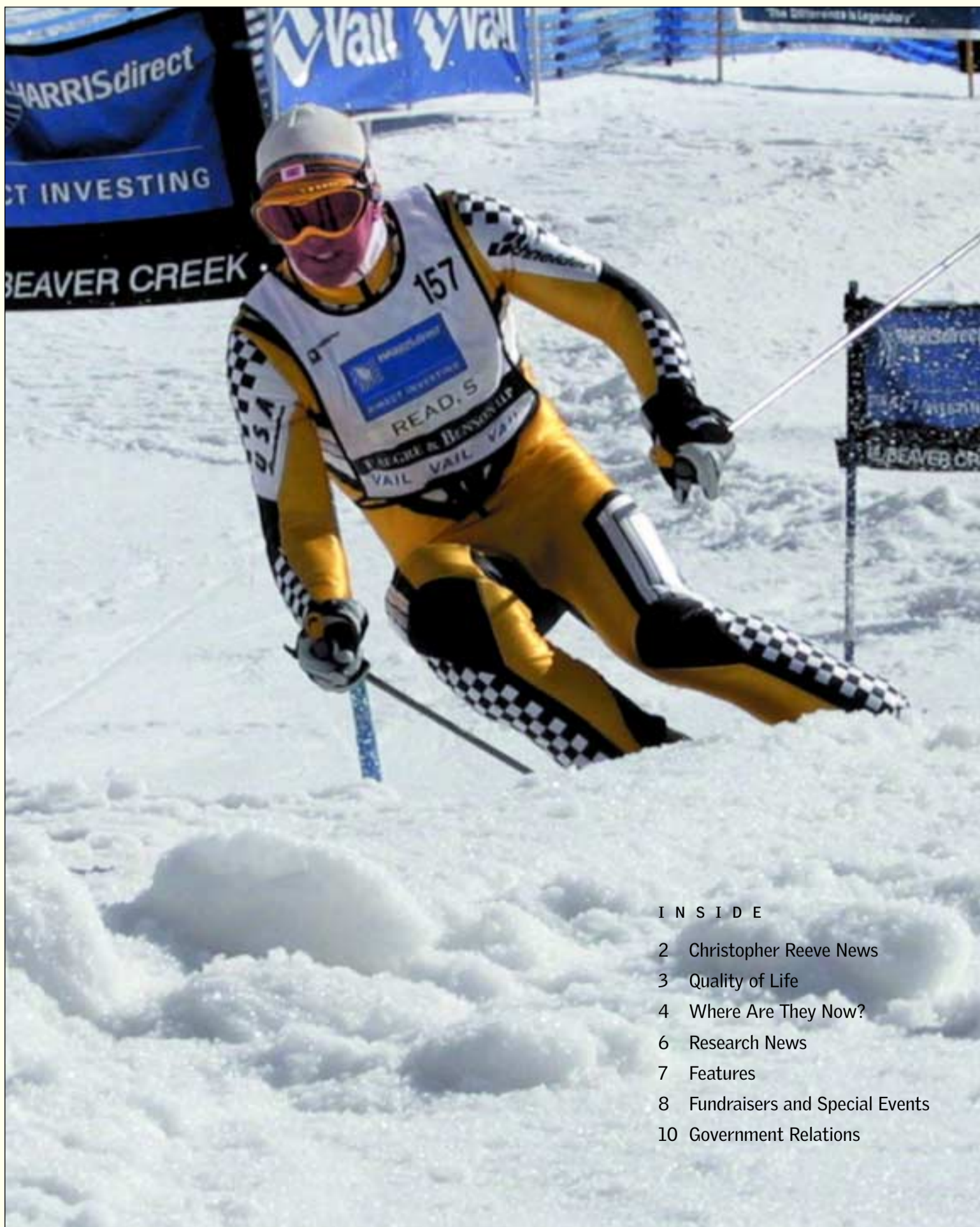


# WALKING TOMORROW

ISSUE 32



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## CHRISTOPHER REEVE NEWS

# Christopher Reeve Receives Two Honors for His Dedication

## Christopher Reeve Gets Prestigious Lasker Award for Public Service

For his activism on behalf of people living with a disability or illness, his advocacy of medical research, and his personal courage, Christopher Reeve received the 2003 Mary Woodard Lasker Public Service Award. This prestigious award is given to individuals whose support of medical research and the health sciences leads to advances in medical care.

Daniel Koshland, Chairman of the Public Service Selection Committee, praised Reeve for his role as an activist on behalf of others who are paralyzed, as well as those afflicted with a broad range of diseases. He highlighted Reeve's persuasive testimony in the U.S. Congress on behalf of the National Institutes of Health (NIH); the formation, with his wife Dana, of the Christopher and Dana Reeve Paralysis Resource Center; his tireless efforts to bring his message to as many people as possible; and his willingness to take unpopular positions, citing his advocacy for stem cell research. Reeve was selected for this award by a jury of scholars and scientists.



"I am delighted and grateful to be the recipient of this year's Lasker Public Service Award," said Reeve. "As an advocate and as Chairman of the Christopher Reeve Paralysis Foundation, I have had the privilege of working to improve the lives of people with disabilities and to seek better treatments and a potential cure for paralysis. The Lasker

Awards recognize world-renowned scientists, physicians and public servants. It is an overwhelming honor for me to be included in such distinguished company."

For 40 years, the Albert and Mary Lasker Foundation has vigorously supported the expansion of research at NIH into virtually every area of human health; educated the public on the importance of disease-based research; and recognized the research accomplishments of outstanding scientists. Attention and interest in these awards have helped to create ongoing public support for a national research effort. Since 1946, 120 Lasker Awards have been given to working scientists, to public figures in recognition of their efforts on behalf of research, and to journalists for excellence in science reporting. Sixty-six winners later received Nobel Prizes.

According to the Lasker Foundation, Reeve's "personal commitment, star power, and desire and capacity to fully comprehend the complex political and scientific realities of medical research" make him a forceful advocate for scientific research and most deserving of this award. ■

## NOW IN PRINT!

## Paralysis Resource Guide

From the Christopher and Dana Reeve Paralysis Resource Center

The Guide is a 310-page comprehensive information tool for people affected by paralysis and for those who care for them. The book provides information on paralysis, including specific information about ALS, stroke, spina bifida, brain or spinal cord trauma, MS and other causes of disability.

