Aspen Times Weekly: Bridging Bionics to Rebuild Lives

June 2, 2016 by Kelly J. Hayes

INSIDE TRACK

While doing research for this story I learned about the mission of the Bridging Bionics Foundation and was enormously inspired. I wanted to do something to assist them in achieving their goals.

This week I turn 60 years of age. To celebrate, I have concocted a plan to achieve something that I don't believe anyone has ever tried before. I call it "The Running Decathlon." My goal? To run the 10 top racing distances over the course of the next year half as fast as the standing World Record in each event. The events are the 100m, 200m, 400m, 800m, 1500m, mile, 5K, 10K, Half Marathon and the Marathon.

This summer, I'll travel to the tracks and stadiums of Europe where the world's fastest runners set their record times. On the same date and on the same tracks where they achieved those world records, I'll run in their footsteps... slower... but just as determined.

In an effort to support the Bridging Bionics Foundation I plan to raise funds through donations to purchase an exoskeleton bionic suit for the use of those who are clients. I hope to turn my running quest into a platform to help others in their quest to walk.

Join me by helping however you can — a sponsorship, a donation, words of encouragement. You can literally turn dollars into steps. For more information, please watch the video at YouTube race2walk2016 or go to race2walk2016.com. To make a donation, please

visit the Bridging Bionics Foundation website at bridgingbionics.org.

You can also contact me at race2walk2016@gmail.com - Kelly J. Hayes

The threat of rain was not going to deter Tim Burr from his appointed rounds. After all, it had been 18 months since he last took a proper walk outdoors.

With his family standing by his side in a corner of the Snowmass Club, Tim placed a wooden board as a bridge between his wheelchair and the chair where "Tucker," the bionic exoskeleton suit that was laid out for his arrival, sat waiting. Dropping his head low and using the power of his arms to propel his entire body, he lifted his butt, maybe an inch, and maneuvered it onto the board. Then he wiggled and slid his body across the board into the chair and the embrace of Tucker. which would assist him on his walk this day.

For 15 minutes, Velcro wraps were strapped, sensors were positioned and checked, and care was taken to make sure Tim was as comfortable as possible in the

exoskeleton. It actually seemed

that Tim was more ready than anyone else. All he wanted to do was walk. Then the moment came. "Ready?" therapist Maria Grufstedt asked with anticipation. "Ready!" came the reply of the 20-year old man, displaying a confidence that is the hallmark of youth.

With that he rose, unfurling his frame from the chair and leaning on a pair of hand crutches with his arms extended and his legs planted firmly on the ground. The young man who had previously been looking up at everyone from under the brim of his Meier Ski cap was now looking down on them. At 6 feet, he was the tallest man in the room, taller than his therapist, his younger brother, his mother, and yes even his father who, out of necessity, had become much more than "just" a dad these last couple of years.

It took a moment or two for Tim to get acclimated. It must be like the end of a long climb when you get to the mountaintop and you are both elated to have arrived, but exhausted from the climb. You want to celebrate but the realization hits, you still have work to do.

With that Tim began his journey. He reached — no, he signaled — with his body movements that he wanted to take a step with his right foot. Tucker, the machine, taking the hint through the sensors attached to Tim's body, moved forward, making exactly the correct step in terms of time and space. Then the left foot took a step. Slow and a touch gangly at first, a rhythm soon developed, and after a dozen strides or so, Tim was at the door leading to the patio by the outdoor pool that sat serenely, reflecting the still snow-covered slopes of Snowmass.

As Tim walked out, standing tall in the sunshine for the first time since the fateful day in November 2014 when the tips of his skis dug into the snow and changed his life forever, he smiled. So did his father. His mother cried and his grandfather Sam muttered from under the bill of his straw cowboy hat, "If I hadn't seen it, I wouldn't have believed it."

Everyone was happy. It seemed miraculous.

THERE'S SOMETHING ABOUT AMANDA

"Oh sure, she's that beautiful blonde in the wheelchair," people say about Amanda Boxtell. Everyone in Aspen knows her, even if they don't. They have seen her over the years, in town doing errands, at parties and fundraisers, on the slopes or in the airport as she gets ready to take a flight to some far-flung destination in search of the future. They have fallen in love with her lilting Aussie accent and her irrepressible spirit.

