



CHRISTOPHER & DANA
REEVE FOUNDATION

TODAY'S CARE. TOMORROW'S CURE.

Become an advocate. Be a hero.

Lend your voice and join the movement. You can make a difference.

"I think a hero is an ordinary individual who finds the strength to persevere and endure in spite of overwhelming obstacles. They are the real heroes, and so are the families and friends who stood by them."

-Christopher Reeve

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Introduction to Advocacy

Why Should I Get Involved in Grassroots Advocacy?

Grassroots Advocacy: Educating elected officials about necessary changes to public policy.

The day you or someone you love experiences a spinal cord injury, you become an advocate. There are many ways a person can advocate - many fancy tools and tactics that are available - but at its core, effective advocacy is about educating someone on a specific issue and moving them to action. It begins with one person, and is most effective when the messenger can communicate on a personal level. Most legislators are not experts on every issue. They need the information that you have in order to make informed policy decisions. With so many issues before them, it is **YOUR** responsibility to educate your elected officials about the costs associated with paralysis, the importance of continued funding for innovative research and the impact that lawmakers' decisions have on the quality of life of people living with SCI and paralysis. You don't need to be a scientist, economist, or paid professional lobbyist to be an effective advocate. In fact, the more personal the communication, the more effective it is.

Building Relationships

Strong relationships translate into effective advocacy. And building relationships with elected officials, as with anyone, does not happen overnight. It takes time and effort over the long term, and it is built upon trust. It may seem obvious, but trust with a legislator and his/her staff is earned by being honest, responsive, respectful, clear in your requests, and persistent. Consistently sharing important information with your elected officials (not only when there is a critical policy debate) will result in your being viewed by your lawmaker as a credible source of information on spinal cord injury and paralysis. This becomes extremely valuable when we need to turn to our legislative leaders for support and assistance regarding a specific piece of legislation or policy.

Opportunities for Advocacy

Christopher Reeve said it best: "Nothing of any consequence happens unless people get behind an idea. It begins with an individual and they share the idea with more individuals...and eventually it becomes a movement." This toolkit provides some basic guidance on how to effectively use letter writing, phone calls, emails, faxes, face-to-face meetings and social media to develop strong relationships and influence your senators or representatives. However, being an advocate for spinal cord injury and paralysis includes more than just direct communication with elected officials. Public awareness can be raised while waiting in line at a grocery store, by sharing information with your child's teachers, by distributing educational material at community events, and by including information on your face book page or in your blogs or tweets. Advocacy takes many forms and often occurs outside of Washington, DC. Good advocates see opportunities and take advantage of them. If somebody seems interested, educate them!

Communicating with Policy Makers

Letters, Faxes and Emails

Written communication is an effective way to convey your message to elected officials. Letters from constituents that clearly state the issue/problem, the specific request, and connect the topic to the elected official's community will be noticed in congressional or state offices.

Addressing Your Letter

Address the letter properly, using appropriate titles. Senators are addressed as Senator; Members of the House of Representatives are referred to as Representative, Congressman (when male) or Congresswoman (when female). Occasionally a legislator prefers another title, such as Doctor. If so, use it!

U.S. Senators

The Honorable (full name)
United States Senate
Washington, D.C. 20510

U.S. Representatives

The Honorable (full name)
United States House of Representatives
Washington, D.C. 20515

Sample Letter Structure

Dear Senator/Representative (last name),

Opening Paragraph:

- State the subject of your letter
- Refer to the bill number or name, if possible
- Describe yourself briefly, but thoroughly, emphasizing your role in the community
Example: "I am a 37-year-old mother whose son is paralyzed," or "I am a part-time nurse."

Body of Letter:

- Clearly state your position on the bill or policy. Do you support it or oppose it?
- Explain how the legislation affects you. Are you paralyzed or do you have a family member who is? Let the reader know exactly why you care about the issue.
- Give a local example of the impact of the issue to make the legislator care.
- Thank the senator or representative for taking the time to read your letter.
- Let the senator or representative know you are a resource for more information.
- Ask for a reply and let them know you will be following up.

Tips for Letter Writing

- ✓ Limit the length of your letter to no more than two pages, one if possible.
- ✓ Never be rude or threatening.
- ✓ Make the letter personal. If using a template, modify it so that it is less obvious. A personalized letter is more likely to influence a legislator's decision than an avalanche of form letters.
- ✓ Email and fax are the preferred methods of communication. Mailed letters are processed through a clearinghouse and take a long time to reach congressional offices.
- ✓ For maximum impact, address your email to an individual. You can call your legislator's office and ask to speak with the Member's Health Legislative Assistant.
- ✓ Make sure to express appreciation for past or future support.
- ✓ Ask the legislator to send you a response stating his or her position on the issue.
- ✓ Describe yourself briefly, but thoroughly, emphasizing aspects that make you an important part of the lawmaker's constituency.
- ✓ Follow up your letter with a phone call to make sure it was received.

