



# Reeve Report

CHRISTOPHER & DAVID REEVE FOUNDATION

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ROBUST RECOVERY FROM  
PIONEERING RESEARCH**

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## THE KEILS: MAKING CHOICES, NOT ACCEPTING 'NO'

**M**att and Tracy Keil may well be the poster parents for working the system, fighting for what they need, and living their lives on their terms.

Tracy and Matt were married in 2007 just before Matt, an infantry squad leader and seven-year veteran of the U.S. Army, was deployed to Iraq for his second tour. Just 43 days later, a bullet hit Matt in the neck. It injured his spinal cord and left him a vent-dependent quadriplegic.

A situation of total chaos eventually settled into a new normal for the Keil family,

the gatekeepers and refusing to accept no for an answer.

"I see many of the spouses who accept no," says Tracy, who quit her job to become Matt's advocate and full time caregiver. "Not me. The squeaky wheel gets the grease. I squeak a lot."

Matt was first transferred to Germany, then to Walter Reed Army Medical Center in Washington, DC; once stabilized he was sent to the Department of Veterans Affairs hospital in Tampa, one of four big poly-trauma units in the VA system. While

older vets just lived there at the hospital. We understood that Matt would probably be there a year, living in some sort of assisted living situation."

Matt was eager to get back into the community; he felt restricted. "They didn't teach us about travel or getting out," says Matt. "They wanted us to stay put. We were begging for an outing. We got no response, so we just left. We weren't supposed to go off campus but we went to Hooters, and we got in trouble for it. They only found out about it because of Tracy's *CaringBridge.org* website."

Tracy didn't know yet if she and Matt had any choices but she and her sister did some research. They reached out to the community of vets and community organizations, including the Reeve Foundation. They found out there might be options for Matt, that the Department of Defense and VA allow and pay for some patients to seek care and rehab at specialized private facilities. The VA health care system doesn't promote the private care option; families hear about it word-of-mouth.

Craig Hospital, which comes up in almost any discussion of quality SCI rehab, was the closest place to Tracy and her family, near Denver. Calls were made, arrangements were set forth; Matt was accepted as an in-patient at Craig. The paperwork needed the signature of Matt's doctor, a neurologist at Walter Reed. The Keils, however, were told the transfer to Craig was denied. Tracy, naturally, did not accept this. She tracked down the doctor and asked him to explain himself: why wouldn't Matt have a better shot at rehabilitation at Craig? "He said, 'I have 25 emails about you and Matt but I never denied this request to transfer. I don't know what's going on.'"

Tracy broke the news to the rehab staff. "We gathered the whole SCI team in Matt's room. 'We are leaving. If we have to bring in the media, 20-20 or Dateline, whatever it takes.'"

The spouse, says Tracy, has to get real tough, real fast. "Service members are told no; it's ingrained in them that no means no. I'm not in the military," says Tracy. "I don't have to abide by those rules. Matt may have to follow protocols with regard to rank and so on. But I can talk to whomever I want in the manner I want."

Within days Matt was flown to Denver



Tracy Keil places Matt Jr. in his dad's lap.

now living in their own 2,500 square-foot home that was built and donated to them by Homes For Our Troops, and taking care of two seven-month old babies.

None of this would have been possible without recognizing choices, challenging

the VA has great expertise in spinal cord injury, Tracy and Matt soon began to wonder if they had any options for a more aggressive approach to recovery. Tracy asked, "This is what life was going to be like? The rehab unit was like a nursing home; many

and began rehab at Craig. He was off his vent in four weeks; a pressure sore healed. "Craig is such a welcoming place," says Tracy. "I know he is much more independent now because of the care he got there."

Once the Keils were settled in their new house, they set out to start a family. Tracy says she was often told that she and Matt should not have children. "I don't think because he is injured we should dream less than anyone else does." So they found a fertility clinic in Denver, and through *in vitro* fertilization welcomed twins Matt Jr. and Faith to the world last November. The twins were very premature and very small, around three pounds each. Says Matt, "Both babies had health problems that were similar to mine when I was injured. They were on ventilators, had chest tubes, were on oxygen...it was all so similar; they overcame everything like I did. My kids are both fighters, like their parents."

Both babies weigh about 18 pounds now; they are healthy and active and just about sleep through the night. Matt is an attentive dad; with the help of an adaptive holder, he's been bottle-feeding the babies.

**T**oday, injured soldiers and their families often reach out to the Keils. Says Tracy, "People are told, 'You want to connect with the Keils. You want the life they found.' And it's true. We found our future. We know where we are going to be. We also recognize there are many past vets who fought for our benefits. We know it's our turn. We are there to help, never too busy to help someone get where they need to go. We want people to know they do have options."

Tracy recently learned of a family with circumstances very similar to hers and Matt's. A young soldier who was shot in the neck in Iraq was in a VA facility on the East Coast. His newlywed wife wondered about their choices. Tracy helped hook the couple up with the Military and Veterans Program (MVP) at the Reeve Foundation Paralysis Resource Center and coached them on seeking options, including private care. "They realize now there may be an alternative. They still have to work this through the system. But we're hopeful for them.

"This outreach is a way for us to give back," says Tracy, "to be able to pass along a gift, the one we received. We feel like we are so blessed to have a chance to help make a difference in other family's lives."



Tracy and Matt Keil with Faith and Matt Jr.

Sam Maddox

After years of dealing with the VA, Tracy has earned her stripes as a fighter. It's a role she won't shrink from but would love to let go of. "Despite what the VA must think, I don't enjoy battling with them for every little thing. It would be nice to just be able to just ask for something and have them say 'Sure, it's in the regulations, here you go.' That would be wonderful."