Usually by her side is a Golden Retriever, first Tucker (yes, the bionic exoskeleton was posthumously named for him), and now Benson, who provides not just support and assistance, but also serves as an opening for people who want to say hello. It's just easier for people to make contact with someone in a wheelchair when they can come up, pet their dog and ask sweetly, "Is he a Golden?" It helps break the ice.

A ski accident on Aspen Mountain in 1992, when she was just 24 years old, crushed Amanda's T10, 11 and 12, and L1 vertebrae. Since that time she has made a life — an important, fulfilling life — seeking an alternative to spending her days committed to a wheelchair.

Going through all of the steps and down all of the rabbit holes in search of ways to help herself, yes, but now, even more importantly, helping others who have been impacted by spinal cord injuries. It has been an emotional and circuitous sojourn through various modes of therapies, legal and insurance mumbo-jumbo and the intricacies of the non-profit world in search of a platform that will allow her to achieve her goals.

After her accident, Amanda was a co-founder of Challenge Aspen in Snowmass. For 11 years, the organization, a nonprofit that enables individuals with disabilities to realize their potential through recreation in the Rocky Mountains, provided her with both a platform for getting back into everyday life and back to sit-skiing on the mountains she loves. It also became a focal point for helping others. But as time progressed and the technologies have changed, she has migrated to a new frontier.

Now, with the Basalt-based Bridging Bionics Foundation, Amanda may have found her footing at last.

THE BRIDGING BIONICS FOUNDATION

"I believe that for the very first time in the history of mobility impairment, we may be able to honestly tell people that there is an option beyond standard wheelchairs. That they may one day be able to walk again," Amanda says with the enthusiasm of both a nonprofit administrator and one who has actual "skin in the game." Her optimism is based on new technologies that have been created in the past five years that utilize electronic devices and mechanical parts to assist humans in performing difficult tasks by supplementing, or duplicating, parts of the body. That is the definition of bionics.

In March 2013, Amanda established the Bridging Bionics Foundation (BBF) to help people make the transition from spinal trauma patient to actually walking. The mission, according to the Bridging Bionics website, is "to provide funding and education, and to advance the research and development for exoskeletons and bionic technology to augment human mobility and capability. We envision that exoskeletons and bionic technology (will) become standard mobility options globally as we strive to improve the quality of people's lives."

Through donations, the non-profit BBF raises funds to purchase equipment, pay for therapists and support Able-Bionics USA, the overarching program that provides services free of charge for clients with mobility impairments. In October of last year, the Aspen Club and Spa, under the auspices of CEO-Owner Michael Fox, made space within their facility to house the operation and provide a home for clients and therapists. Now that the Club has closed for development until 2017, the operation has moved to the Snowmass Club.

HOPE IN SNOWMASS

The Friday that Tim took his walk outside by the pool at the Snowmass Club was just like any other at the small corner space where Bridging Bionics now makes its home. Patients, or clients, as Amanda prefers to call them, come in hourly for sessions with one of the three trained physical therapists on staff. Currently, there are 28 clients who utilize the services, but that figure is expanding quickly.

In addition to Tucker, the bionic suit, there are other technologically advanced apparatus that help patients with not just recovery, but also their day-to-day activities. A vibrating hand weight that was created for NASA and gravity-free

space flight helps tone the arms of clients who are often sedentary. There is also a table that will tilt upright once a client is strapped in, and then vibrate intensely under the feet.

Called the Galileo Neuromuscular Tilt Table, the stimulation system activates thousands of involuntary muscle contractions that intensely "exercise" the body in a short period of time. The Galileo was a gift to the Foundation from Lenny "Boogie" Weinglass, who has long been a supporter of the BBF.

While the bionic exoskeleton is the "sexy" apparatus, the one that generates the most attention, these other devices help patients perhaps even more. "To walk one day, all of our clients must have prepared their bodies for the experience," explains Amanda. "It may be using their upper body strength for support or having the lung capacity to move for a period of time. If you are not healthy to begin with, then you may not be able to make the most of the emerging technology when the time comes."

And just the seemingly simple act of being upright can have dramatic effects, both physically and psychologically. "When you are constantly sitting, there are complications that develop," Amanda emphasizes. "Your body temperature varies, your bladder and bowels lose their ability to function, muscles break down. If you do not move your body it will atrophy and die." By using the Galileo Table, these effects can be modified.