Phone Calls to your Elected Officials

Making a phone call to your legislators is certainly the quickest way to be heard just before an important vote is scheduled. Be sure to ask the person answering the phone if you may speak to the person handling the specific issue. For spinal cord injury and paralysis, this is usually the Health Legislative Assistant. If you are successful in getting connected to the appropriate staffer, identify yourself as a constituent and ask them how the legislator plans to vote on your particular issue. Clearly communicate your position, thank them politely, and ask that they thank the legislator as well. If you are transferred to voicemail, leave a concise message. Legislative offices often count the number of calls they receive either for or against an issue. As with all grassroots advocacy, your call is most likely to receive attention if you have developed a personal relationship with the legislator or staffer.

If you don't know your senator's or representative's telephone number in Washington, D.C., you may get connected to their offices by calling the U.S. Capitol Switchboard at (202) 224-3121.

Tips for Making Phone Calls

- ✓ Keep your call brief and focused. Be sure to focus on a single issue, making two or three key points.
- ✓ Prepared talking points or notes can be useful to help structure your call.
- ✓ Be sure to demonstrate the impact of a bill or proposal on the legislator's constituents.

- ✓ Clearly state what you are asking the senator or representative to do (vote for/against, introduce an amendment, delete a provision, etc.)
- ✓ Provide your name and contact information in case they have any questions for you at a later time.
- ✓ Record the name and contact information of the staff member with whom you spoke. This way you can ask for him or her by name the next time you call. This will help you to begin building a relationship.
- ✓ Make sure to thank the staff member and the legislator for their time. If possible, try to send a thank you note.

Meeting with Your Elected Officials

A face-to-face meeting with your legislators is another powerful advocacy tactic. When you take the time to meet with your elected officials, you put a face on paralysis, and remind your elected officials of the important role they play in improving the lives of those living with spinal cord injury.

It is important to remember that you don't have to travel to Washington to meet directly with your legislators. In fact, it is often best to meet with legislators when they are home in their district offices during a legislative recess. When elected officials are on recess, they have fewer distractions from legislative business. To find out when your members of Congress will be in your district, you can visit www.house.gov or www.senate.gov. You can also call your legislator's office directly.

Remember: Never be offended if your legislators are unable to meet with you in person. Lawmakers often rely on their staff to meet with constituents, draft legislation and make policy recommendations. Staff members, such as health legislative assistants, will have more time to get to know you and your issues. Use this time to get to know the staff, to develop meaningful relationships and to become a source of reliable information on paralysis and spinal cord injury in your community.

Before the Meeting

- Schedule and confirm all legislative appointments ahead of time. If your meetings are in Washington, allow at least 30-45 minutes between appointments for travel between Capitol buildings.
- Each Federal legislator has an office scheduler; call them to schedule your meeting well in advance of your trip.
- Some offices will request an emailed or faxed appointment request. Comply with all of the requirements of each office.
- When you request a meeting, explain who you represent and the reason you want a meeting with the senator or representative.

- Be prepared – know how the legislator has voted on the issues that are important to you or if he/she has cosponsored the bill you want to discuss. If the topic is one of the Foundation’s priorities, you can find information on the Foundation’s website in the Advocacy section.
- If possible, bring statistics that are specific to the legislator’s district.

During the Meeting

- Arrive prepared, and early.
- Keep your visit brief, focused and straightforward.
- Introduce yourself as a constituent, and explain why the issue of paralysis is important to you.
- Be flexible. Meetings usually run about twenty minutes, but oftentimes they are cut short so be prepared to deliver your message in five minutes if needed.
- Be positive and firm, but not confrontational.
- Emphasize that paralysis is NOT a partisan issue.
- If you are requesting action, communicate that up front.
- Establish yourself as a paralysis/spinal cord injury resource in the community.
- Don’t be upset if you meet with a legislative assistant instead of your legislator. These assistants help keep elected officials informed about issues and help them make decisions on how to vote. They are important allies!
- Be respectful at all times, even if you disagree with the legislator’s position.
- Leave a packet of information for your legislator to review after your meeting is over.