The Guide offers information on:

- sports and fitness;
- travel;
- recreational activities, and also covers:
- tools and adaptive equipment;
- understanding "the system";
- choosing a rehabilitation center;
- parents and kids with paralysis;
- caregiving and family issues.

Individuals and organizations may obtain one free copy of this useful guide, with additional copies available for \$10.

To order visit [www.paralysis.org](http://www.paralysis.org), or email [info@paralysis.org](mailto:info@paralysis.org) or you can call 1-800-539-7309 toll free, 9 am - 5 pm, Eastern time.

## Christopher Reeve Receives Lifetime Achievement Award

The 4th Annual World Awards took place in Hamburg, Germany on October 22nd to honor men of distinction for their outstanding achievements.

Christopher Reeve was honored with the Lifetime Achievement Award, "for his efforts on behalf of people with disabilities and giving millions of people hope."

"The World Awards takes pride in honoring men whose lives are filled with passion for ideals and visions, whose success in their fields helps them help others who have not been as fortunate." Reeve received the award from former Soviet Union President, Nobel Peace Prize winner and current President of the World Awards, Mikhail S. Gorbachev. The 2003 honorees included Michael Douglas, Placido Domingo, Jan Ullrich, Morgan Freeman, Larry King and Karl Lagerfeld, among others.

The mission of the World Awards is to select "extraordinary individuals for their achievements in a variety of areas. These individuals however have a common thread, excellence in their chosen profession as a compassion for their fellow men. They represent the best qualities of mankind in the 21st century. Particularly in today's still troubled world, it is of immense importance to reflect on the good and the positive in

order to inspire others to follow these examples. For only by doing good can more good be accomplished."

According to the World Awards, Reeve was honored for his indefatigable spirit, "He became more of a hero in real life than he ever was on the big screen. Considering he portrayed Superman this hardly seemed possible. He received this year's Lifetime Achievement Award for his tireless efforts on behalf of people living with disabilities as well as his work in supporting researchers attempting to conquer the most complex diseases of the brain and central nervous system." ■



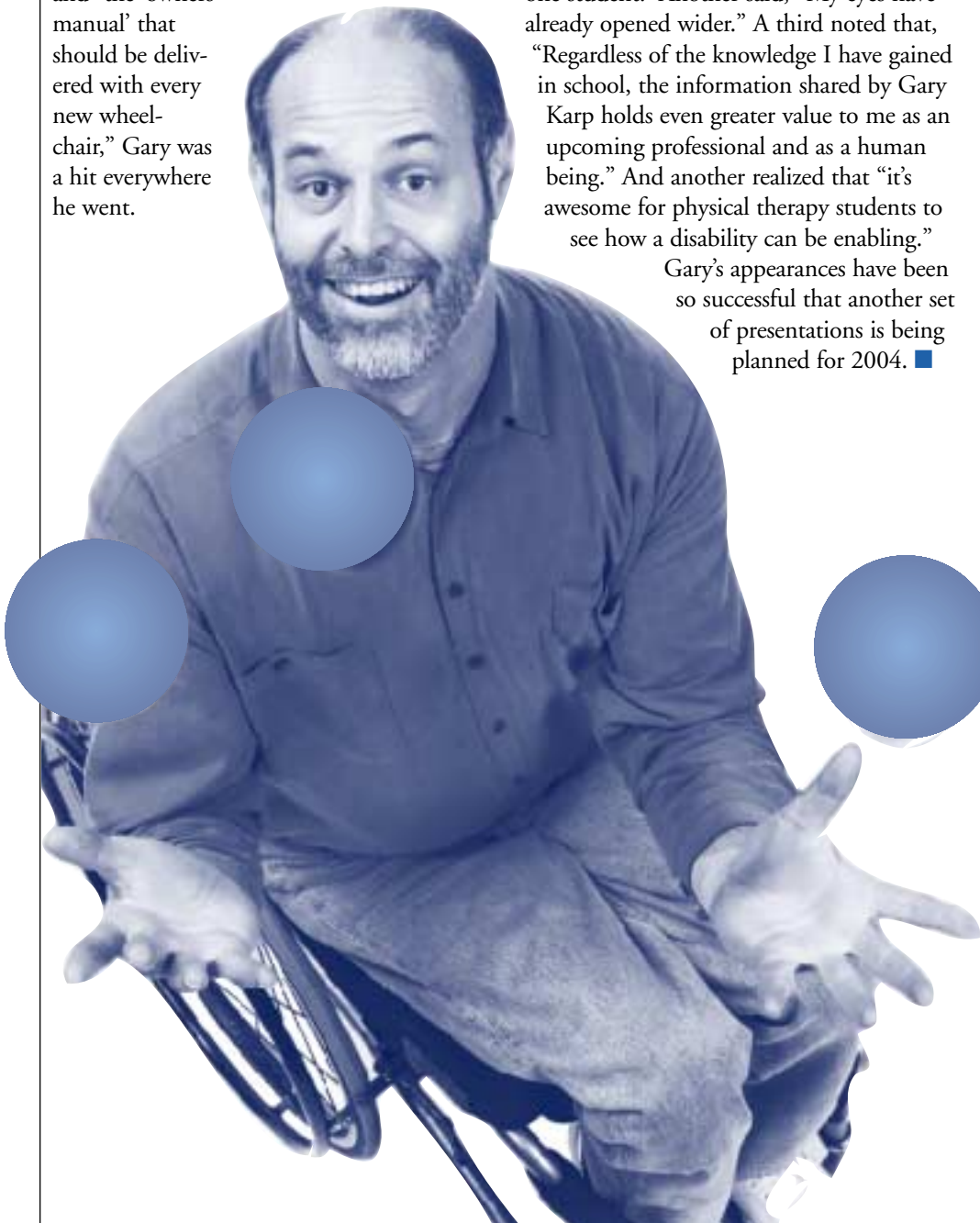
## QUALITY OF LIFE

## Author-advocate Gary Karp goes on the road for PRC. His impact is called "Simply, Amazing!"

**G**ary Karp is an author, juggler, founder of an ergonomics consulting firm, musician with a CD of original music, and a riveting professional speaker. Gary, 48, is also a T12 paraplegic, injured at the age of 18 when he fell out of a tree.