Clients are also able to do something that puts them at eye level with others, to allow them to see the same view from above that they had before their injury. "You know, I always hated cocktail parties," Amanda good-naturedly laughs. "It's not fun to be constantly looking up at people. Here on the table, when it is raised, you just get a different view of the world. It really makes a difference."

ABOUT THE EXOSKELETONS

Amanda has currently taken somewhere in the neighborhood of 140,000 steps in bionic exoskeletons, not quite the distance from Glenwood Springs to the top of Independence Pass. Her first walk took place in 2010 when she was invited by a company called Berkeley Bionics, now known as Ekso Bionics, to come and "test-pilot" a prototype for a National Geographic special.

Today, there are as many as seven companies in five countries working on

production of various exoskeletons that range in price from \$70,000 to over \$100,000. Weighing between 22 and 50 pounds each, the quest is to make them more affordable and lighter so that they may become more mainstream. In 2014, the "ReWalk 6.0" system, made by an Israeli based company, became the first exoskeleton to be approved by the FDA for at-home use with a spotter.

One of the most exciting innovations in recent years has been the production of suits produced using 3-D printer technology. These custom-made suits share technology with other designs as they work to meld the subtle movements of the body with the machine enhanced support. "These are an amazing example of the power of combining science, engineering and the human spirit," Amanda enthuses.

It is technology that can make a difference.

IT TAKES A VILLAGE

Given the facilities that have been made available (first at the Aspen Club and now at the Snowmass Club), the equipment that has made its way here through generous donations, and the personal resolve of Amanda Boxtell herself, there is possibly no place better to be than the Roaring Fork Valley if one suffers a serious spinal injury.

Consider the Tim Burr story. Injured in November 2014 while backcountry skiing off Kebler Pass, Tim rode in an adaptive sit-ski this past winter, allowing him to not miss a single ski season despite a severe C-5 spinal cord injury.

Or 18-year-old Mackenzie Langley, who was nearly killed in an Aspen automobile accident in June 2014. This February, Mackenzie walked in a bionic exoskeleton alongside Amanda at a Bridging Bionics fundraiser, and she is now preparing for college.

There are others. The Christopher and Dana Reeve Foundation estimates that there are as many as 5.6 million Americans, that is 1 in 50 of us, who are living with paralysis. The Bridging Bionics Foundation is trying to make a difference in those lives.

But perhaps just as significantly, there are people in the Roaring Fork Valley who are not impaired but who have been impacted by the mission of the Bridging

Bionics Foundation as well. Volunteers like Nancy Nevin and Michele Peterson show up at the facility to help with the day-to-day tasks of getting clients out of their wheelchairs and ready for their exercises or stints in Tucker. Each expressed their joy at being able to share in the experience of helping others work to achieve their goals.

Philanthropists like Boogie, and Greg and Billie Erwin, have held fundraising events in their homes or raised donations for the BFF. And Missouri Heightsbased photographer Summers Moore took her talents to the Aspen Club to produce a series of black-and-white portraits of the clients and therapists that tell tales of courage and perseverance in ways that words simply cannot.

And then there is 6-year old Lilly Anna Sirbu of Basalt. On the day that Tim took his first walk outside he was able to actually see himself in a new mirror as he was strapped into Tucker. Lilly Anna had heard that the mirrors in the Snowmass Club were too high for the clients. She went to the Habitat for Humanity store and found one that was just the right height. Her donation made things a little easier for everyone.

It's just possible that, for those who care about helping others, there is no better place to be than the Roaring Fork Valley as well.

BACK TO TIM'S WALK

Tim Burr's walk that spring afternoon saw him take 833 steps — about a third of a mile. But those 833 steps transcended time and space. They were about hope. The hope that one day in the many days that Tim has ahead of him, technology, medicine, science and will power will all coalesce to help him walk on his own, of his own free will.

It is a hope that would not have seemed possible just a few short years ago. Now, in the Roaring Fork Valley, a bridge is being built to help make it a reality. And one day, with the help of Amanda and the Bridging Bionics Foundation, Tim, Mackenzie and others like them just might cross it.

Online Link: <u>http://www.aspentimes.com/news/22201001-113/aspen-times-weekly-bridging-bionics-to-rebuild-lives</u>