After the Meeting

- Be sure to thank your legislators and their staff for taking the time to meet with you. Legislators hear complaints all of the time. Like anybody else, they are grateful when they are shown appreciation for actions they may have taken on your behalf.
- Your thank you letter should summarize your discussion and the major points or specific requests for action that you discussed during the meeting. Remind him or her that you are available as a future resource.
- Stay in touch via phone calls and emails. Don’t fall off their radar!

Tell the Truth and Follow Through

- Honesty is critical to a successful relationship.
- If asked a question about the other side of your argument, answer the question as completely as you can, giving your particular perspective.
- If you don’t know the answer to a question, say you don’t know, but offer to find the answer and get back in touch with the legislator or staff as soon as possible.
- If you say you are going to follow up with the office with additional information, do it and do it as quickly as possible. If the request is going to take you a while to respond to in full, let the office know that.

Raising Public Awareness

Although direct communications with elected officials is a powerful tool for communicating your views on a particular issue, it is important to remember that there are additional steps that you can take as an advocate at home in your own community. The following is just a sample of the type of activities you could undertake.

Get Involved – Stay Informed!

To be an effective advocate, you must be informed. Although many resources exist to help connect advocates with the latest SCI and paralysis news and developments, one of the easiest ways to stay current is by registering for online newsletters. If you are unsure where to start, we encourage you to begin by subscribing to the Reeve Foundation eNewsletters at <http://www.christopherreeve.org/newsletters>. These eNewsletters will not only provide timely information on the issues facing people living with SCI and paralysis, but will also help advocates learn more about the Foundation and its upcoming events.

Community Advocacy – Approaches and Opportunities

An easy way for advocates to get involved is by participating in existing Reeve Foundation activities. To do this, we encourage you to join the Foundation's Action Network today by visiting the following website: <http://www.christopherreeve.org/advocacy>. If you are already a member, you can help get others involved by sending a personalized message to a friend encouraging them to join as well. <http://www.ChristopherReeve.org/advocacyinvite>.

A good way to increase your effectiveness as an advocate is by getting others to help share your message. There are many ways to do this, including the use of online networks, message boards and community forums dedicated to spinal cord injury and paralysis. Many of these message boards and online communities already exist – including the SCI and Paralysis Community created by the Reeve Foundation <http://www.ChristopherReeve.org/Community>. If you haven't already, we encourage you to join the Foundation's SCI and Paralysis Community to meet other advocates, to share your story, and to discuss issues related to SCI and paralysis. Many successful call-ins and community events have been organized by one or two people using this method of communication. If you meet someone who shares your position on a particular issue, work together to form a coalition to take action!

In addition to networking with people who share your position on SCI and Paralysis issues, it is important for advocates to reach out beyond the paralysis community. An easy way to do this is by using social media tools to connect your existing network of friends, family, neighbors and community members to your issue.

The Reeve Foundation has a presence on many of the social media networks that you may already use. These include Facebook, Twitter and YouTube. If you already have one of these accounts, we encourage you to join us today by following the links provided below. If you do not currently use these tools, we encourage you to visit the sites below to learn how easy it is to participate.



Facebook: Facebook is a social networking website that can be used to connect friends, family and business associates. Check out and “like” the Reeve Foundation Facebook pages below:

- <http://www.facebook.com/ReeveFoundation>
- <http://www.facebook.com/ReevePRC>
- <http://www.facebook.com/TeamReeve>



Twitter: Twitter is a tool that can be used to share information and links to stories in 140 characters or less. These short posts can then be shared with other friends who also have twitter accounts. To follow the Foundation on Twitter, please visit any of the links below.

- <http://www.twitter.com/ReeveFoundation>
- <http://www.twitter.com/TeamReeve>



You Tube: YouTube is a video-sharing website on which users can upload, share, and view videos. You can use the link below to view some of the videos posted by the Foundation and its supporters.

- <http://www.YouTube.com/ReeveFoundation>

Other Ways to Get Involved:

- Distribute educational material at community events. If you need this material, please don't hesitate to contact the Foundation. You can also download this information in PDF format at <http://www.ChristopherReeve.org/brochures>.
- Educate community members during chance encounters. Remember – every time you take the time to talk about spinal cord injuries and paralysis, you are acting as an advocate!
- Form coalitions with other community members, organizations and influential individuals who may share your position.
- Offer to coordinate a community forum on spinal cord injury and paralysis for your senator or representative.
- A well-written alert about an event or upcoming legislation, strategically placed around the Internet, can reach thousands. If there is a forum that allows participation or comments, post your alert there.

Letters to the Editor and Press Releases

Because your local community and legislators read the paper to get a pulse on community issues, letters to the editor and press releases are often extremely effective advocacy tools.