It's never quite that easy but it may be getting better. Recently the VA agreed to offer compensation to caregivers of wounded warriors. This came about because of constant pressure from families and caregivers themselves, including Tracy. "I take wonderful care of Matt and I enjoy it," she says. "But he would be institutionalized without me. It's nice to be recognized for my role in his independ-

ence. They should value what I do."

Says Matt, "It's great the VA is finally recognizing the sacrifice spouses and caregivers have made."

### Military & Veterans Program

The Reeve Foundation helps service men and women with issues related to paralysis, as well as benefits and services.

See [www.christopherreeve.org/military](http://www.christopherreeve.org/military)

Ask our MVP experts a question:

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Email: [Military@ChristopherReeve.org](mailto:Military@ChristopherReeve.org)



## EPIDURAL STIM PIONEER SUMMERS: ROBUST RECOVERY

Rob Summers was known for having what they call a 12 - 6 curveball. It's the nastiest pitch in baseball. "That's the one that breaks straight down, clockwise," he says. "I also had a mid-90s fastball and a very effective cutter. I had gone in as a starter but because of my velocity and ball movement, I was moving toward being a closer."

In July of 2006, Summers, not yet 21, was playing for the Aloha Knights, based in Portland, OR, part of the West Coast Collegiate Baseball League. He was headed toward his junior year at Oregon State, which had just won the college World Series. "Ever since Little League it had always been my dream to play professional baseball. I was in the best shape of my life, pitching as well as I ever had, and continuing at that rate, I was expecting to be a key player on the college pitching staff. Everything would have fallen into place for the Major League Baseball draft the following year."

Pro ball wasn't meant to be. That July Summers was mowed down by a hit and run driver. He was spinal cord injured, paralyzed below the chest.

Last May, however, news broke of Summers' remarkable recovery. In an experiment funded in part by the Reeve Foundation, he was the first patient to get an epidural stimulator implanted over his spinal cord. The epidural stim, plus aggressive Locomotor Training on a treadmill, enabled Summers to stand on his own, take steps and after seven months, to the surprise of the research team at the University of Louisville and UCLA, regain voluntary motor function when the stim was on. Even more surprising, Summers regained bladder control and near normal sexual function, even when the stim was off. The research team speculates that this unprecedented recovery was due to the epidural stim awakening spinal nerves or by way of nerve sprouting

or regeneration triggered by training.

The Rob Summers story is about the long road to scientific discovery. It's also a testament to stubborn motivation; there is drama, even romance. Summers tells his story to Reeve staffer Sam Maddox.

*So, the driver hit you and just left you there?*

Right. It was a Tuesday night. I was going out to my car to get my workout bag. I was

I know about the window of early acute care and I did speculate: what if I had been found earlier. But after speaking to my surgeons, they said I had been one of six hit and run victims in Portland that week, that I had come in with the worst injuries. I had far more severe injuries than the other five in the ER with me. They thought I wasn't going to make it. But as it turned out I was the only who survived. I was able to leave the ICU in three days.



Photo by Christopher Voelker

*Then what, rehab?*

I was in trauma care for seven days and was transferred to an inpatient rehab center; they wanted to keep me for three months. I convinced the doctors at about six weeks to let me go home.

*Had you plateaued?*

No, I was still recovering. I thought I could improve more being at home trying to figure out how to take care of myself as opposed to having everything done for me. As I have learned through my sports career, anytime I am put in a situation where there is adversity involved, overcoming that makes me stronger mentally and physically. From day one, I set some very high goals. I knew to achieve those I'd have to be out of the hospital.

*So, coming to terms, getting used to the idea that there is a tomorrow ...*

It was very difficult to comprehend everything. Overwhelming. Being told I will never move again, never feel again, never stand again, never walk again or never play baseball again, I had that going through my head as well as trying to learn what all this means. I mean, learn how I can fix it. The most difficult part to comprehend was that my goals and dreams, since I was a little kid, everything I had ever known, baseball, was taken from me in the blink of an eye. But I learned that moping or dwelling

standing at the end of the driveway; in the corner of my eye I saw headlights coming around the corner too fast. The car took out my legs, I flipped up on the hood, landed on my neck at C6, leaving me paralyzed from the elbows down. I was trying to yell for help but nothing would come out. The car kept going. About four hours later a neighbor found me. My ankle had been shattered; there was blood everywhere. I was unconscious.

*It's not fair to speculate but supposing someone had found you sooner?*

on the situation and saying the what-ifs, it would only put me further into a mental state that would be harder to improve.

*That transition isn't easy.*

Definitely there were days when I was very frustrated, upset, sad about the whole situation. What I could have been doing, where I could be today, those kind of feelings would come in but I would look towards my support system. I had friends and family to fall back on when I wasn't able to be strong for myself.

*You said you set goals. What were these?*

Initially, to get my hands back. I couldn't feed myself, couldn't flip through the channels with the remote, couldn't do anything with my hands. I exercised my hands six to eight hours a day. My right pointer finger came back first, then I could move all fingers, in unison, then I could individualize each finger, then, after about a month, I could make a fist. I worked on strengthening it until I could pick things up again. Eventually I regained strength to the point I could do pull-ups and hold my weight on a pull up bar with just my fingers. My next goal was to regain feeling and to be able to stand independently, then to take steps on my own.

