

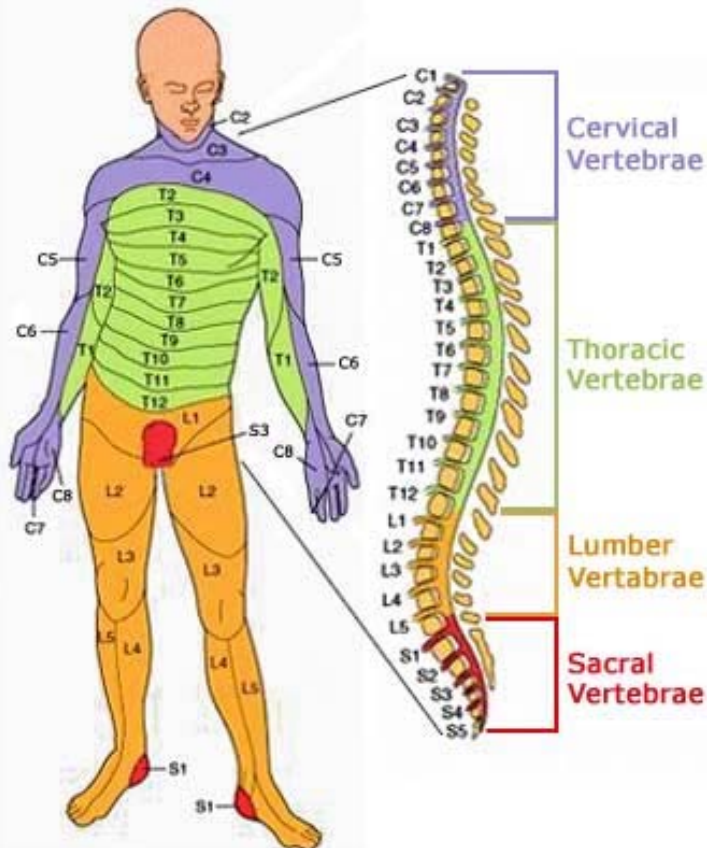
Imagine, you've just been in a horrific car accident, or had a traumatic fall. In an instant, all your hopes, your dreams, your way of life, were taken from you. You have sustained a spinal cord injury, which has been described as, "one of the greater calamities that can befall a human being<sup>1</sup>." How would you adapt? How would you go on?

Life Rolls On gives the injured person permission to live again!

### SPINAL CORD INJURY

The spinal cord is the major bundle of nerves that carry nerve impulses to and from the brain to the rest of the body. The brain and the spinal cord constitute the Central Nervous System. Motor and sensory nerves outside the central nervous system constitute the Peripheral Nervous System, and another diffuse system of nerves that control involuntary functions such as blood pressure and temperature regulation are the Sympathetic and Parasympathetic Nervous Systems.

The spinal cord is surrounded by rings of bone called vertebra. These bones constitute the spinal column (backbones). In general, the higher in the spinal column the injury occurs, the more dysfunction a person will experience. The vertebra are named according to their location. The eight vertebra in the neck are called the Cervical Vertebra. The top vertebra is called C-1; the next is C-2, etc. Cervical



Spinal Cord Injuries usually cause loss of function in the arms and legs, resulting in quadriplegia. The twelve vertebra in the chest are called the Thoracic Vertebra. The first thoracic vertebra, T-1, is the vertebra where the top rib attaches. Injuries in the thoracic region usually affect the chest and the legs and result in paraplegia<sup>2</sup>.

<sup>1</sup> Guttman, L. (1973). Spinal Cord Injuries: Comprehensive Management and Research. London: Blackwell Scientific Publications

<sup>2</sup> National Spinal Cord Injury Association. (n.d.) Common Questions about Spinal Cord Injury

## **HISTORY OF LIFE ROLLS ON**

In 1996, on the verge of becoming a professional surfer, Jesse Billauer suffered a spinal cord injury while surfing. While physically rendered a quadriplegic, Jesse's spirit was not broken, and the phrase "Life Rolls On" was born. The first few years the Billauer Family organized golf tournaments to raise money for Jesse's cost prohibitive medical bills. Within a few years the philosophy changed – there was a bigger issue at hand.