How to Write a Letter to the Editor

- Follow the publication's guidelines. Do not go over the maximum word count.
- Research the publication to get a feel for what type of articles are usually printed.
- Assume your readers are unfamiliar with the issue.
- Be as objective and rational as possible. Speak from personal experience.
- Be polite and respectful. Politely disagree with the opposition, and clearly state why.
- Have a friend or family member proofread for clarity, spelling and grammar.
- Provide your contact information with your submission.
- Don't be frustrated if your letter is rejected. Don't stop writing!
- If your letter is printed, send a copy of your letters to appropriate state and federal elected officials.

TEMPLATE LETTER TO THE EDITOR

(Date)

Dear Editor,

A study released last month by the Christopher & Dana Reeve Foundation shows that 1 in 50 Americans is living with paralysis. That's almost 6 million people. Among the millions of Americans living with paralysis, almost 1.3 million are spinal cord injured. The numbers are dramatically greater than previously thought. One of those 1.3 million is (INSERT SENTENCE HERE ABOUT YOUR FAMILY MEMBER WHO IS INJURED).

As we move forward in the debate about health care reform, these findings create a mandate to develop better treatments and promote opportunities for people with disabilities to live independently and return to work.

(INSERT PARAGRAPH ABOUT PERSONAL EXPERIENCE WITH PARALYSIS IN YOUR FAMILY – OBSTACLES – IN TWO TO THREE SENTENCES)

Addressing the needs of a community of 6 million Americans simply makes good business sense. We must promote opportunities for employment and independent living, as adaptive technologies and unprecedented connectivity now make it easier than ever to integrate people living with disabilities into the workforce.

Sincerely,

Name, Address and Phone #

How to Write a Press Release

A press release is a short, pseudo-news story. Written in third person, it is meant to persuade the journalism industry that your story or event is worthy of their attention with a more in-depth follow-up. Press releases should be timely and news-worthy. If you are organizing an event, please contact the Foundation to see if a press release is appropriate. Any press releases containing use of the Christopher & Dana Reeve Foundation name must be pre-approved by the communications department. Please send your draft press release to media@christopherreeve.org for approval and distribution guidance.

Advocate Profiles

Kris Gulden

In 1992, Kris won three gold medals in swimming at the International Law Enforcement Olympics. In 1996, she won the gold medal in the women's triathlon at the International Law Enforcement Olympics. In 1998, she won The Kiwanis Club of Alexandria, VA - Police Officer of the Year. Then, in 1998, Kris sustained a spinal cord injury after being hit by car while riding her bicycle to train for the AIDS Ride. Just a few years later, she became an active advocate for stem cell research and testified before the Senate Commerce Committee Science Subcommittee in January 2003. From March 2007 through August 2007, Kris was a research participant in the Reeve Foundation's NeuroRecovery Network locomotor training program, bodyweight-supported ambulation at Frazier Rehab Center in Louisville, KY. Kris currently teaches criminal justice at T.C. Williams High School in Alexandria, VA. In addition to sitting on a committee appointed by the State of Virginia to study the medical, scientific, and ethical implications of stem cell research, she is a Reeve Foundation ambassador.

Eva and Joseph Briseno



In 2003, Eva and Joseph's 20-year-old son, Army Reservist Joseph "Jay" Briseno Jr., had been in Iraq less than three months when he was shot in the back of the neck at point-blank range. Jay was treated at Walter Reed Army Medical Center and at the Hunter Holmes McGuire VA Medical Center in Richmond, VA. The bullet severed Jay's spinal cord, paralyzing him from his chin down. He also suffered two cardiac arrests, resulting in blindness and brain injury. Jay survived, but was unable to move, speak or eat on his own. He was ventilator-dependent and paralyzed.

"There are many newly wounded warriors from Iraq and Afghanistan," says Joseph. "Most are not familiar on how to navigate the system... Their families need to stick together. They need to stay strong as a family. Our technology is better and there are more resources when it comes to SCI and TBI." Joseph feels the VA can offer phenomenal medical services, but cannot do all the work alone (especially for TBI and for vets with complex injuries such as his son's). "We've become Jay's voice, his eyes, his ears. We keep screaming and fighting for him." As to rejections of any kind, be it coverage, service or belief, Joseph says, "Whenever we hear 'No, no, no.' We say, 'Yes, yes, yes.'"