*What was the word from the physical medicine professionals around you?*

They were very positive with me but they also tried to keep my goals realistic. They would say, 'That's a great goal, great thing to work toward, but as you work with that let's get you comfortable living day to day life in a wheelchair.' It was my doctors who said I would never stand again, walk, move, feel again. I said to them, 'Obviously you don't know me very well. When I set a goal, I achieve that goal, no matter how long it takes.'

*So you went on your own...*

At that point, I knew that instead of passive hospital therapy I wanted to find something more physically challenging. I ended up at Project Walk at Portland [now closed]. I was there a year. This helped me get my hands and upper body stronger. I said to myself, 'OK, now I've got my first goal done, now on to next, to stand.' They did

good things in Portland but I felt there were other places in world that could do more.

*There's a lot to sort out.*

My mom and dad were on the Internet nonstop. We started sending emails to every Reeve Foundation NRN [NeuroRecovery Network] center in the U.S., to doctors and rehab centers from London to Israel, China, Brazil, all over the world. We tried to match me with what we felt was the best program. We ended up at TIRR in Houston at the NRN center. The first time I went down I didn't qualify. They sent me home to continue my training. I was too complete. I spent the next six months getting stronger. Finally we got a call from TIRR; they wanted me back down there.

*You strapped in and went to work?*

I met with Susan Harkema in Houston; she was in from Louisville, KY, doing a training. She liked my attitude, she liked how much I had recovered on my own just through my work ethic. After about three weeks at TIRR she invited me to Louisville. I liked the program, everything they were doing was absolutely what I wanted to do. Susie got me doing daily doubles as they called them, stepping in the morning on the treadmill, then stepping in the afternoon. I did upper body exercises in between just to try and qualify for a human experiment she had hinted to me about. I did all I could on my own. I plateaued for a year and a half, two years.

*As it turns out, that's what the experiment called for – for you to have leveled off – no motor function, some sensation.*

Dr. Harkema didn't really tell me much. She never told me that I had to be at plateau level. But I learned what I could about this area of science, what Reggie Edgerton has done at UCLA with the animals and what Susie and her team have done with the NRN. I read every article dating to the late 1950s.

*So you're doing locomotor training for 26 months and then one day, hey, you are it for the big experiment?*

After I had done all those months of sessions Dr. Harkema goes, 'Well, we think

## EPIDURAL STIM: THE FACTS

Epidural stimulation applies continuous electrical current, at varying frequencies and intensities, to the lower part (lumbosacral) of the spinal cord. An epidural stimulator with 16-electrodes was implanted over the spinal cord of a human subject at T11-L1. This corresponds to dense neural bundles that control movement of the hips, knees, ankles and feet.

Rob Summers, who has no muscle control below his chest, was able to reach a standing position while his spinal cord was being stimulated. He was able to stand independently, bearing full weight, for up to four minutes at a time without assistance. When stimulated and suspended on a treadmill, he was able to initiate robust, rhythmic stepping movements, with assistance in placing his feet. Prior to using the stimulator, Summers underwent 170 Locomotor Training sessions over a period of 26 months, with no effect; the treadmill therapy alone did not affect his function.

After seven months, Summers could also voluntarily move his toes, ankles, knees and hips. The research team was surprised by this. They speculate that this voluntary recovery may have been caused by the epidural stimulation awakening weak spinal nerves. The recovery may also have been the result of nerve regeneration or sprouting from activity-based training.

Epidural stimulation is not the same as functional electrical stimulation, which directly activates muscle. In this case, epidural stim activated nerve circuits that exist in the spinal cord, substituting for nerve signals that would normally have come from the brain to modulate these spinal networks. Stimulation of the spinal circuitry itself activates what scientists call a central pattern generator – a network of nerves that are able to initiate stepping function without input from the brain.

It turns out the spinal cord is, to some degree, "smart." If certain sensory information is provided, the spinal cord can recognize this information and respond by generating a stepping pattern of muscle activity. This activity can be enhanced with repetition and training. The spinal cord retains a level of automatic function; the spinal cord already knows what to do, it just needs to be reminded what to do, which is what happens as sensory information comes from treadmill stepping. Motor function can be improved if nerves in the lumbar spinal cord are made more receptive to sensory information. This is what electrical stimulation appears to do. In animals, it has been shown that certain drugs also increase the cord's sensitivity and further improve motor recovery. No such drugs exist yet for human trial.

we want you to be the first candidate.' She never told me specifically, but from what I've heard from trainers is that it had to do with my athletic background, my drive, determination and focus, as well as my willingness to go through this.

*Your parents deserve major credit....*

My mom was supposed to retire five years ago. She's a school teacher; she kept working to make sure that I was taken care of. Everything I did in the research was funded by grants and CDRF, none went to me. My family supported me the entire time.

*Now the date has been set for surgery? They laid it all out for you?*

The FDA came in in November 2009 and said the team in Louisville could proceed with the first human. Within two and a half weeks, we were in surgery. The last thing I remember, I saw doctors and scientists all in lab coats or gowns, there must have been 50 people in there. Before I went under, one of the doctors said, 'Ladies and gentlemen, we are about to witness history.' Up to that point I had been too close to all of this to understand the big picture – I realized then just how many people had gone into making this happen. I understood how big an impact this was going to have.

*Any second thoughts?*

No. I signed a number of consent forms, which were pretty scary; there are so many unknowns. They listed everything and anything that could possibly happen – including death and everything else. At some point you have to yield to it. I looked at it as having trust in everyone around me. I said, 'Lets go, let's do this.' Whatever happens, happens. I'm going in with an open mind so if it benefits me, wonderful, if it doesn't, then you guys will learn enough that will improve everyone after me and I'll later be able to come back to the new improved stuff.