Three years after sustaining a spinal cord injury Jesse's love of the ocean was too much for him to bear. With the help of friends and professional surfer Rob Machado, Jesse found himself back in the ocean, surfing again! Within just a few years, these efforts would be showcased in the motion picture, Step Into Liquid.

In 2001, Life Rolls On found a way to enhance the quality of life of individuals who have sustained spinal cord injuries, by collaborating with Richard Yelland; founder of the "They Will Surf Again Foundation," a program was developed to provide surfing opportunities for individuals who have sustained spinal cord injuries. As the program continued to grow, the relationship with They Will Surf Again also grew and in 2004, They Will Surf Again merged with Life Rolls On.

The They Will Surf Again program has received international recognition and has been featured in such media outlets as: Good Morning America, Dateline NBC, TLC's While You Were Out, Nonprofit Times, Los



### **Life Rolls On**

Spirited quadriplegic surfer Jesse Billauer teaches everyone a few lessons about not sweating the small stuff in his effort to live life to its fullest.

Angeles Times, New York Times, Orange County Register, San Diego Union Tribune, Ability Magazine, Surfer Magazine, Surfing Magazine, Transworld Surf, Riverside Press, E! Entertainment, and will be featured on the December 10, 2006 airing of Extreme Makeover Home Edition on ABC. Life Rolls On is also the #1 nonprofit organization on MySpace.com. We have the most members and more recognition than any other nonprofit agency that has a group on MySpace!

## **PURPOSE OF LIFE ROLLS ON**

Life Rolls On is a non-profit 501(c)3 Foundation that exists to be a grassroots resource that provides hope and is an advocate on behalf of young people whose lives have been affected by spinal cord injury. Life Rolls On focuses on three areas:

- 1) They Will Surf Again
- 2) Spinal Cord Injury Research
- 3) Motivation and Awareness

Research has found that individuals with a spinal cord injury have lower quality of life and are five times more likely to commit suicide than those without, and this is likely a low estimate<sup>3</sup>. However, the spinal cord injury itself does not result in a decreased quality of life, it is the impact of the injury on an individual's ability for self-care, mobility, and especially on their ability to fulfill normal social roles and engage in family and social life that results in a decreased quality of life<sup>4</sup>. Often times society's negative attitudes and discrimination towards people with disabilities affects their quality of life<sup>5</sup>. If the issue of quality of life of individuals that have sustained a spinal cord injury is not addressed these individuals will continue to feel alienated from activities, social networks and will struggle with reintegrating into society.

Based on this knowledge, Life Rolls On utilized Richard Yelland's vision and expanded the They Will Surf Again program so that it will enhance the ability of an individual with a spinal cord injury to engage in opportunities to create autonomy, experience and growth, gain self-acceptance, achieve competency in activities they enjoy, build positive relationships with others, all of which will help them find purpose in life.

From previous They Will Surf Again events, Life Rolls On has found that it is not only important to focus on the individual that has sustained the spinal cord injury, but also create a support network for their friends, families, and others whose lives have been altered by this tragic occurrence. Not only does the They Will Surf Again program give individuals with a spinal cord injury permission to enjoy life again, it gives their families, friends and society the opportunity to view these injured athletes as able.



**If you can't tell which one has a spinal cord injury, why should we?**

<sup>3</sup> Dijkers, M., Buda Abela, M., Gans, B.M., Gordon, W. (1995). The Aftermath of Spinal Cord Injury. In S. Stover, J. DeLisa, G.G. Whiteneck (Eds.), *Spinal Cord Injury: Clinical Outcomes from the Model Systems*. (pp. 185-212). Rockville, MD. Aspen Publishers.

<sup>4</sup> Dijkers, M. (2005). Quality of Life of Individuals with Spinal Cord Injury: A Review of Conceptualization, Measurement, and Research Findings. *Journal of Rehabilitation Research and Development*, 42(3), 87-110.

<sup>5</sup> Dijkers, M. (1996). Quality of Life After Spinal Cord Injury. *American Rehabilitation*. 96(3), 18-25.