Melissa Pitts



Melissa Pitts is a caregiver for her son Alex, who suffered a C/6-C/7 complete spinal cord injury during labor and delivery. His twin brother, Ryan, had a normal delivery. Alex has received multiple types of therapy, including activity-based therapy which Melissa, a physical therapist, has used with some of her own patients. Every day, Melissa sees the benefits it brings to Alex in improved health and muscle mass, and credits the Reeve Foundation for its widespread support of activity-based therapy and its efforts to train and encourage others to participate in its use. Melissa now eloquently argues in support of innovative interventions, and even produced a video appeal to President Bush.

Taylor Price



On July 8, 2004, then 18 year old Taylor Price, was involved in a catastrophic accident, while vacationing with his family on Long Island. After diving into the ocean and hitting his chin on a hidden sandbar, he was instantly rendered a C5-C6 quadriplegic. He spent eleven days at Stonybrook University Hospital, before being moved to The Shepherd Center in Atlanta, GA, where he participated in extensive physical and occupational therapies over four months.

In the fall of 2005, Taylor began studying at Georgetown University where he majored in finance and marketing. Despite his disability, he was one of the most "active" and visible people on campus. During his undergraduate years, Taylor served as the student representative on Georgetown's Board of Directors for two years, was involved in Georgetown University's Student Association, co-founded one of the largest scholarship funds at Georgetown in memory of a friend's father, and is one of Georgetown's biggest sports fans. Taylor received his Bachelor of Science in Business Administration as a member of the class of 2010, graduating *cum laude*.

Taylor had an amazing opportunity to intern for The White House, in the spring of 2010, as a member of The Office of Intergovernmental Affairs. His responsibilities included communicating directly with mayors nationwide regarding the President's agenda and local priorities, preparing briefing materials for senior staff meetings, and assisting with events.

On the advocacy front, Taylor spoke on Capitol Hill in 2005 to help introduce the "Employer Worker Incentive Act for Individuals with Severe Disabilities" alongside Senators Bob Dole, Ted Kennedy and Pat Roberts. Furthermore, Taylor was a co-founder of the Conference on Employment of People with Disabilities hosted by Georgetown University. The conference is designed to examine the public policy choices and the business and technological challenges and opportunities that affect the employment of people with disabilities.

Arielle (Elle) Rausin



In November 2003, while in fourth grade, Arielle's parents went on a holiday to Mexico, and Arielle Rausin and her brother, Kai, stayed home with grandparents. Tragically, Arielle and her grandmother were involved in a car accident in which Arielle's spinal cord sustained a bruise, and Arielle became paralyzed at the T/11 level. Arielle's parents, Krista and Eric, made every effort to keep Arielle active and to travel as a family as much as possible.

When Elle entered sixth grade her PE teacher, Ms. Black, encouraged her to become active. By seventh grade, Elle and her father started racing in local 5K races. Ms. Black then advocated for Arielle to become a member of the middle school track team. Arielle found she loved track and loved competing. In October of 2007 Arielle and her dad competed in Disney's Race for the Taste 10K. A representative from the Challenged Athletes Foundation (CAF) saw that Elle was racing in her everyday chair. Thanks to CAF and Elle's grandfather, a custom fit racing chair was made and three months later Elle raced with professional athletes in the Elite Wheelchair Division of Tampa's Gasparilla 15K.

In March 2009, Elle made history in Southwest Florida. In the quiet little town of Punta Gorda, when, after much local lobbying, she was allowed to race in a high school track meet open mile along with twenty seven other high school teams. For the very first time, Elle could race on a track with other girls.

Now, she is a member of the North Fort Myers High School track team. Elle has set a goal to compete in the 2012 Paralympics in London.

Many of the schools in South West Florida are now welcoming Elle to participate in their track meets. Elle races alone against her own time while the crowd cheers for her. Students come up to congratulate her for a job well done. Elle in turn motivates her teammates to keep up with her in practices. Elle loves being a member of the track team and advocating for others living with physical so they can become more integrated members of society.

Advocacy Priorities

The mission of the Christopher & Dana Reeve Foundation (REEVE FOUNDATION) is to cure spinal cord injury by funding innovative research, and to improve the quality of life for people living with paralysis through grants, information and advocacy. The Foundation's advocacy priorities are focused around a core set of issues connected to this mission.