*OK, they put the stimulator in, sew you up. When did they turn on the switch?*

We turned it on right after Christmas. I was excited and anxious after two weeks of bedrest. I didn't know what to expect. They said we're going to take it extremely easy for the first month until everything

healed. On the third day, they said, 'Let's just see how it goes to stand.' They put me in a harness over the treadmill suspended 100 percent. They lowered it down and down until I'm standing, full weight-bearing. It was just an incredible feeling. I hadn't moved anything in four years. My legs were supporting me. There was nothing to help me balance. I could feel my legs working, I could feel my feet under me on the treadmill.

*Videos of you standing up show you leaning forward from a seated position. This provides sensory input your nervous system needs?*

Yes, you have to load weight on the legs to get the sensory input to trigger the pattern for standing. If you were to stand up now, you would lean forward, put weight on your legs and stand up. I do the same thing. Once my weight goes into my feet, I tell my legs to stand up, I pull myself up, my quads activate, my glutes activate, it pushes me up.

*Everyone was surprised how soon the stim activated patterns for standing and stepping.*

True, we accomplished in weeks what they thought might take years. Then, after seven months we found out that while the stimulator was on, I was able to voluntarily control my toes, ankles, knees and hips, on command. This was something that was completely unexpected. The research team didn't think that was possible.

*And when it's off you have sensory function?*

When I used to go out in hot weather, I was unable to sweat. My blood pressure would rise, I would get autonomic dysreflexia and a wide array of things. The summer after the surgery I was in Florida coaching a baseball academy –in the heat of the day in the hottest month, eight hours a day, it was hot but I was sweating. Also, I have feeling back when my bladder is full and can even void on my own. I used to have a bowel program, now it's when needed, as needed. Circulation in my body is better; I feel healthier overall, my skin has improved, I don't worry about pressure sores anymore. My cardiovascular is better. My lungs are better. My urologist a while back told me that in order to have kids I'd have to do this and that, and it was tens of thousands of dollars for everything to make it happen. More recently, he said I

will be able to have a family completely normally.

*When the stim is off, any motor function?*

No. I am getting a little bit of toe movement but it's not enough or consistent enough to say I have motor function.

*You still fire up the stimulator?*

Two hours a day, an hour of standing and an hour of voluntary movement. I'm getting stronger everyday. I can stand independently for longer durations, without a break. I used to try for two or three reps. I can now pick my knee up and put it down, 40 times, that's huge progress.

*A documentary is being made?*

Yes, we want to show the process of what I've been through from surgery to the first few months of the training. We are also looking at doing a feature film, with more of my life story going in to it. My girlfriend is a screenwriter and actress, that's how I met her. We have a mutual friend from Portland. He called her and told her I was going through this amazing once-in-a-lifetime surgery, that we needed to document it. The only person he knew in Hollywood was Rachel; she put together a crew, came out as producer the night before the surgery, and filmed everything after that. We fell in love.

*How far do you see this going?*

I want to thank the scientists and the Reeve Foundation for supporting them. The researchers will test this in others, fairly soon. Then, I believe in the next two to five years, we are going to see lot more development and refinement. There is a lot of work to do but with improved technology and better understanding of the biology, I think in a few years we will see this in a clinical setting, in wide use around world. Epidural stimulation and training – and perhaps a drug that will come along – will give so many the opportunity to recover. They didn't expect me stand on the third day. They didn't expect me to move my toes and knees and hips on command in seven months. They didn't expect me to take steps. No one knows what the future holds. In my mind, it's up to how hard I work. How hard I want it. How hard I push myself.

# PLANNED GIVING AND THE ART OF PAYING IT FORWARD

*Philanthropy is the engine that powers the Reeve Foundation's mission: without the generosity of individuals and families compelled by the legacy of Christopher and Dana Reeve, the Foundation could not address the health and quality of life of people dealing with paralysis. This financial support is most common when donors are alive. In this article, we will visit three donor families whose generosity reaches into the future, beyond their own lifetimes.*

**J**ohn McConnell is a Reeve Foundation Board member; he heads up a committee to spur development and fund raising. You can't tell by looking at



John McConnell

him but McConnell experienced a severe spinal cord injury after a bike crash. He recovered but the close call ignited in him the need to join the Reeve cause. "After I had my accident, I was reminded

of the importance and need for resources and help; when you're part of a community you have to support people who can't do things on their own and who require time, commitment and money from those able to offer it."

McConnell offers his time and money to the Foundation; he raised thousands of dollars two years ago, for example, running the New York City Marathon, alongside Matthew Reeve. McConnell has also made plans to leave part of his estate to the Reeve Foundation.

"My estate gift is through my life insurance, which is perhaps the most simple way to approach this. You aren't taking away from those you care about because often those funds are not typically available to anyone while you are alive.

"It can be a tough thing to talk about, death, but I've gotten close to it a few times. It's part of the deal. But people often wait too long or until the very end to deal with this issue. I find it liberating to deal with it now so in the event something were to happen, it would not burden my family.

"Estate planning or making a will doesn't have to be a complicated process.

You hire professionals to do it. You know what your numbers are. I know what my children and my family need, and I know what others need. That's a part of it. If you are in a fairly good place, there is room to extend your giving for many years down the road.

"I feel that we have a responsibility when we are able to take care of ourselves, which most of us are, to give back and to pay forward.

