again. Most of my clients deal

Tom Simon loves going to Capitol Hill to advocate for those with disabilities.

During one of his many advocacy trips, Tom Simon visits the U.S. Capitol to help advance issues important to the disability community.

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Tom Simon and his wife, Staci, at one of their favorite places, Walt Disney World, celebrating America's 250th anniversary.

Quilt made from Muscular Dystrophy Association Summer Camp T-shirts gathered during Tom Simon's 30 years of volunteering as a camp counselor.

with the grief, but then they figure out: 'How the hell am I going to do my thing today? I'm not going to let this hold me down.' That inspires me every day."

Capitol Hill Advocacy

"I do a lot of Capitol Hill advocacy work for iNRRTS. We try to get senators and representatives to understand that what we're trying to do makes sense. I'll speak about iNRRTS and CRT. We're trying to get bills passed to allow people to have access to the equipment they need.

"If there were no durable medical equipment companies or CRT companies around, people would never be able to leave their house, much less move around in their house. They'd be sitting on the couch, or they'd be sitting in bed. And more than likely, they would die a lot sooner than if they had a mobility device," Simon emphasized.

CRT Predictions

"I've been doing this for 23 years. The technology that we have is light years from what it used to be. I think (generative) AI is going to play a huge part in the ability to drive a chair and the ability to function.

"Also, there's a tremendous amount of work going on right now with brain implants (neuro implants) to allow communication and allow function. I think in the next five years, we're going to see someone really driving their chair just by their thoughts.

Tom and Staci Simon enjoy a vacation in Switzerland.

Tom Simon in Switzerland.

"Now remember, if you can drive a chair, you can operate a computer, you can operate a phone, you can operate any environmental control in your house. Whether you have a door opener, a garage opener or any app that you could put on your phone, you can operate it through your wheelchair," Simon explained.

A Richly Textured Personal Life

When Simon isn't working with CRT clients, he spends time outdoors with plants, flowers and potting mix. "I'm a gardener. I work in the dirt."

Simon and his wife, Staci, enjoy visiting Orlando, Florida, theme parks. This year, they visited

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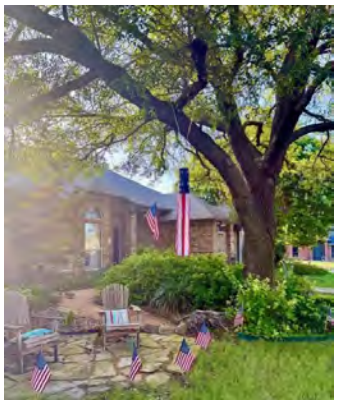
Epcot Center to celebrate America's 250th anniversary. He was pleasantly surprised by the Florida weather. "We had a great time. The weather that week was beautiful."

Looking back, Simon's career reflects a beautiful symmetry, as if guided by divine design. In each role, he has used his skills, bringing him great satisfaction while helping improve his clients' quality of life.

In his spare time, Tom Simon enjoys working in the yard.



Tom Simon's front yard at his home in Rowlett, Texas.

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