Accelerating Research

Funded by the Foundation through a cooperative agreement with the Centers for Disease Control and Prevention (CDC), the NeuroRecovery Network (NRN) is a network of seven cutting-edge rehabilitation centers that provide and develop therapies to promote functional recovery and improve the health and quality of life of people living with paralysis. NRN is a perfect example of basic science being translated to the clinic and changing lives. Participants in the NRN program become part of a network-wide database that collects comprehensive medical information about the progress of each patient. By collecting and analyzing this information, the NRN is able to accurately measure program outcomes. The work of the NRN has led to significant improvements in participants' function, which translate into better ability to perform activities of daily living and reduced dependence on caregivers. With additional Federal support, the NRN will be able to reach a broader population, grow the number of community fitness and wellness facilities around the country and possibly add sites within the veteran's health system.

A second research initiative supported by the Foundation is the North American Clinical Trials Network (NACTN), a network of nine clinical centers and a data management and pharmacological center dedicated to bringing therapies out of the laboratory and into clinical trials. Supported by the Department of Defense, NACTN is the only established standing network for clinical trials for spinal cord injury in North America. NACTN has established a spinal cord injury database which is being used to establish trajectories of recovery for defined injuries and to develop models to predict outcomes of recovery. NACTN has also organized a Neurological Outcome Assessment initiative (NOA), an international task force of scientists and clinicians to develop, test, and validate new, more sensitive outcome measures to detect improvements for use in clinical trials. With continued Federal support, NACTN will be able to expand its civilian and military sites and conduct more clinical trials.

Providing Critical Information and Support to the Community

Through a cooperative agreement with the CDC, the Foundation's Paralysis Resource Center (PRC) provides quality information on paralysis to the community. It is the only resource of its kind for people with paralysis in this country. As insurers pay for less and less time in rehabilitation centers after paralysis, people have less time to learn how to live healthy independent lives and more people are turning to and relying on the PRC for information and support. An integral part of the PRC is connecting people with the Foundation's Quality of Life (QOL) Grants program recipients. This program awards grants to organizations providing community-based services and programs to increase health, wellness, and quality of life.

With additional federal support, the Foundation is planning to connect its new Peer Certification program to the PRC and QOL Grants program to provide more effective support. The Foundation will also conduct outreach to military communities to leverage the PRC services throughout the military/veteran communities. In addition, the implementation of an ongoing national survey of people living with paralysis will identify both problems and solutions to overcoming all aspects of secondary conditions in the lives of the paralyzed. This information will be translated into PRC information services and guide the QOL Grants program.

Ensuring Access to Health Care Services

The Patient Protection and Affordable Care Act of 2010 includes provisions that have the potential to impact the lives of those living with spinal cord injury and paralysis. Where needed, the Foundation will work to revise or comment on the provisions and regulations that may negatively impact the spinal cord injury and paralysis communities. Among others, the Foundation is monitoring: the CLASS Act, the Community First Choice Option, the cap on Medicare outpatient rehabilitation services and changes to

the Medicare first month purchase option for power wheelchairs. The Foundation will also continue to advocate for an end to Medicare's two-year disability waiting period.

NeuroRecovery Network (NRN)

What it is:

The NeuroRecovery Network (NRN) is a cooperative network of seven cutting-edge clinical rehabilitation centers that provide and develop therapies to promote functional recovery and improve the health and quality of life of people living with paralysis. NRN is a perfect example of basic science being translated to the clinic and changing lives. The Locomotor Training (LT) that NRN centers are now deploying is the result of research that the Reeve Foundation began supporting decades ago. This program, currently working with individuals who have incomplete cervical and thoracic injuries, involves suspending patients in harnesses over treadmills while therapists move their legs to simulate walking.

Participants in the NRN become part of a network-wide database that is collecting comprehensive medical information about the progress of each patient. As of June 2010, 355 subjects had been entered into the database. By collecting and analyzing this information, the NRN can accurately measure program outcomes. The NRN publishes data from its studies in peer-reviewed scientific journals. The effort is currently funded by the Reeve Foundation through a cooperative agreement with the Centers for Disease Control and Prevention.

In late 2008, the Foundation expanded its NRN to include a Community Fitness and Wellness (CFW) Program, designed to provide support for the development of specialized health and wellness facilities for individuals with spinal cord injury (SCI) and other physical disabilities. NRN CFW facilities are an opportunity for people with physical disabilities to improve their life-long health and fitness through activity-based exercise including locomotor training, electrical stimulation cycling, and strength and cardiovascular training. CFW facilities give people living in their communities access to affordable and effective activity-based exercise. They are staffed by athletic trainers, personal trainers and exercise physiologists, together referred to as activity-based technicians who are trained annually by the NRN's clinical centers. This insures that all CFW facilities deploy fitness and wellness exercise in a standardized way.