Joe Canose, Director of the Christopher and Dana Reeve Paralysis Resource Center (PRC), met Gary about a year ago through a CRPF board member. He was convinced that Gary was the perfect person to help the PRC educate the public, including healthcare providers, students, and disabled individuals, about quality of life issues for people living with paralysis. The result has been what Joe calls, "a wonderful and successful association."

This past spring, Gary went on his first "PRC tour" to three rehabilitation centers and three physical therapy schools in Georgia and Colorado. As the author of the popular book, *Life on Wheels* ([www.lifeonwheels.net](http://www.lifeonwheels.net)), which reviewers have called a "goldmine" and "the 'owners manual' that should be delivered with every new wheelchair," Gary was a hit everywhere he went.



He discussed the emotions that are a "natural part" of the response to injury and recovery and raised awareness about the "cultural myths" that have been perpetuated about paralysis. These include assumptions that paralyzed people hate being disabled, feel that they have no control over their lives, and feel that their sex lives are over. Gary convinced his audiences that disabled people don't want and don't deserve to be pitied – they can achieve anything they want to achieve. "I'm not 'confined' to a chair," Gary said; after he was injured he simply had to learn to "adjust to his new 'tool.'" And to disabled people, Gary sends the message loud and clear: "Don't let people wheel all over you! Put your wheel down!"

"We were particularly pleased with the impact on students in physical therapy schools," says Joe, who reports that evaluations after Gary's talks were universally glowing. "Mr. Karp's presentation was amazing," wrote one student. Another said, "My eyes have already opened wider." A third noted that, "Regardless of the knowledge I have gained in school, the information shared by Gary Karp holds even greater value to me as an upcoming professional and as a human being." And another realized that "it's awesome for physical therapy students to see how a disability can be enabling."

Gary's appearances have been so successful that another set of presentations is being planned for 2004. ■

## QUALITY OF LIFE GRANTS

### Grant Helps Habitat for Humanity Combine Affordability with Accessibility

**W**ith a \$15,000 Quality of Life grant, the Twin Cities Habitat for Humanity in Minnesota was able to add state-of-the-art features to a disabled couple's home. The man and woman, both of whom use wheelchairs due to cerebral palsy, required a house that would be considerably more expensive than the average Habitat structure.



Thanks to support from various sources, the home now has a host of amenities, including: an outside light that is sensitive to light and motion; a porch that camouflages a wheelchair ramp; exterior doors, windows, and shades that open electronically; windows that automatically shut when it rains; and a tilted mirror above the stove so that someone in a wheelchair could more easily see what is cooking. The Twin Cities Habitat has built several houses in the past for people with disabilities, but this home has more assisted technology than any other Habitat house in the country. The house was such a success that it was featured on the public television show, *Hometime*, which highlights unique home improvement and remodeling projects. ■

### PRC Helps to Get Assisted Technology to People who Need It

**T**he Foundation for Rehabilitation Equipment and Endowment (FREE) in Roanoke, Virginia was established to improve recovery and self-sufficiency among people with disabilities. It does so by providing essential rehabilitation equipment and home modifications to "underserved individuals." A piece of equipment or a home improvement can make all the difference for those who want to live independently. Thanks to a \$25,000 Quality of Life grant, FREE will be able to reach further into the disabled community and provide more support to low-income adults with disabilities. ■

*Grants continued on page 11*



With cutting-edge skills and a strong sense of purpose, young researchers are emerging from the CRPF Research Consortium on Spinal Cord Injury deciding to dedicate their professional lives to reversing the toll of spinal cord injuries. Some even attribute their career choice to their experiences in the Consortium.

Seven senior scientists comprise the multi-disciplinary Consortium, meeting regularly to pool their skills and research and to plan joint experiments. Each scientist selects at least one postdoctoral research fellow to be a Consortium associate, who will attend all Consortium meetings and work closely with the other

associate is “a unique introduction to the field, and it is starting to pay off,” he says.

Among the latest Consortium alumni to have set up research laboratories are Aileen J. Anderson, Ph.D., at the University of California-Irvine; Philip J. Horner, Ph.D., at the University of Washington in Seattle; and Keith E. Tansey, M.D., Ph.D., at the University of Texas-Southwestern Medical Center in Dallas. (An article on the first three associates to strike out on their own – Daniel Liebl, Ph.D.; John McDonald, M.D., Ph.D.; and Giles Plant, Ph.D. – appeared in the CRPF 1999 Annual Report.)

Dr. Aileen J. Anderson was an associate from 1997 to 2001 under Carl Cotman, Ph.D., director of the Institute for Brain

of the genes and signaling pathways that influence brain plasticity also are active in Alzheimer’s disease and some forms of Down’s syndrome. Deciding to study this relationship further, she completed her Ph.D. with Dr. Cotman, studying this area.

In 1996, she was at Harvard still exploring brain degeneration when Dr. Cotman asked her to attend a Consortium meeting in San Diego. Dr. Anderson recalls answering: “I’ll go, but I am not doing spinal cord research.” She returned to Boston from the meeting “enormously impressed” by the extent of the collaboration and the accomplishments of the Consortium members and associates.

# Where Are They Now?

[ Life after the CRPF Research Consortium on Spinal Cord Injury ]

associates on inter-laboratory experiments. There have been 29 Associates since the Consortium was formed in 1995. Sixteen have rotated out of the Consortium and nine now lead their own spinal cord injury research teams.