## WHO GETS THE MOST OUT OF THEY WILL SURF AGAIN?

*I was nervous at first when I got into the cool salty water. I had four volunteers to help me onto the board and then we started out further into the water, as the waves pounded my face, I started to panic. I could taste the salt on my lips, and feel the salt burn my eyes. Once we were out far enough the volunteers turned me around on the board, and once a big enough wave had come, all I heard was "OK here we go, Jenn!" and I felt the water rush me forward. I felt out of control, and the wave over came me and the board, then up and over I went! I hit the water and felt a hand instantly on my arm and around my waist. As quickly as it had happened, I was quickly snatched back up out of the water! I didn't have time to panic! I was back on the board in no time! Once again ready, the next big wave came along and again I was push off and went a few feet and wiped out again! This time the board rolled over the top of me and I had remembered Brendon saying to me "Just let your body float up to the surface."*

*I once again felt a hand reach out and grab me. Laughing with a nose full of water I was ready for an other go at it! The third time's a charm I rode the wave all the way into the beach! It was the most incredible feeling, the sense of accomplishment. I had done it! Laughing and smiling I was ready for an other wave! After a few high five's, the volunteers turned me around and we headed out again! I told the volunteers I wanted a longer ride! So we went out a little further and the wave came up and I was pushed off, it was fantastic! I thought to my self "You can do this if you put your arms strait out board, Drop one shoulder, and look to right, will it turn the board?" I did just that and low and behold, IT WORKED! The board turned with my body, and I had cut into the wave! I turned my head the other direction and dropped my left shoulder and the board once again cut back to the left. I knew right then I was never going to be the same! I am so excited I can't wait to ride my next wave!*

*Thank you so much, Brendon, Richard, and the volunteers from TWSA your all outstanding!*

*I had a wonderful time, and will be back!*

*- Jennifer Mac Monagle (Ms. Wheelchair California 2003)*

*Hi, I came to help because one of my surf buddies offered to help. I didn't know what to expect, except for colder water, and smaller waves then in the South Bay that morning. I was a little bummed out, to be honest with you.*

*My attitude immediately changed while helping the first guy on the paddle board/kayak through the waves. For the next three hours, it only got better. Everyone involved from the participants to the volunteers were a joy to be around. I have never had so much fun being of service to others. One guy I was getting through the surf looked at me and said, "If I could just catch one more wave like I used to do." It really made me appreciate that health that I have. It also made me realize that nobody is guaranteed another wave; that I should really enjoy everyone I catch.*

*Thank you for one of the greatest, most rewarding days of my life! You run a first class organization that is sure to grow. I look forward to being a part of future events. You should be very proud of your efforts. You can see the results in all of the smiling faces. Keep up the good work. - John Sakacs*

*How about Saturday!!!! That had to be the most amazing day I've had in years, hands down! Let me tell you, I've got so many of my distant family and friends who have heard about it calling me and really thanking me for turning Jason onto this whole deal, 'cause its been six years since his accident and I have to say, since then he has slowly given up, you ca just see it in his eyes, and this has really re-inspired him. So I just want to take all the thank yous that I have received and give them to you and God. You really put together something special that I can't describe with words. I think at this point I plan to keep on encouraging and motivating my cousin Jason to push on and keep going for something that he knows deep down inside he can do now. In fact, I just got off the phone with his mom and she said that he really wants to be exercising more and he wants more therapy, so he can be stronger to this kind of thing. I've had a few ideas myself for a board that I'd like to design for him with some sort of stilts to hold up his upper body to keep his face out of the water, and so he can see. I really have a big heart for people who can't do the things that we can, and it's very special to them when we do things like this to help them be inspired. I appreciate everything you did to put the event together, it was a true success and we will never forget it. We look forward to the future of all this. Thanks a ton. -Your friend, Philip*

Three stories, one from an injured athlete, one from a volunteer, and one from a family member, and the question is, who gets the most out of participating in a They Will Surf Again event? To each individual the experience is meaningful, life changing, and inspirational. The joy a person that has sustained a spinal cord injury gets when they realize they can do something they previously thought was impossible is amazing. The pride a volunteer has in helping a person forget that they are injured or the comfort a family member receives in knowing that their son, daughter, wife, husband, father, mother or sibling has a smile on their face for the first time they were injured is impossible to measure. You just know in your heart that you made a difference, that you helped someone find happiness despite sustaining one of the most horrific injuries that can befall a human being.