What it has accomplished/what we have learned:

All participants change, but all change differently. Some show significant improvements in function, including trunk control, endurance, speed of walking and balance, which translate into better ability to perform activities of daily living and reduce dependence on caregivers. There are demonstrable improvements in cardiovascular, pulmonary, and bladder function and increased bone density. In general, participants are showing improved overall physical well-being and quality of life.

What are the next steps:

Presently, the NRN clinical centers are accepting only individuals with an incomplete cervical or thoracic spinal cord injury with some movement or muscle tone in their legs. However, planning is underway to expand this population in the NRN clinical centers, as well as to grow the number of NRN CFW facilities around the country.

For additional information about the NeuroRecovery Network (NRN), please visit:

<http://www.ChristopherReeve.org/NRN>.

North American Clinical Trials Network (NACTN)

What it is:

NACTN is a network of nine clinical centers and a data management and a pharmacological center dedicated to validating best practices in the care of spinal cord injury (SCI) and carrying out clinical trials of the safety and efficacy of new therapies. NACTN is clinical and biostatistical infrastructure for testing new promising therapies, evaluating their efficacy, bringing them through the regulatory process, and if shown to improve outcome, incorporating them as standards of care. NACTN is the only established standing network for clinical trials for SCI in North America. It has been supported by the Department of Defense since 2006 and in July 2010 was awarded a new two-year contract for its continued expansion. Walter Reed Army Medical Center became a NACTN site in 2007 and the new award will enable other military hospitals to join.

What it has accomplished/what we have learned:

NACTN has established an SCI database characterizing spinal cord injuries. This database is being used to establish trajectories of recovery for defined injuries and to develop models to predict outcomes of recovery. As of June, 700 patients had been screened, 399 enrolled and data on 368 patients collected and entered.

NACTN has also organized a Neurological Outcome Assessment initiative (NOA), an international task force of scientists and clinicians to develop, test, and validate outcome measures to detect incremental improvements (Motor, Autonomic, Sensory and Pain) for use in clinical trials.

NACTN began its first clinical trial in March of this year, a Phase I safety study of the neuroprotective drug, Riluzole. As of this writing, 21 newly injured patients have been enrolled; a total of 36 will be needed to complete this initial study.

What are the next steps:

NACTN investigators have developed a rigorous process by which they review potential therapies and the basic science behind them and then reach consensus about which the network should test in trials of therapy.

NACTN continues to enroll acutely injured patients into its data registry and analyze myriad data points in order to share findings with the spinal cord field at large. Its first manuscript on the medical complications that accompany acute injury has been submitted for review and publication; others will follow shortly.

NACTN is preparing to expand beyond its present nine clinical sites, including bringing at least one new military hospital into the network.

For additional information about the North American Clinical Trials Network (NACTN), please visit: <http://www.ChristopherReeve.org/NACTN>.

Paralysis Resource Center (PRC)

What it is:

The PRC's mission is to be a comprehensive, national source of information for people living with paralysis and their caregivers to promote health, foster involvement in the community and improve quality of life. Through a cooperative agreement with the Centers for Disease Control and Prevention (CDC), it provides quality information on paralysis in a variety of ways; through highly-trained Information Specialists who can be contacted via telephone or e-mail; through in-person visits to its office; through visits to its website paralysis.org and social networking sites; or through loans from its national clearinghouse library of paralysis-related publications. An integral part of the PRC is connections made by the Information Specialists between clients and the Foundation's Quality of Life Grants program recipients. This program awards grants to organizations providing community-based services and programs throughout the nation to increase health, wellness, and quality of life.

What it has accomplished / what we have learned:

As insurers pay for less and less time in rehabilitation centers after paralysis, people have less time to learn how to live healthy independent lives and more people are turning to and relying on the PRC for information and support. The PRC has reached tens of thousands of those living with paralysis and their families with useful, often life-saving and life-changing information.

Annual evaluation surveys have been conducted to inform the direction of PRC programs and services. The PRC has also led a movement toward a functional view of paralysis as a disability. Our 2009 population-based survey identified approximately 5.6M people living with paralysis caused by central nervous system disorders. Grouping mobility impairments requiring a range of assistive devices from canes and walkers to high end power wheelchairs allows us to better understand the public health impact of these conditions and direct efforts appropriately. Other survey data documented disparities in African-American and Native American populations now targeted for services by the PRC.

What are the next steps:

The implementation of ongoing national surveys of people living with paralysis will identify both problems and solutions to overcoming secondary conditions due to paralysis. This information will be translated into PRC information services and products and guide the Quality of Life Grants program.