"Ask yourself, how do you want to live your life? I know how I want to live mine. I want to be kind to people. I hope the world is better off because of my contribution. Since I have the opportunity, I will leave behind resources to help push ahead on issues that are important to me."

**G**ladys Field was a homemaker her entire life but when her husband Norman died in 1991 she took over the family finances. She had worked as a mathematician during World War II and seemed to have a knack for investments. Before she died in 2009 at 85, Gladys made arrangements to leave several legacy investments.

"My mother was a very bright woman," says Richard Field, one of four children. "When she became a widow she really took the reins with regard to the family's finances. She kept the family house until she had a stroke and then moved to an assisted living facility."

Gladys had managed her resources well. She made plans before her death to invest in several charities. "She looked long and hard at how to best disburse her funds," says Richard. While the Field family had no direct connection to spinal cord injury or to Christopher Reeve, Gladys set up a charitable annuity trust to make an annual gift to the Reeve Foundation for 10 years.

"My family was always drawn toward science and toward medical research and health," says Richard, who is executor of Gladys's charitable trust. "She was very careful to pick an organization to fund that was the most productive, most exciting, and most useful. She liked the fact that the Reeve Foundation was working toward medical cures, but also that the organization addressed the care side too."

Richard said that when his mother made up her mind, she was living in an assisted care facility, and appreciated how

quality of life was directly affected by the quality of her care; this too resonated with her commitment to the Reeve Foundation.

"As a family we are very pleased my mother was able to make a contribution to the Reeve Foundation. We see good things there and trust the money will be used wisely," said Richard.



Gladys Field

**B**ill Day recently retired from a long career in computer programming at Lexmark. He and his wife have grown children and a six-year old grandson who is the light of their lives.

Day joined the spinal cord community 22 years ago after falling from a roof. He remained active in family and business affairs and has been recognized for his community service. Day was attracted to the Reeve Foundation many years ago; its mission was his mission. After years of making annual gifts through the Reeve direct mail program, Day wanted to do more; he updated his will to include the Foundation in his estate plans.

"We're in good shape for our retirement," Day said, "and I have always considered myself fortunate. I want to give back, not only now but also beyond my lifetime."

Each of these donors, leaving legacies through diverse giving vehicles, has been welcomed as a member of the Reeve Foundation's *Michael A. Hughes Planned Giving Society*, an esteemed circle of friends who have made generous commitments to include the Foundation in their estate plans.

*For more information about how you can leave a lasting legacy in support of the Reeve Foundation's mission, please contact Patricia Stush, Director of Development, at 800-225-0292, ext. 7112.*



Bill Day

# PEER MENTORING: ONE-ON-ONE WITH THE REAL EXPERTS

**B**ill Cawley tells a hypothetical story about how peer coaching might click between two people with seemingly nothing in common except quadriplegia. Cawley, Director of Community Programs Development for the Reeve Foundation, rolls into a hospital room to meet a man to whom paralysis is very new, and very much a bad dream; he may be scared, he may be mad, he is usually

in some stage of denial.

“So here’s the guy sitting in rehab. His nurse tells him, ‘You can live a great life, you have all sorts of options.’ Yeah, right. He’s in bed with bolts in his head. In I roll. “Hi, I’m Bill, sorry I’m late, I just got out of work and couldn’t find a place to park.’ Then my cell phone rings. I take the call. “Yes, honey, I’ll pick up the diapers.”

In less than a minute the guy knows Cawley has a job, that he drives a car, is married and has a family. “And most importantly, he’s hearing it from a guy in a wheelchair, not from a doctor or therapist. “You just can’t measure the difference getting the message from a nondisabled professional versus a peer – from someone who has been there. But someone who also appears to be thriving, realistic and optimistic.”

Twenty years ago, when Harold Aguilar was first injured, he was visited by an SCI peer, a quad with about Harold’s level of function. It wasn’t dramatic. “I didn’t take it seriously,” says Aguilar. “I just didn’t feel the need to discuss my situation.” But soon after Aguilar got into outpatient rehab, staff couldn’t help but notice what he describes as a “let’s get into the swing of it” attitude; they often asked him if he wouldn’t mind paying a visit to a patient in the earliest days post-injury. “I got roped into being a coach or peer counselor as a favor to my therapists.” Aguilar liked it, got good at it, and has been peer coaching at the

Kessler Institute for Rehabilitation for many years. Aguilar, a veteran Information Specialist at the Paralysis Resource Center, is now Coordinator of the Peer & Family Support Program (PFSP), helping to build a national network of mentors.

“I can totally relate to the people who give us the brush off,” says Aguilar. “We have to be patient. We’ll be there for them when they are ready, when they do have questions. We’ll feel them out, let them talk. Of course, many newly injured patients want to talk to a mentor fairly soon after they get to rehab. They want to know about driving, about sex, about bowel and bladder issues. They want to know how this wheelchair lifestyle works.”

In many ways, peer mentoring is an extension of rehab. Many newly injured folks are discharged from rehab before they have all the tools they need to manage their paralysis. Says Aguilar, “They just get them stabilized. They send them out of rehab without the right equipment, and with less



**CHRIS CHAPPELL**, Graduate Relations Coordinator for Craig Hospital near Denver, is Rocky Mountain regional coordinator for the Reeve Foundation Peer & Family Support Program.

I fall back on my 20 year career in investment banking. We are blessed with two ears and one mouth – always do twice as much listening as talking. I apply that same style to patients. I may ask open ended questions, who they are, what they are about, what their interests are, what their focus is, what they are upset about. But I spend a lot more time listening. They will lead you down the path of where they want to go. Then it’s a matter of finding the resources for what they are interested in.