“The Consortium has set up Centers of Excellence where younger people are exposed to scientists who are really good at their particular approach to spinal cord research,” says Guy McKhann, M.D., professor of neurology and neuroscience at Johns Hopkins Medical School. Dr. McKhann, who serves on the Consortium Advisory Panel that evaluates the work of the group, says the associates also benefit from interacting with the other members of the Consortium and viewing spinal cord injuries from different perspectives. Being a CRPF asso-

ciate is “a unique introduction to the field, and it is starting to pay off,” he says. Among the latest Consortium alumni to have set up research laboratories are Aileen J. Anderson, Ph.D., at the University of California-Irvine; Philip J. Horner, Ph.D., at the University of Washington in Seattle; and Keith E. Tansey, M.D., Ph.D., at the University of Texas-Southwestern Medical Center in Dallas. (An article on the first three associates to strike out on their own – Daniel Liebl, Ph.D.; John McDonald, M.D., Ph.D.; and Giles Plant, Ph.D. – appeared in the CRPF 1999 Annual Report.)

Dr. Aileen J. Anderson was an associate from 1997 to 2001 under Carl Cotman, Ph.D., director of the Institute for Brain Aging and Dementia and a professor in the departments of neurology and psychobiology at UC-Irvine. Today she manages the Consortium’s core animal laboratory at UC-Irvine, where members run collaborative experiments. In her own work, she specializes in two areas: the immune response to spinal cord injuries and the therapeutic potential of one type of human stem cell. As a graduate student at UC-Irvine, Dr. Anderson looked at how messages from the sensory system cause changes in the brain, a process known as activity-dependent plasticity. She eventually found that some

She returned to UC-Irvine in 1997 as Dr. Cotman’s Consortium associate and gradually abandoned her Alzheimer’s work. She began her new research by looking at what happens in the immune system when the spinal cord is injured. Her focus is the complement cascade, a series of molecular events that activate immune cells. This reaction helps the body ward off illness and infection but also causes inflammation that can destroy healthy cells and worsen an injury. She recently has shown that the complement is fully activated after spinal cord injury, and she traced how that process unfolds in rodents. Dr. Anderson now is testing how mice lacking some of the genes that trigger the complement cascade fare after a spinal cord injury, and how external factors like exercise affect the immune system. She believes that scientists eventually will be able to harness the immune response to treat spinal cord injuries.

In her stem cell work, Dr. Anderson studies human neural progenitor cells, the



*Dr. Aileen J. Anderson*

parent cells that spawn neurons and all of the other cell types in the brain and spinal cord. The progenitor cells may be easier to use therapeutically than embryonic stem cells, which are more primitive and must be “coaxed” to become neurons and their supporting cells. She plans to test whether transplants of neural progenitor cells can repair the damage from spinal cord injuries in mice bred to reduce the chances their bodies will reject the stem cells.



*Dr. Philip J. Horner*

Dr. Philip J. Horner did not intend to become a spinal cord researcher. He expected to be a civil engineer until he discovered that he disliked engineering and enjoyed biochemistry. Eventually, he chose to study degenerative brain disorders because his family has a history of Alzheimer’s disease.

While he completed his master’s and doctorate degrees in physiology at Ohio State University, Dr. Horner’s biochemistry skills earned him a training spot in the Spinal Cord Injury Research Center there. He learned to use animal models of spinal cord injuries and saw how nerve cells could be coaxed to regenerate after such injuries. “I became passionate about researching spinal cord injuries,” he remembers. “I also thought they might be easier to cure than degenerative diseases.”

After graduate school, he wanted to acquire the sophisticated tools of molecular biology by working under Consortium member Fred Gage, Ph.D., professor in the Laboratory of Genetics at The Salk Institute in San Diego. Dr. Gage invited him to join his research team and to become a Consortium associate. Dr. Horner was surprised when he was asked to present a paper on gene therapy and spinal cord injury at his first Consortium meeting.

“The great minds in the field were treating me like a long-time colleague,” he explains. “I went from having one world-class mentor to having six more. “Too often,” adds Dr. Horner, “research is done in a vacuum. If you have a great idea, you don’t tell anyone.” He says that the Consortium shows the “far-reaching benefits” of working openly with other scientists.

In the Gage laboratory from 1996 to 2000, Dr. Horner contributed to the discovery that the brain makes new cells throughout life. The Gage team identified

glial cells, a type of stem cell deep in the brain of adult rodents that spawns new cells. Dr. Horner found that these cells, which support, feed, and protect neurons and account for forty percent of the central nervous system, also are replaced in the spinal cord. He wondered why so many glial replacements were needed. He hypothesized that people’s ability to recover from a spinal cord injury or to avoid degenerative neurological diseases might hinge on how well they produce new cells.

For the last two years in his own laboratory at University of Washington in Seattle, Dr. Horner has been searching for the characteristics of the glial replacement mechanism. One challenge is to develop ways to identify and analyze the glial parent, or progenitor, cells that give rise to new glia. He is also trying to pinpoint how glial cells respond to brain and spinal cord injuries, especially how these cells create scars that pose both a physical and chemical barrier to the regeneration of nerve cells.

**“The Consortium has set up Centers of Excellence where younger people are exposed to scientists who are really good at their particular approach to spinal cord research.”**

“Most people have focused on the impact of the scar and how to dissolve it,” he says. “We look at how the scar is made. We believe that it forms through the birth of new cells that then “choose” a glial fate. We may have an opportunity to go in and change the fate of those newborn cells.”

Dr. Keith E. Tansey also found that the talent and the technology of the CRPF Consortium elevated his research. “I got exposure to the leaders in the field and a broad spectrum of disciplines, from neuro-immunology to electrophysiology,” says Dr. Tansey. From 2000 to 2002 he was the Consortium associate of V. Reggie Edgerton, Ph.D., a physiologist at UCLA.



*Dr. Keith E. Tansey*

Dr. Tansey’s career has had dual tracks since his undergraduate days at Stanford, where he simultaneously earned a bachelor’s degree in biology and a master’s degree in biomechanics. He completed a joint M.D. and Ph.D. program at the University of Texas-Southwestern Medical Center, specializing in neurology and neuroscience. How the spinal cord sparks movement especially fascinated him and continues to inspire his research.

“Some 300 motoneurons control a single muscle,” Dr. Tansey says. “How do the brain and spinal cord activate them? How is the spinal cord organized in the first place, and how does it reorganize after an injury?”