At the same time, the Foundation is developing more local and regionalized approaches to information and support through a Reeve Foundation Peer Support program to grow the opportunity for face to face service delivery throughout the nation. This network of experienced individuals will work hand-in-hand with the centralized PRC and grants programs to provide more effective support. We will also implement additional targeted outreach to current and former members of the military to leverage the PRC services throughout the military/veteran communities.

Health improvement programs to address obesity reduction through exercise and nutrition, tobacco abuse cessation, and aging with a spinal cord injury, are specifically targeted for development in partnership with other organizations.

For additional information about the Paralysis Resource Center (PRC), please visit:

<http://www.paralysis.org>.

Health Care Reform

What it is:

In 2010, the Patient Protection and Affordable Care Act of 2010 was passed by Congress and signed into law. This legislation includes a number of provisions affecting people with spinal cord injury and paralysis. The Christopher and Dana Reeve Foundation is working to ensure that the provisions cited below are implemented in the most effective way or, in some instances, revised to be most beneficial to people with spinal cord injury or paralysis.

CLASS Act

The healthcare bill includes a new voluntary long-term care insurance program called the Community Living Assistance Service and Support (CLASS) program. This program will go into effect in 2011 and is designed to help people who are unable to perform two or more functional activities of daily living pay for nonmedical services and supports – to help them remain within their homes and communities for as long as they can. Individuals pay premiums while they are working and then are eligible for cash benefits if they become functionally impaired. Under the CLASS Program, every American will be able to voluntarily participate in this self-funded, insurance program. Individuals qualify for benefits after paying premiums for five years, and must have worked for at least three of those five years. Beneficiaries receive a lifetime cash benefit, which is expected to pay roughly \$75/day or more than \$27,000 per year. Benefits can be used to pay for such things as home modifications, assistive technology, accessible transportation, homemaker services, respite care, personal assistance services, and home care aides.

Working individuals will be given the option of having a small amount of money (yet to be determined) deducted from their paychecks. The money will go into a fund to help the individual purchase nonmedical supports and services needed to maintain independence, should he/she ever become disabled. Unlike Medicaid, the CLASS program does not require people to be impoverished to qualify for the program. The law also requires HHS to develop an actuarially sound benefit plan so that the program is self-sustaining.

Community First Choice Option

The new Community First Choice Option allows States the option of offering home and community based services, rather than institutional care, as the rule rather than as the exception to disabled individuals through Medicaid. This is an optional program, and to encourage states to participate, states that opt in will receive an additional six percent to the federal government's share of Medicaid costs for five years. This program takes effect on October 1, 2011. Although this is an optional program in the Act, it is an important first step towards making it permanent.

Elimination of Medicare first month purchase option for power wheelchairs

The bill restricts the Medicare option to purchase power-driven wheelchairs when they are initially supplied to complex, rehabilitative power-driven wheelchairs. The purchase option is eliminated for other power-driven wheelchairs, which will be reimbursed on a rental basis with ownership title transferring to the individual after 13 months of continuous use. During the 13 months rental period Medicare will pay 80% and the individual 20% of the rental cost.

We are concerned that elimination of the purchase option will make it difficult for individuals to have his/her wheelchair fitted to specific needs. A wide range of advocacy organizations support preserving the first-month purchase option, and there may be efforts to reinstate this provision.

Paralysis and Spinal Cord Injury Statistics

How many people are affected?

- Approximately 5.6 million people or 1.9% of the population have difficulty or inability to move one or more upper or lower extremities
- More than 1.275 million people have a spinal cord injury

What ethnic groups are affected?

- For all forms of paralysis, 77.8% are Caucasian, 17.2% African American, and 3.7% Native American
- In spinal cord injury, 77.1% are Caucasian, 15.6% African American, and 7.3% Native American

What are the leading causes of paralysis?

- Stroke – 29%
- Spinal Cord Injury – 23%
- Multiple Sclerosis – 17%
- Cerebral Palsy – 7%
- Post Polio Syndrome – 5%
- Other – 19%

What are the leading causes of spinal cord injury?

- On-the-job Accidents – 28%
- Motor Vehicle Accidents – 24%
- Sporting/Recreation Accidents – 16%
- Falls – 9%
- Other – 23%

How does paralysis affect annual household income?

- 59.2% of the paralyzed population reports household income of less than \$25,000, compared to 27.1% of the U.S. population as a whole
- With spinal cord injury, 62.7% report household income of less than \$25,000

Source: Christopher & Dana Reeve Foundation Paralysis Resource Center. One Degree of Separation: Paralysis and Spinal Cord Injury in the United States.

<http://www.christopherreeve.org/facts>.