The key is to show these folks that the world is still a very wide open place. I keep them open-minded; the door to life is not shut. You just have to figure out which door you want to open, how you want to open it and where you want to go with it.

Probably 80 percent of those who are spinal cord injured never see a specialty hospital. They don’t know what the Reeve Foundation is, they never see a place like Craig or Shepherd, or TIRR; they may be in a stroke ward in the middle of Des Moines or somewhere – wearing diapers when they leave the hospital. I encourage people to engage in the community, at the Reeve website, for example. Ask questions; don’t be a hermit. Don’t stop moving. What ever you define as movement, keep moving. Get on with life.



**PAUL MORTENSON**, right, with Reeve SVP Joe Canose. Mortenson’s Arizona peer network is the model for the Foundation’s program.

When to go in? This of course depends on the individual. We have had families ask us to come in right away, to the emergency room. Typically we wait until the hospital notifies us that the individual is ready. We depend on rehab staff.

What makes a good mentor? The ability to listen. And it’s really important that the coach has an injury. I can counsel families but not the person who has been injured. We want people who are passionate about helping other people. We need them to have good social skills.

than the appropriate amount of education to effectively manage their situation. Many don't know what a bowel program is."

Enter the mentor: "What we want our peer mentors to do," says Aguilar, "is to be a tour guide to a person's new lifestyle. We want to be able to point them in the right direction when faced with the obstacles."

Paul Mortenson's daughter Wendy was spinal cord injured in 1997. She didn't have anyone her age or level of injury come to see her in rehab. When she got home again she was nowhere near prepared for her new life. "At that time there were no services in the state, no support groups, no peer-to-peer support, no social recreation programs, nothing. As parents, we knew nothing about spinal cord injury. I knew Christopher Reeve broke his neck but I didn't know a thing about paralysis."

Mortenson did some research and talked to others, including those with injuries. "We realized we needed to get information to people and the best way is by way of peer mentors. We started the Arizona Spinal Cord Injury Association in April of 1999. A peer mentoring program was one of the first things we implemented." As many as 400 people with SCI joined the peer network, with as many as 200 active, Mortenson said.

The Arizona program is in many ways the model for the Reeve initiative to create a national peer-to-peer network. Last February, a group of 15 in Phoenix became the

first to get certified as Reeve peer mentors. That was followed by a training in Jacksonville, FL. More trainings are in the works to add counselors to eight national regions, each now overseen by a part-time coordinator.

The certification process involves a nine-part online module to assess each candidate's basic knowledge of SCI and related topics, as well as awareness of resources and connections to the community. A full day of training then takes place in each region. The curriculum and certification process was developed by Tony Cahill, Ph.D., from the University of New Mexico.

Says Joseph Canose, SVP, Quality of Life for the Reeve Foundation, who oversees the PFSP, "The need for those living with paralysis as well as family members and caregivers may never be greater. Hospital stays for the newly injured have been reduced three weeks in some states; services at local and state levels have been reduced and all but vanished in some cities and states. This void in service and support will most likely continue to grow; a national peer mentoring program can help fill that void. We believe in empowering those affected by paralysis with the best knowledge, resources, support, and community. The PFSP will provide critical emotional support as well as local and national information and resources."

Cawley notes that there is a public

health policy aspect to the peer-to-peer program: "Our goal is that a person being mentored will have a clearer understanding of his or her body, and of maintaining health and wellness. In particular, we want them to be wary about avoiding secondary conditions – skin sores, bladder infections, depression, and so on.

"We also want to initiate an honest, realistic and optimistic discussion about the future. We want people to have peace of mind that they are part of a nationwide community, that no question is too small, that nothing is off limits."

For more about the PFSP, see [www.ChristopherReeve.org/Peer](http://www.ChristopherReeve.org/Peer).



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**THE REEVE REPORT**  
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*Produced and edited by Sam Maddox  
Cover photograph by Christopher Voelker*

## REEVE FOUNDATION GOES PREP WITH VINEYARD VINES

Break out your seersucker and madras plaid – the Reeve Foundation has gone prep. During the months of June and July, the Reeve Foundation partnered with vineyard vines®, the preppy, beach-inspired clothing company famous for its printed silk ties and smiling pink whale logo, through the company's Tied to a Cause program.



vineyard vines highlighted Matthew Reeve, Christopher Reeve's son and quality of life committee member, and Michael Murphy, an elite handcyclist, member of Team Reeve® and Paralympic hopeful, in a three-page spread in their summer 2011 catalog; Matthew and Michael modeled clothes from the company's summer line.

As a Tied to a Cause partner, the Reeve Foundation received 100 percent of the proceeds from the sale of a special tie that was custom designed with tiny flying superheroes in Reeve Foundation colors.

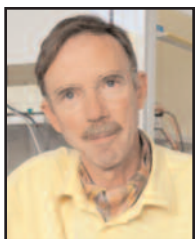
See [www.vineyardvines.com](http://www.vineyardvines.com).

## CONSORTIUM ASSOCIATES: ENERGIZING THE SCI FIELD

The Reeve Foundation's International Research Consortium on Spinal Cord Injury was created in 1995 to speed progress toward repair and functional recovery in acute and chronic spinal cord injury. At that time, the idea was quite unprecedented in modern biomedical research: a group of top labs, working together to maximize efficiency and optimize transparency as competitive urges are toned down. Consortium projects are coordinated between the six labs in the U.S. and Europe. The sharing of knowledge, personnel and tools builds an infrastructure of trust and collegiality.

