



# Reeve Report

CHRISTOPHER & DANA REEVE FOUNDATION

Fall 2010

## REEVE CEO WILDEROTTER: UNIFYING A MOVEMENT

*Peter T. Wilderotter is President and Chief Executive Officer for the Christopher & Dana Reeve Foundation. He has spent his entire career in the non-profit sector, the part of the marketplace "where the business community isn't ready or isn't interested in the problem or solution and the government isn't capable." He sees spinal cord injury and paralysis as a civil rights movement; this movement is being led by the legacy of Christopher Reeve. The following interview took place between Wilderotter and Reeve staff member Sam Maddox.*

Now, almost 30 years later, we have the opportunity to transform that movement. Historically, the spinal cord injury (SCI) field has been Balkanized, both in terms of the science and within the community as a whole. On the research side, this led to unfocused, less efficient use of funds. In the community, it has meant the 'cure' proponents didn't talk to the 'care' advocates, and vice versa. If the field is to fully mature, we see the need to come together in a new way. We believe the time is right for a more unified vision, a more cohesive strategy and that this can best be achieved under the unique umbrella of the Reeve Foundation.

### *You still hear a care vs. cure discussion?*

We need the energy of both in order to synergize the issues. The tagline for the Reeve Foundation is Today's Care, Tomorrow's Cure. We hear much less care versus cure debate now, but sometimes when we speak about quality of life, we get accused of changing direction or focus. We haven't. We have not changed our ultimate goal, or the resources we devote toward that goal, which is to be out of business. We recognize today, however, that we must devote more of our attention toward the immediate needs of people living with paralysis and their families.

### *You see the Foundation growing?*

What I have seen – at our Road Shows, our events, visits to a number of organizations that have become chapters or affiliates or collaborators – is that the SCI field is ready for unification. The community wants us to be much stronger so that we have greater resources to meet the challenges at hand. Last year's release of our paralysis prevalence study, which documented that there are many more people living with paralysis than we knew, is an

example of something that has brought our community together. Paralysis could strike your mother, father, sister, colleague, a friend you haven't seen in a while – the reality is that paralysis affects one in 50 Americans. It really is just one degree of separation from each of us.

We want to grow and expand to meet the needs of a community that is so much

*continued on page 10*

## Inside

**YOGA & PARALYSIS:  
THE MIND-BODY LINK**

**NEXTSTEPS CHICAGO:  
AGGRESSIVE REHAB**

**REEVE ROAD SHOW:  
TRUTH AND HOPE**

**FUNDING SCIENCE'S  
NEXT GENERATION**

**SURF PRINCESS MAILE**

**ADA AT 20: SETTING THE  
GUINNESS RECORD**



Photo by Sam Maddox

### *Where is the Reeve Foundation headed?*

The Reeve Foundation got its start almost 30 years ago or so when Henry Stifel was spinal cord injured. His father, Hank, reached out to their friends and they came together to form a foundation in their name. They didn't realize it at the time, but their organization, by creating hope where there was none, would become the birth of a movement.





# YOGA: DISCOVERING THE MIND-BODY CONNECTION

*Mind-Body Solutions is a Minneapolis-based nonprofit that teaches yoga to both traditional students and those living with disabilities. The program is a two-time recipient of a Reeve Foundation Quality of Life grant. Here is the story of this unique center, and of its founder.*

**M**atthew Sanford teaches the ancient secrets of yoga, even though he can't do the most basic yoga moves. Forget about the downward facing dog. He can't do the dolphin, either,

disability. But you can't overcome your body. They never told me that something else was possible, that there were subtle connections between mind and body, ones that would never make me walk again but were essential to a full recovery. Instead, they told me to make my upper body really strong and drag my paralyzed body through life.

"It was then that I came across yoga – what better way to start than an ancient discipline expressly dedicated to the union of mind, body, and whatever we call spirit."

Sanford found a yoga teacher in San Diego, Jo Zukovich, who taught him that the more efficient distribution of gravity, alignment and precision integrates mind and body – without muscular action. "Jo and I discovered that this is true even through my paralysis. In other words, the inward energetic experience of increasing alignment and precision crosses the mind-body rupture

created by my severed spinal cord. This simple truth is the cornerstone of adapting yoga for people living with disabilities. When I teach my adaptive yoga class, I simply bring this heightened attention on

alignment and precision to people who desperately need it."

From the start, Sanford began to feel benefit from the simplest of yoga poses. Upon "taking his legs wide" for the first time, he described a rush of energy he had not thought possible. He says it's "an energetic awareness—a tingling, a feeling of movement, not outward but inward. The mind is not strictly confined to a neurophysiological connection with the body. If I listen inwardly to my whole experience my mind can feel into my legs. I do not have the luxury of confirming my presence through flexing muscles," Matthew says. "And yet, I still experience a level of integration."

Sanford says the subtle flow of energy that makes him feel "whole." It is this shift in consciousness, he says, that the medical people told him to ignore. Now, he said, his goal is to bring these techniques back to the medical community and to educate people who are involved in rehabilitation.