After a neurology residency and fellowship at Washington University School of Medicine in St. Louis, he went to the Edgerton laboratory, where he explored the effects of locomotor training on rats with incomplete spinal cord injuries. In this type of training, animals are suspended over a treadmill so that their hind limbs move in a stepping pattern. In time, this regimen “teaches” the spinal cord below an injury to activate the muscles needed to walk, restoring some function. Previous animal studies had looked only at complete injuries.

“Had it not been for the Consortium,” he says, “I would not have been able to finish the work.” As evidence, he notes that to create his animal models he collaborated with Dr. Anderson, who used equipment from the Consortium animal core laboratory at UC-Irvine. Another associate in the Cotman laboratory helped him use the Consortium’s gene chip core laboratory to identify the many differences in gene activity between the trained animals and the untrained controls. And, a new robotic device developed at UCLA enabled Dr. Tansey to check for improvements in the animals’ gait over the course

of the experiment

For the past year, Dr. Tansey has been setting up a regional center at the University of Texas that will feature comprehensive services

for spinal cord patients and sophisticated research facilities. The interdisciplinary Spinal Cord Injury Center is a partnership between Parkland Medical Center and the University of Texas. The new Center will include a special intensive care unit for spinal cord patients, an inpatient rehabilitation unit, and an outpatient

*(Continued on page 11)*

## RESEARCH

## CRPF Awards \$1.8 million in Individual Research Awards

In its second funding cycle of 2003, CRPF awarded 16 exceptional investigators individual grants totaling \$1,811,134 to further their work on spinal cord injury research. Since 1982, CRPF has invested more than \$43 million in research grants to almost 500 researchers worldwide.

"There were several notable aspects of this current funding cycle," said Susan P. Howley, Director of Research and Executive Vice President of CRPF. "CRPF received the largest number of applications ever, which is testament to the rapid and exciting growth in the spinal cord research field. CRPF's individual grants are catalytic – they get a project or a new investigator started, and almost without exception lead to additional, more long-term support. This is especially crucial to the ten of our sixteen grantees who are either postdoctoral fellows or young investigators. It is also a classic example of how CRPF so effectively leverages its funding."

All grant proposals are selected through a rigorous process of peer review by CRPF's Science Advisory Council (SAC), a group of expert neuroscientists who volunteer their time and knowledge to carefully evaluate proposals based on the science, relevance to the Foundation's research priorities and promise for clinical application. SAC maintains CRPF's scientific integrity by recommending funding only for those projects that demonstrate the highest merit and potential for developing effective therapies for paralysis and dysfunctions caused by spinal cord injury and other central nervous system disorders.

For information on grantees, their projects and funding categories, visit [www.ChristopherReeve.org](http://www.ChristopherReeve.org) ■

## The Flip Side of Neuroscience: Finding Funding

On November 11th during the annual Society for Neuroscience meeting in New Orleans, CRPF's Director of Research, Susan P. Howley, participated in a workshop to give scientists guidance on the grantmaking philosophies, policies, and mechanics of private foundations and public charities.

The goal of "Obtaining Funding from the Foundation World" was to provide insights into the variety of research programs that are available, how such granting agencies make funding decisions, and the responsibilities of holding research awards. Panelists also gave their insider perspectives on how to develop and submit successful proposals and they went to great lengths to highlight the differences between applying for foundation and federal dollars.

Other panelists participating in the 90-minute workshop included Sarah J. Caddick, Ph.D., Executive Vice President of the Center for Accelerating Medical Solutions, Debi Brooks from the Michael J. Fox Foundation, Martin Ionescu-Pioggia, Ph.D., of the Burroughs Wellcome Fund, and Roxanne Ford of the W.M. Keck Foundation. ■

## Making a Difference with Planned Giving

Lynn Tardiff Howe, Nancy Bach, and Elmira Irene Randall did not know one another, but they had something in common. All three made bequests in their wills to the Christopher Reeve Paralysis Foundation (CRPF). Their planned gifts demonstrated their commitment to the goals of CRPF – to fund promising research leading to a cure for paralysis and other devastating diseases and to support programs that improve the quality of life for people living with disabilities.

Why engage in planned giving? Because it provides valuable tax benefits and/or income for life to the donor and benefits the critical work of CRPF. Planned gifts can increase the donor's current income, reduce income tax, avoid capital gains tax, or pass assets to family at a reduced tax cost, while substantially increasing the dollars that CRPF contributes to research.

Your planned gift truly will make a difference. With so many options available (see side bar), we believe you can find the one that will achieve your philanthropic goals, meet your financial needs, and significantly advance the work of CRPF.

### Becoming a Legacies of Hope Member

Membership in Legacies of Hope is open to all those who include the Christopher Reeve Paralysis Foundation in their estate plans. [See sidebar for qualifying gifts.]

### Recognition

As a Legacies of Hope member you will be recognized in the following ways, with your permission, of course:

- Your name and story will be added to the CRPF Book of Legacies
- Your name(s) will be permanently listed in a Legacies of Hope Honor Roll
- Your name will be included in select CRPF publications
- You will be invited to select CRPF events

Above all, you will gain the satisfaction of knowing you have provided hope to millions of people living with paralysis.

### Here's How You Can Make A Difference

There are a number of planned giving options, which are briefly described below. CRPF will provide a private consultation to explain each option in-depth and suggest a gift plan that suits your needs and meets your ideals.

To learn more, please call Ida Cahill at CRPF, 800-225-0292, or email her at [icahill@crpf.org](mailto:icahill@crpf.org)

- **Bequest** – A gift made through a will, a life insurance policy, or a retirement account policy.
- **Charitable Remainder Trust** – This trust makes payments, either a fixed amount (annuity trust) or a percentage of trust principal (unitrust), to whomever the donor chooses. At the end of the trust term, CRPF receives the money that remains in the trust.
- **Charitable Lead Trust** – This trust makes payments, either a fixed amount (annuity trust) or a percentage of trust principal (unitrust), to CRPF during its term. At the end of the trust term, the principal can either go back to the donor (a grantor lead trust) or to heirs named by the donor (a non-grantor lead trust).
- **Retained Life Estate** – A donor may make a gift of his or her personal residence or farm to CRPF and retain the right to live there for the remainder of his or her life. At the donor's death, CRPF can use or sell the property.
- **Non-cash gifts** – real estate, antiques, etc.