One lesser known outcome of the Consortium that has made a major impact on the field is the Associates' program. Each lab is directed by a PI – a principal investigator. Each PI picks a graduate or postdoctoral student (called Associates) to oversee the day-to-day collaborative work within the Consortium. The Consortium meets twice a year; before the PIs and advisors arrive, the Associates come together on their own for a day to discuss their projects and any issues that benefit by the brainstorming of young minds.

Over the years, dozens of Consortium Associates have rotated through the program and most have stayed in the SCI field. Many former Associates have lined up major funding to create labs of their own. By recent count, 25 former Associates have set up their own labs; another handful continues to work in prominent SCI labs.



Martin Schwab

Susan Howley, Executive VP, Research, has overseen the Consortium since its formation. The fruits of collaboration, she notes, have accumulated over time. The labs learned to share and unify their approach to research problems. The Associates aspect, which was the idea of Swiss scientist Martin Schwab, has been more under the radar:

“Dr. Schwab insisted from the outset that Associates were the key to running the everyday business of the Consortium. He thought the program would create cohesion and also be a good way to nurture new talent in the field.

“Indeed, the Associates program has been an unequivocal though unheralded

success. Measured by the number of former Reeve-funded post-docs who have gone on to form their own labs, the program has energized spinal cord injury research and magnified many times the research progress of the individual Consortium labs. There are more well-funded, top-grade scientists working on the problem of spinal cord repair and regeneration than ever, thanks in large part to this program.

“What’s interesting,” notes Howley, “is that in the early days of the Consortium, each lab had but one Associate. Today, all labs have two or three; the Pfaff lab at the Salk has four! Clearly this aspect of the research network has been a resounding success.”

The first Associates' class included several young scientists who are now leaders in the field. **Aileen Anderson**, who was a post-doc in the Carl Cotman lab, now directs a lab at the University of California Irvine (UCI) and is seeing her work with stem cells move into a Phase I clinical trial. She is also Scientific Director of the Foundation's Animal Core Laboratory at UCI. **Giles Plant**, the Associate from the Mary Bunge lab at the Miami Project, was recently recruited back to the U.S. from Australia to direct the brand-new Stanford Partnership for Spinal Cord Injury and Repair in Palo Alto, CA.

**Phil Horner**, Ph.D., is a scientist at the University of Washington whose lab, by his reckoning, is the only one in the state doing spinal cord research. When Horner came out of grad school and was looking for a post-doc position, he heard a lecture by Rusty Gage, a prominent investigator at the Salk Institute and then chair of the Reeve Science Advisory Council. Although he was trained at Ohio State in Brad Stokes's SCI-based lab, Horner was thinking about a career studying Alzheimer's Disease. Gage's approach caught his attention. Horner approached Gage, who signed the post-doc to the first

Associate class; they worked together for more than four years.

“The thing we were doing at the Consortium, which was unusual then in scientific research, was learning how to work together. Can multiple labs do projects together? We put our best ideas together. The goal wasn't that we cure spinal cord injury. The goal at that time was: Can you take a developmental biology lab, a physiology lab, a molecular lab, can you get



Phil Horner

Sam Maddox

them to work together on one project and functionally integrate? The answer was yes. And we became friends and to this day connect and communicate about the issues of spinal cord injury.”

**John W. McDonald**, M.D., Ph.D. is a researcher in the spinal cord injury field and directs the International Center for Spinal Cord Injury at Kennedy Krieger Institute. He was also in the inaugural Associates' class as a post-doc in the Dennis Choi lab at Washington University in St. Louis. McDonald, who was headed for a career as a stroke neurologist, was asked by Choi to attend the organizing meeting of the Consortium, in spite of its focus on the damaged spinal cord.

“We met for three days, sitting among some of the acknowledged leaders in the neurosciences – Rusty Gage, Ira Black, Martin Schwab, Luis Parada, Carl Cotman, Richard and Mary Bunge, Albert Aguayo, Eric Shooter. I was blown away. I walked out of the meeting thinking regeneration was possible.

“Some of the Associates had SCI back-

ground – Lisa Schnell (from the Schwab lab), Phil Horner and Giles Plant. I really learned a lot from them. The Associates from all eight labs spent days and nights combining interventions in one experimental project – the earliest attempts at a combinatorial approach to spinal cord repair. We learned to trust each other, to share methods and tools and in a sense, to think and problem-solve collaboratively. In some ways this is the single most important investment made by the Reeve Foundation. The Associates’ program puts a growing number of shoulders to the wheel. Every one of us went on to get funding and become leaders. I wouldn’t be in the SCI field today if not for the Consortium.”

**Keith Tansey, M.D., Ph.D.**, Director of Spinal Cord Injury Research at the Shepherd Center, was the first Consortium Associate in the Edgerton lab at UCLA. Tansey’s experience as an Associate firmly tipped his career toward the SCI field, both in research and clinical practice, having also become board certified in SCI medicine. Tansey’s lab looks for ways to improve neural plasticity and repair that lead to functional recovery after SCI.

Says Tansey: “I was asked to join the Consortium as Reggie Edgerton’s first Associate when I was a fellow at UCLA. The model was to work on a ‘common experiment.’ By the time I left for my first faculty position, Associates worked on multiple collaborations between Consortium labs. The best part was the exposure we got to leaders in the field and to the scientific strengths they brought to the table.”