### **QUANTIFYING THE EXPERIENCE**

Up until now, all the data that we have collected has qualified the experience of participants in the They Will Surf Again programs. With the lack of quantifiable data, we feel it is our obligation, to conduct a study that will quantify the quality of life of individuals that have sustained a spinal cord injury and examine how participating in action sports, specifically surfing, affects their quality of life.

From the research Life Rolls On has done, numerous studies indicated that fitness activity programs may improve the quality of life for individuals with a spinal cord injury and improved fitness and increased physical activities can result in enhanced function and improved health among individuals with spinal cord injuries<sup>678</sup>. However, these studies

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<sup>6</sup> Manns, P.J., & Chad, K.E. (1999). Determining the Relation between Quality of Life, Handicap, Fitness, and Physical Activity for Persons with Spinal Cord Injury. *Archives of Physical Medicine and Rehabilitation*, 80, 1566-1571.

<sup>7</sup> Stotts, K.M. (1986). Health Maintenance: Paraplegic Athletes and Non-athletes. *Archives of Physical Medicine and Rehabilitation*, 67, 109-114.

<sup>8</sup> Noreau, L., Shepard, R.J., Simard, C., Pare, G., & Pomerleau, P. (1993). Relationship of

also indicated that more research needs to be done and we have been unable to find any research that examines how participation in action sports affects the quality of life of individuals that have sustained a spinal cord injury.

We have developed a study that will quantify the quality of life of individuals that have sustained a spinal cord injury and analyze how participation in action sports, specifically surfing, will affect their quality of life. The program will emphasize the following five areas we found relate to a persons' quality of life: participation in social networks; frequency of physical activity; knowledge of self-care opportunities; participation in family and social life; and decreased depression. After speaking with Dr. Marcel Dijkers, a leading authority on quality of life studies for individuals that have sustained a spinal cord injury, he suggested that we use "Short Form 12" and the "Satisfaction With Life Scale" to quantify the quality of life of our participants.



We will recruit fifty participants from the Southern California area that have sustained a spinal cord injury and have a desire to surf but have not had the opportunity to do so. These fifty individuals will be divided into two groups. One that will participate in quarterly surfing events and the other will not. This will allow us to compare the data collected from both groups. Before anyone participates in the surfing events, they will be asked to fill out Short Form 12 and the Satisfaction With Life Scale. After each surfing event, we will

have the participants fill out the survey again. This will happen four times over a one-year span. At the end of this year, we will take all the data we collected and then evaluate the results and hopefully be able to show that participation in action sports does indeed increase the quality of life of individuals that have sustained spinal cord injuries.

### **QUANTIFYING YOUR DONATION**

This study to quantify the quality of life of individuals with a spinal cord injury is a large financial undertaking for Life Rolls On. It will cost nearly \$200,000 a year to carry out this study, and because we are modifying an existing program, many agencies are interested in the results but are not willing to underwrite the costs. In order to make sure that we are able to hire the appropriate staff, obtain the proper materials and find enough participants and volunteers we will need to rely on private donations. While we have been able to secure gifts from a few corporations, people like you truly make Life Rolls On what it is today. **Please consider one of the following gift opportunities.**

### **They Will Surf Again Program Director**

It is easy to find a program director that will do the basic needs of an organization; however, to find the right person who is willing to be a self-starter, who will research beaches around in Southern California, and will take the time to review numerous quality of life studies that have been conducted, will be a difficult task. To address this need, our highest priority is to hire a qualified program director that will be able to take the They Will Surf Again program to the next level and help Life Rolls On receive formal recognition for their attempts to enhance the quality of life of individuals with spinal cord injuries. It is our vision that this individual will implement and evaluate a high quality study that will be worthy of being published in a well-respected medical journal.