## FEATURES

## A Small Town Achieves a Large Goal

Just nine months after logger Scott Remington was paralyzed in a work accident deep in the Adirondack forests, he held his first fundraiser with the help of a dedicated band of family and friends. Since he came from a tiny town in upstate New York, everyone was shocked when the Scott Remington Family and Close Friends Spinal Cord Research Benefit exceeded its goal of \$10,000 and sent \$21,000 to CRPF. "But you have to remember," says his sister Renee, a driving force behind the event, "that first year, the shock of Scott's injuries was still quite fresh. What's been even more amazing is that every year the event continues to defy expectations."

Since that first fundraiser in 1999, each year Scott and his committee have thrown a

daylong party in his hometown of Brant Lake with bands, raffles, and food. All proceeds have gone to CRPF. As part of the fundraiser, the group also solicited direct donations to CRPF from individuals and businesses. In the first three years, they sent a total of \$71,000 to the Foundation.

This year, for their fourth fundraiser on March 29th, the group set a special goal: to raise enough money to bring their four-year grand total to \$100,000. They not only met but exceeded that milestone, sending \$31,450 to CRPF. Two CRPF representatives, Mary Vining and Julie Kwon, attended this year's fundraiser, and Scott said he was extremely honored to have them there.

When Scott came home from rehab at the Kessler Institute, he vowed to his sister that he wouldn't spend the rest of his life in a wheelchair and would do his part to find a cure. He remains confident that a cure will come in his lifetime, but his mission extends beyond his own needs. "I met so many kids down at Kessler who were a lot worse off than me. Even if I don't get to walk again, let's get this done for all of them." ■

## A Year of Surprises for CRPF Booster Bill Cawley

"I think we surprised the Foundation," says Bill Cawley, about the \$100,000 that was sent by Friends & Family Curing Paralysis to CRPF. Bill, who was injured in a diving accident about ten years ago, has supported CRPF through his foundation over the past four years; but this year's donation was especially generous.

"We've been donating proceeds from the fundraisers," he explains, "but we also built up a pretty good kitty. We wanted to take our time and make sure we put the money that people have been so generous in giving us to good use. We now feel strongly that CRPF is an organization that we'd love to support. The mission is similar to ours in terms of providing for both research and

quality of life. This donation is the cumulative effect of this year's New York event and fundraising over the last few years."

The event at the Larchmont Country Club in New York's Westchester County was especially "awesome," says Bill, thanks to an appearance by Christopher Reeve. "It's wonderfully educational for the audience," he says. "[Christopher] is obviously very inspirational, and when he spoke about research he was right on message in telling people that we really are getting closer [to a cure] and that individually you can make a difference. It's a point we as an organization try to make, but when you hear it from him it really makes a big difference."

Bill's fundraising success caps off an incredible year for him personally. He was married last May, and on July 3rd witnessed the birth of his first child. Liza Jane is "beautiful," he beams. "It's amazing. I don't know how to explain it. My daughter has me whipped already." ■



## CRPF Salutes Kent Waldrep, Paralysis Research Pioneer

Kent Waldrep never quit. Not when he was a junior running back at Texas Christian University, not when he suffered an incomplete spinal cord injury at the C-6 level during a football game in 1974, and certainly not when he was told that he would never walk again. Determined to find a cure, he was a true pioneer in paralysis research.

In 1979 he founded the Kent Waldrep International Spinal Cord Research Foundation, the first national private sector organization dedicated to finding a cure for spinal cord injury. Due to Kent's efforts the foundation (which later evolved into CRPF) raised over \$5 million for medical research.

In 1985, he founded the Kent Waldrep National Paralysis Foundation (KWNPF), through which he realized his dream of establishing a major paralysis research facility in Dallas, Texas, his home. The Waldrep Foundation Center for Nerve Growth and Regeneration Research, jointly funded by KWNPF and the University of Texas Southwestern Medical Center (UTSWMS), is a world-class basic science research facility.

Over the past 18 years, KWNPF has raised and granted more than \$21 million for research. Most recently, its efforts were focused on launching The Southwestern Spinal Cord Injury Center, also at UTSWMS. This Center, with a mission to transfer discoveries in the laboratory to the bedside, is directed by Keith Tansey, M.D., Ph.D., who was an Associate in CRPF's Research Consortium (see page 5).

Eager to promote education and employment opportunities, Kent served as Vice Chairman of the National Council on Disability and co-authored the Americans with Disabilities Act, providing an estimated 43 million Americans with disabilities equal rights for the first time.

Although KWNPF closed recently, Kent's vision and mission will continue. Sports had taught him to never give in. "To never give up," he wrote in his inspiring book, *Fourth and Long*. "Anybody who truly knows me realizes that somehow, some way, I will make the cure a reality." ■



# Fundraisers and Special Events

People all over the country continue to support CRPF with special events that are raising funds for both research and quality of life programs. We are grateful to all of them because every event raises awareness, and every donation brings us closer to our goals of finding a cure for paralysis and improving the quality of life for people with disabilities. Here are highlights of this year's events.



American Ski Classic, Hope in Motion

## Hitting the slopes to promote a cure

For the past 21 years, the Vail Valley Foundation has sponsored the American Ski Classic in Vail, Colorado, a three-day ski competition featuring celebrities and former Olympic and World champions. For the fifth year, the Classic earmarked proceeds from its grand finale dinner and auction for CRPF. The gala, called Hope in Motion, was held on March 22, 2003. Hosted by actor John Lithgow, and featuring remarks by actor Richard Schiff (West Wing), this event raised more than \$75,000. ■

Celebration of the Human Spirit

## Friends rally for a cure

While in college, Daniel Heumann was paralyzed in an accident. For the past three years, his friends, who are an invaluable source of support to him, have held fundraisers for the Daniel Heumann Fund for Spinal Cord Research. This year, the organizers reached out to CRPF and asked us to be part of their event, called Celebration of the Human Spirit. Christopher Reeve spoke at this very special gathering, which was held in Chicago on May 21, 2003 and hosted by actor Richard Kind. The Human Spirit Award was presented to Chicagoan, Neal Goss, who was injured in high school and is now pursuing an accelerated MBA at the University of Pennsylvania. The event raised over \$400,000, netting about \$175,000 each for CRPF and the Daniel Heumann Fund. ■