**Karim Fouad, Ph.D.**, is professor of Rehabilitation Medicine at the University of Alberta in Edmonton. He came to Canada in 2001 having completed a stint

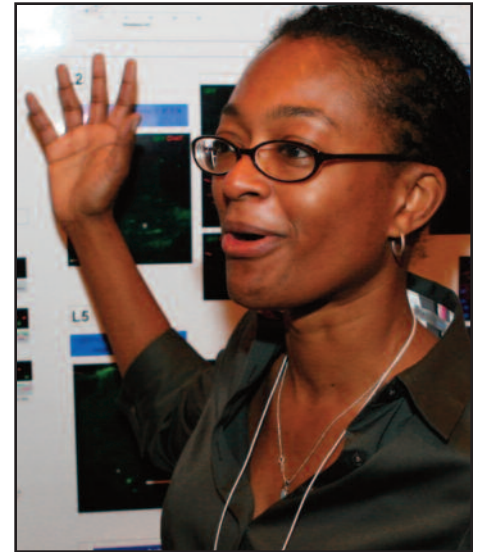
as Martin Schwab’s Associate in Zurich. His research aims to promote functional recovery following spinal cord injury by understanding injury induced plasticity and attempting to enhance this naturally occurring repair mechanism.

“I figured Martin Schwab was too big a star to be interested in me. But I made a presentation in Germany. Dr. Schwab was there. He said, ‘We could use you.’ I was there with him for 4 ½ years, the last two as an Associate. The Consortium meetings were great for science, and for getting to know each other. The old guys, the PIs, would chat and discuss projects and send us post-docs off to do experiments together. There is no doubt, the Consortium has produced many talented people. It inspired me, it helped me get started. Truly, without having been an Associate I would not be where I am now.”

**Gregoire Courtine, Ph.D.**, a former Consortium Associate for the Edgerton lab at UCLA, has his own lab, the Experimental Neurorehabilitation Laboratory at the Rehabilitation Institute and Technology Center, Zurich. His work looks at neurorehabilitation interventions, including implantable electrode arrays and pharmacological aids to improve the recovery of function from training and activity.

“I saw Reggie Edgerton at a conference. I loved what he was doing. I approached him. I told him I wanted to come work at his lab. He said, ‘Why not.’ I was with the Edgerton lab five years, two as a Consortium Associate; that experience has been the key to my career. Having access to top people, doing the kinds collaborations we did. It was an unbelievable opportunity, being able to break bread with the top minds in the field.”

**Vanessa Boyce, Ph.D.**, is a Research Assistant Professor in Lorne Mendell’s laboratory at the State University of New York at Stony Brook and a current Consortium



Vanessa Boyce

Sam Maddox

Associate. Her work involves growth factors BDNF and NT-3, which appear to modify the function of neural pathways that survive after spinal cord injury, and which appear to promote recovery.

“Being an Associate has been extremely beneficial. If I have a problem – some immunostaining isn’t working, for example – I call one of my Associate colleagues. I always get good advice. Before the PIs get together at Consortium meetings, we Associates gather for a day of brainstorming to share progress and troubleshoot our projects. When I first came to a meeting I was wide-eyed at all the prominent scientists in the room; now I am comfortable as part of something very significant, something with such potential to help people.”

– Sam Maddox

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## CHARLES TATOR: LIFETIME ACHIEVEMENT, UNFINISHED

*Charles Tator, M.D., Ph.D. was awarded the 2011 ASIA Lifetime Achievement Award earlier this summer. Dr. Tator, a neurosurgeon and spinal cord injury scientist at Toronto Western Research Institute, has been active for many years in the prevention of neurotrauma; he founded the prevention group, ThinkFirst Canada. He developed the first acute spinal cord injury unit in Canada in 1974 at Sunnybrook Medical Centre. He is a member of the Advisory Panel that provides guidance to the Reeve Foundation International Research Consortium on Spinal Cord Injury. He is an investigator in the Foundation's North American Clinical Trials Network (NACTN), which is currently evaluating the drug Riluzole for acute spinal cord injury. Dr. Tator, funded by the Reeve Foundation, is currently studying stem cell therapies in combination with guidance channels, scaffolding and growth promoting substances. Meet Dr. Tator:*

Early on in my medical career I was aware that while we were getting better and better at enhancing survival after spinal cord injury we really hadn't made a dent in enhancing neurological recovery. I began what is probably the first spinal cord basic science lab in Canada. That was 42 years ago. I've been looking for a breakthrough all that time. I haven't found it but as a brain surgeon, you have to be optimistic. We have to keep trying.

Sam Maddox



NACTN has been a terrific service to the field; it brings together a number of major centers and clinicians, linking us together to solve the problem of SCI. We don't know if Riluzole will hit or miss. There are other drug candidates we might consider. The fact is, if we don't look we are not going to find it. We have to keep looking. And we have to look beyond rats to human patients in a real setting. In my lab, we are 100 percent devoted to stem cells, both endogenous and transplanted. Our combination experiments, with Reeve funding, are the most likely way to enhance recovery in a chronic injury.

My legacy, if I were to write it, would be "full steam ahead." There is a lot of work to be done and we need an army of people to do it. We need to find treatments for SCI and we need to discover the mechanisms of injury. I like research and the process of putting it in action. You can't be squirreled away by yourself in this work. You need teamwork. Over the years I have

welcomed many to the team, and have seen many of them – for example, Michael Fehlings – go on to form their own teams. I guess I am disappointed I haven't been able to solve more of these problems .... yet. I'm not giving up.