*A gift of \$40,000 a year over the next two years will provide the funds to ensure that we are able to hire the most qualified individual for the program director position and will ensure that the proposed study will be implemented. For this gift, we are more than happy to name the program director position in your honor, or to name it in honor of a person you so choose.*

### **Support of Specialized Surfboards**

For the individuals that have sustained spinal cord injuries to be able to surf, they need to use specialized surfboards that have been modified so that they balance weight evenly throughout the board and allow for easier control and maneuverability while on the water. We use specially modified surfboards for this program. One surfboard, made of foam, is designed for beginner surfers or those readjusting to the water. The foam is softer and allows for more comfort for the participant, but does not allow for as much maneuverability. The second board is a fiberglass board, very similar to the ones that any every day surfer would use, however this is also modified to distribute the weight evenly throughout the board and allow for additional comfort.

*A gift of \$20,000 will allow us to purchase these much needed boards and give the individuals with spinal cord injuries the opportunities they so desire to enhance their quality of life by participating in surfing events. This gift will ensure that the participants will be able to maximize their enjoyment at They Will Surf Again events.*

### **Wonders of Wetsuits**

Not only is Jesse Billauer the only professional surfer with a spinal cord injury, he is also a designer. In collaboration with Hurley, he has designed a special wetsuit for individuals with spinal cord injuries that has extra padding in the elbows, forearms and knees, and is designed so that it is easier to put on and take off. This design minimizes the risk of injury and protects the more vulnerable parts of the surfers bodies. It also allows for maximum comfort to enhance the experience of the participants.



*A gift of \$8,000 will allow us to purchase enough wetsuits in varying sizes to fit the needs of all They Will Surf Again participants. This gift will ensure the protection of the participants and allow them to enjoy themselves with minimal fear of injury.*

### **They All Float**

Since the majority of participants will have limited or no use of their legs and limited use of their upper extremities, it is critical that each participant wear a life vest. Specially designed lightweight neoprene life vests will be used to maximize the mobility of participants and minimize the burden of added weight. These vests also maximize comfort and minimize the risk of injury.

*A gift of \$2,500 will allow us to purchase enough life vests in various sizes to ensure that every participant has a comfortable vest. This gift will guarantee that everyone that comes to a They Will Surf Again event and wants to participant will be able to do so.*

### **The Gift of Mobility**

Transportation and mobility have been identified as challenges that continually face people with spinal cord injuries. We want to make sure that everyone who wants to participate in a They Will Surf Again event has the opportunity to; therefore, we want to be able to provide transportation to and from our events. This transportation comes at a cost, as we need to rent vehicles that accommodate individuals that use a wheelchair.

*A gift of \$10,000 will provide us the funds to rent specialized vans that will allow individuals who would not have otherwise, the opportunity to travel to and participate in a They Will Surf Again event. You are giving the gift of mobility, which is one of the greatest gifts you can give an individual with a spinal cord injury.*

Once the participants arrive at the beach, many of them do not use chairs that can be used



on the sand. Therefore, we must provide chairs that people can use to get around on the beach and assist the volunteers in getting participants into the water. These chairs will decrease the amount of time it takes to get an individual in and out of the water and increase the number of times participants can go into the water. They will also enhance the comfort of participants and increase their mobility while they are on the beach.

*A gift of \$12,500 will provide us the funds to purchase enough chairs to increase the opportunities for participants to surf and increase their mobility while they are on the beach. These chairs will also decrease the strain on the volunteers and increase their abilities while they are in the water.*

## **LIFE REALLY DOES ROLL ON**

The Christopher and Dana Reeve Foundation has recognized us for our efforts to enhance the quality of life of individuals with spinal cord injuries. In our brief history, Life Rolls On has received recognition from numerous media outlets and has garnered the support from world-class surfers, actors, athletes, politicians, and people who just want to make life better for humanity.

Life Rolls On gives individuals that have sustained spinal cord injuries permission to hope and dream again. It gives them the ability to live again. It lets these individuals, their family, and their friends hope that one day there will be a cure for spinal cord injuries, but until that day, we will continue to make life as meaningful and as enjoyable as possible. You can make a difference, please consider a contribution today.



**They Will Surf Again:  
Giving Individuals with Spinal Cord Injuries  
Permission to Hope and Dream Again!**



LIFE ROLLS ON  
FOUNDATION