Indianapolis Speedway Fundraiser

## Accelerating a cure

Ever since race car driver Sam Schmidt was rendered quadriplegic in an accident several years ago, he's been working to find a permanent cure for paralysis. His fundraising efforts have included establishing the Sam Schmidt Paralysis Foundation and Sam Schmidt Motorsports. On May 12, 2003, Sam held a fundraiser to coincide with the Indianapolis 500. Christopher Reeve spoke to the crowd at the event, which was dubbed "Racing to Recovery, An Evening with Christopher Reeve." Sam split the proceeds among the Sam Schmidt Paralysis Foundation, the Rehabilitation Hospital of Indiana, and CRPF. In addition to generously giving \$40,000 directly to CRPF, Sam donated \$150,000 to fund one of CRPF's research grants for two years. ■

The 25th Annual American Image Awards

## Style brings substantive help

The American Apparel and Footwear Association held its 25th Annual American Image Awards in New York City on May 19, 2003. Christopher and Dana Reeve attended this black-tie gala, hosted by CNN's Paula Zahn.

Christopher addressed the star-studded audience, and Dana was honored with the association's Spirit of a Woman Award for her humanitarian achievements as co-founder of the Christopher and Dana Reeve Paralysis Resource Center. The event raised \$350,000 for CRPF. ■



Somewhere in Time

## Combining fun, elegance, and hope

The Orange County (California) Guild, a West Coast chapter of CRPF, raised more than \$100,000 for the Foundation at its 16th annual black-tie dinner and silent auction. Christopher and Dana Reeve attended the event which was held in spectacular Monarch Beach, California on March 10, 2003. "Somewhere in Time," the theme for this enchanting evening, was reminiscent of the 1980 film starring Christopher and Jane Seymour. ■







## GOVERNMENT RELATIONS

## Reeve Act Reintroduced in Congress: *You Can Help*

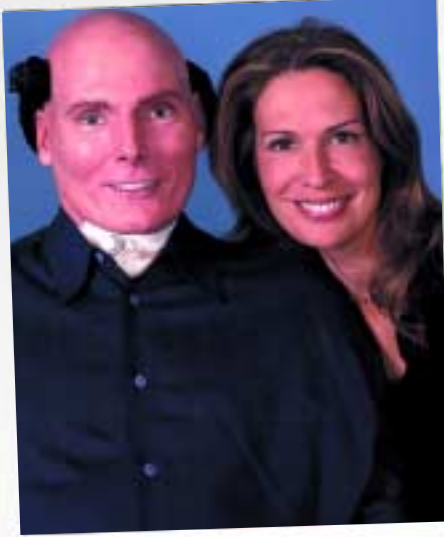
The Christopher Reeve Paralysis Act was reintroduced in Congress on May 7, 2003. With a strong bipartisan co-sponsor list, it is slated for action in the House Energy and Commerce Committee and the Senate HELP (Health, Education, Labor, and Pensions) Committee. Lead sponsors include Senators Tom Harkin (D-IA) and Arlen Specter (R-PA), and Representatives Michael Bilirakis (R-FL), Sherrod Brown (D-OH), Bill Young (R-FL), and Jim Langevin (D-RI).

The bill is designed to strengthen the role of the federal government in advancing research into paralysis and improving rehabilitation and quality of life. It calls for the establishment of Christopher Reeve Paralysis Research Consortia throughout the country to bring together researchers from diverse disciplines. It would also establish a Paralysis Clinical Trials Network, and authorize the Centers for Disease Control and Prevention (CDC) to implement quality of life programs modeled on those offered by the Christopher and Dana Reeve Paralysis Resource Center.

"We're very hopeful about the bill's prospects," says Tricia Brooks, CRPF's Director of Government Relations. Given the strong bipartisan backing, Tricia is confident that the bill will be considered in the House committee before legislators in early 2004. Later it will be considered in the Senate committee and then brought to the floor for a vote. But public support is critical. You can help us make the Act a reality by joining our Christopher Reeve Action Network. You will find the link on our website ([www.ChristopherReeve.org](http://www.ChristopherReeve.org)). Joining is free and, with a few clicks of your mouse, you will learn how to contact your legislators. ■

# "Once we choose hope, everything is possible."

—Christopher Reeve



The Christopher Reeve Paralysis Foundation (CRPF) is committed to funding research that develops treatments and cures for paralysis caused by spinal cord injury and other central nervous system disorders. The Foundation also vigorously works to improve the quality of life for people living with disabilities through its grants program, paralysis resource center, and advocacy efforts.

CRPF relies on your generosity and commitment. Your gift will move us closer to treatments and cures, so **please make a donation today!**

CHRISTOPHER REEVE  PARALYSIS FOUNDATION  
WWW.CHRISTOPHERREEVE.ORG

500 Morris Avenue, Springfield, NJ 07081 800.225.0292 973.379.2690 fax: 973.912.9433

## Celebrating a Milestone 5th Anniversary of Stem Cell Research

The pioneers of embryonic stem cell research, Dr. James Thomson of the University of Wisconsin-Madison, and Dr. John Gearhart of Johns Hopkins University, were honored by Christopher Reeve at a Coalition for the Advancement of Medical Research (CAMR) sponsored event at the National Press Club in Washington D.C. Held on October 27, 2003, the event celebrated the fifth anniversary of these scientists' groundbreaking papers on stem cells.

Dr. Thomson was the first to isolate and cultivate human embryonic stem cells, and Dr. Gearhart was first to isolate and culture human germ cells. Both men joined Christopher in expressing their concerns that the current limits on federal funding have delayed efforts to learn how stem cells could be used to cure diseases and conditions, such as spinal cord injury, Parkinson's, Alzheimer's, cancer, and heart disease. "It is painful to contemplate where we might be today if embryonic stem cell research had been allowed to go forward with full support of the government," Christopher said. "The United States is in danger of losing its preeminence in science and medical research because of politics, and that is unacceptable and that must change." ■



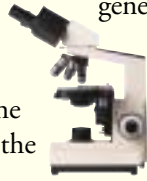
CHRISTOPHER REEVE PARALYSIS FOUNDATION

## [Where Are They Now?]

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clinic. The Center also will house both animal and human spinal cord research laboratories. Patients will have access to clinical trials based on promising therapies from animal studies.