Sanford's began teaching adaptive yoga at Courage Center, a rehabilitation facility in Minnesota. A few years later he created his yoga business, Mind Body Solutions, around the idea that minds and bodies work better together.

Sanford encourages people living with disability to listen to their body. "This is so they can hear a different level of sensation, so they can experience freedom that comes from connecting to this subtle level of sensation. It's not going to reverse their condition, but if you can listen to it and follow it, it'll lead to a better life," he says.



Matthew Sanford

not without a lot of props. If you think yoga in terms of its physical new-agey pretzel logic, Sanford, who has paraplegia without much trunk stability, would be hopeless before the gods of gravity.

But yoga isn't just posing. It's about keeping the mind and body in the same frame, even if the body doesn't have all its functions. Sanford figured this out and has made it his life's work to spread the word.

Sanford faced a huge change when he was 13. A car wreck killed two family members; he was paralyzed. He was very athletic and physical before his disability and he longed to reconnect to his body. "I needed to feel my whole body again – both what I could move voluntarily and what I could not."

Sanford says he once thought about getting rid of his lifeless legs. "But it isn't the body that fails you. It's the mind that fails; the body keeps trucking along. The doctors, nurses, and therapists taught me to overcome my paralysis, to overcome my

## QUALITY OF LIFE GRANT PROGRAM: RESPONDING TO NEEDS OF THE COMMUNITY

The Reeve Foundation Quality of Life Grants Program has provided over 1,700 grants totaling over \$13 million to nonprofit organizations worldwide that help improve opportunities, access and day-to-day quality of life for individuals living with paralysis and their families.

Quality of Life grants, conceived by the late Dana Reeve, are funded twice yearly (deadlines are March 1 and September 1) to programs in three broad categories:

**Actively Achieving** – helping people to get out and live – ride a bike, compete in sports, hike a trail, train for a job, play with friends on an accessible playground.

**Bridging Barriers** – helping people overcome obstacles to full participation in society – accessing advanced computer technology, modifying homes and buildings, helping with legal issues, transportation services, etc.

**Caring and Coping** – helping care for individuals with paralysis, caregiver support and respite, peer networks, support groups, consumer and healthcare professional educational conferences, specialized training for professionals and more.

For more information about the program, to see a list of grantees or to apply for a grant, visit [www.christopherreeve.org/qol](http://www.christopherreeve.org/qol)





Sanford, on right, leads a group in adapted yoga.

Sanford sees the benefits in his own life, and those of his students. "I have never seen anyone truly become more aware of his or her body without also becoming more compassionate. On the flip side, when we become more disconnected from our bodies, we become more self-destructive. We need people to come through the health care system and leave that experience more connected to their body, not less. The simple idea is they'll take better care of themselves and help others to live more vibrantly in their bodies."

"I didn't become a yoga teacher because I overcame anything. That's exactly wrong. I'm a yoga teacher because I live in an altered mind-body relationship. Your body is the best home your mind will ever have, and it's the only one you get. I can never change what happened to me, but I can live within the body I have. Yoga is a vehicle to re-enter the body and to explore it."

This approach has a wide range of benefits including increased strength, balance and flexibility. Sanford says he has an easier time making transfers. He also says his capacity to live more fully within his body is better, and that he is better able to manage stress. Yoga helps deal with depression, and some students say they feel more confident, less self-conscious.

Says Sanford, "I want people with disabilities to get the message that they are engaged in a practice that is strengthening

them. It is a life skill that will help them build a level of resilience that is amazing. There's more potential there than we've been taught."

Here are several student comments: Samantha Drost is a quad with no hand function. "When you're in a wheelchair you lose the feeling of being grounded," she says. "Yoga gives me a body awareness; I can feel my weight on my sits-bones." Drost adds that yoga improves her lung capacity and allows her to project her voice

more. "I feel more confident and present in my body. I don't disappear into my chair. Now, people see me, not the chair."

Tiffany Carlson has limited function due to spinal cord injury. She says yoga makes her feel more connected to her body, and therefore, "more feminine." It's a subtle feeling, but she says she feels the energy in her body. "I know I'm not getting better neurologically but with yoga I do feel more alive. And more attractive."

Kevin Bjorkland, after his first session with Sanford, says he could feel "the outline of my entire body – for the first time ever. I really notice the difference when I practice yoga and when I don't. When I don't I'm not as content, I'm crabby, I'm out of whack."

Mind Body Solutions offers adaptive yoga classes and workshops for people living with a wide range of mobility disabilities, as well as individual instruction through one-on-one sessions. Workshops and resources have also been developed for caregivers and healthcare professionals. Mind Body Solutions also offers adaptive yoga training for yoga teachers from around the country. The organization is also bringing its work to disabled veterans.

*Matthew Sanford has written a book, **Waking: A Memoir of Trauma and Transcendence**. It is available for no-cost loan from the Paralysis Resource Center library. See [www.paralysis.org](http://www.paralysis.org); library link is on homepage. Visit [www.mindbodysolutions.org](http://www.mindbodysolutions.org) for more information about Sanford's program.*



Sanford helps yoga student Chantilly, who is paralyzed below the waist due to spina bifida, to find balance and expand upwards.