Dr. Tansey will head the Center, which represents the



Similarly, the CRPF Consortium was organized with an eye toward the future. "We recognized that the next generation of spinal cord researchers would need rigorous training and would have to be willing to dedicate themselves to

**"There is no better way to do research. Patients benefit and the pace of research quickens."**

merger of his medical practice and his spinal cord research, allowing him, as he puts it, "to move bench-top discoveries to bedside interventions."

"I was never satisfied with just doling out existing treatments to patients," he says. "I have always wanted to help develop the next ones."

solving the many complexities posed by a spinal cord injury," says Susan Howley, Executive Vice President and Director of Research at the Christopher Reeve Paralysis Foundation. "The associates truly are one of the Consortium's greatest strengths." ■

### GATHERING MINDS



CRPF will host its first Spinal Cord Symposium Sunday evening, March 21st, through Tuesday afternoon, March 23rd, 2004 at the Oak Brook Hills Resort of Oak Brook, Illinois. (A symposium, according to Webster's Collegiate Dictionary 10th edition, is defined as a "social gathering at which there is free interchange of ideas; a formal meeting at which several specialists deliver short addresses on a topic; a collection of opinions on a subject.")

The meeting will bring together those scientists who have active contracts through CRPF's Individual Grants Program. Its goals are to engender a sense of community and provide the investigators an opportunity to interact with colleagues and perhaps form small network collaborations to further advance their work.

"The Spinal Cord Symposium will be a relatively small, intimate gathering designed to maximize opportunities for dialogue between scientists and lay people," said Susan P. Howley, CRPF Director of Research and Executive Vice President. "The meeting is highly interactive, mixing science presented in user-friendly ways with social venues to encourage conversations between scientists and other members of the spinal cord community. This is a real departure from most scientific meetings and we believe it will foster constructive exchanges of knowledge, ideas, and patient perspectives."

If you'd like more information on the CRPF Spinal Cord Injury Symposium please call Douglas Landsman, Ph.D. at 800.225.0292 or email him at [dlandsman@crpf.org](mailto:dlandsman@crpf.org) ■

### QUALITY OF LIFE GRANTS

*Continued from page 3*

## Grant Supports Efforts to Integrate Disabled Athletes into Mainstream Sports

Northeastern University's Center for the Study of Sport in Society works to promote the benefits of sports for all athletes. The Center's Disabled Sport Research Initiative, however, has a special mission, to "create more access, equality, inclusion, respect, and legitimacy" for athletes with disabilities. With a \$25,000 Quality of Life grant, the Center is taking that effort to a new level. It will use the money to help fund on-site visits to mainstream sports organizations, such as the NFL, NBA, and NHL, with an eye toward finding ways to integrate athletes with disabilities into the highest levels of professional sports. ■

## Neuron Pathfinder Celebrates Nuptials by Giving Back to CRPF

Patrick Sarmiere, Ph.D., is in his second year of a CRPF grant to research how neurons "path-find" or reorient themselves and "find out where they should be after injury." If scientists can figure out the underlying mechanisms of that process, they might be able to figure out how to promote the healing of an injured spinal cord.

Patrick is optimistic about the chances that science will find a way to unlock the mysteries of neuron pathfinding and regrowth, but he admits that, "progress can be slow and you always hope for things to move along faster." Patrick is doing all he can in the laboratory to speed things along, but he and his fiancée Casey, a physical therapist who works primarily with people who have suffered back injuries, wanted to do more. Making plans for their wedding in September, they decided that instead of giving gifts to friends and relatives who participate in the ceremony, they would give donations to CRPF and St. Jude's Children's Hospital in their guests' names.



"I'm in this field because I really do want to contribute to treating people with spinal cord injuries," says Patrick. "This is a particularly difficult condition because there's a lot that we don't understand. But I'm very hopeful that in the next several years there will be treatment for people, and in the next 10 to 20 years, that's when you'll really

see major advances." With Patrick's work and his and Casey's generosity, that time might come a little sooner. ■

SPECIAL EVENT

Shop for a Cure

**Michael C. Fina partners with CRPF!**

Michael C. Fina, a family-owned and operated corporation since 1935, dedicated to providing its customers with the greatest products, has generously joined forces with CRPF to help raise critical funds to further our mission.

Christopher and Dana Reeve have personally selected their favorite items from a vast assortment of home furnishings, table-top, jewelry and timepieces to create a signature collection.

From now until December 31, 2004, 15% of all proceeds from items purchased at Michael C. Fina from the Christopher and Dana Reeve Collection as well as 20% of items purchased from the Michael C. Fina Estate Silver Collection will be donated to the Christopher Reeve Paralysis Foundation.

When you purchase from these collections, your donation will help to further the mission of CRPF, impacting the lives of over 250,000 people living with spinal cord injuries in the United States.

“We are thrilled to be working with Michael C. Fina, and are joining forces to create a lasting partnership that will truly make a difference and raise both dollars and awareness for the Christopher Reeve Paralysis Foundation,” stated Dana Reeve. “The selections that Christopher and I chose are indicative of our own personal taste and style. I see this collection as the beginning of a relationship with a unique family-owned business that very much reflects the values of the Foundation.”

Please look for the Christopher and Dana Reeve Collection on display at the Fifth Avenue and 45th Street store in New York City or online at [www.michaelcina.com](http://www.michaelcina.com). You can also visit [www.ChristopherReeve.org](http://www.ChristopherReeve.org) for more information about the Foundation and for a direct link to shop at Michael C. Fina. ■



CHRISTOPHER REEVE PARALYSIS FOUNDATION

# WALKING TOMORROW

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For additional copies of this publication or further information about CRPF and its programs, contact:

*Christopher Reeve Paralysis Foundation*  
500 Morris Avenue  
Springfield, NJ 07081  
(800)225-0292

[www.ChristopherReeve.org](http://www.ChristopherReeve.org)

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