Welcome to the Fall 2013 issue of Spinal Cord Injury Updates from the International Center for Spinal Cord Injury (ICSCI) at Kennedy Krieger Institute. The past few months have been filled with exciting achievements and new or expanding programs for ICSCI.

Activity-Based Restorative Therapy (ABRT) is a central concept to the ICSCI model of care and research. Several years ago, ICSCI began to develop an evidence-based ABRT curriculum training program to share our knowledge of ABRT modalities and implementation with physicians, therapists, nurses, and administrators all over the country. We have recently been awarded a $50,000 grant by the Paralyzed Veterans of America to continue expanding this educational program, and we will be offering more educational workshops and symposiums all over the country.

In addition, we have recently published two studies on the positive effects of ABRT programs for those with spinal cord injury. The first was a clinical study by Cristina Sadowsky, Ed Hammond, John McDonald et al. titled "Lower extremity functional electrical stimulation cycling promotes..." (continued on page 3)

Adaptive Skiing

Most rehabilitation professionals agree that adapted sports and recreation can offer patients opportunities to achieve success, which can build self-confidence and help patients focus on possibilities, instead of dwelling on what cannot be done. At ICSCI, we strongly promote the potential of adaptive sports and recreation. Over the years, ICSCI has developed a thriving Virtual Sailing (VSail) program and the Kennedy Krieger Baltimore Running Festival team. We also regularly refer patients and families to the Baltimore Adapted Recreation and Sports (BARS) program.

This past April, Drs. Daniel Becker and Cristina Sadowsky led an inaugural adaptive skiing trip in collaboration with the Adaptive Sports Center team in Crested Butte, (continued on page 3)

Our Mission

Transitioning today’s science to near-term therapeutic applications, we focus on developing and applying advanced restoration strategies for optimizing spontaneous recovery in those living with paralysis.
Message from the ICSCI Director of Operations

By Tom Novotny, MBA

We Are Growing

Over the past two years, the International Center for Spinal Cord Injury (ICSCI) has enjoyed steady growth. Our outpatient center has seen an increase in patient appointments for both the medical clinic and the therapy programs. The outstanding work of our physicians, therapists, and researchers has been recognized, and has resulted in a steady flow of new patient referrals. While this is exciting and rewarding, it has created a temporary new challenge. Our medical appointments are fully booked four to six months in the future, our short-term two-week therapy appointments are booking several months in the future, and our therapy space is limited.

Help is on the way! Starting in July, our current Spinal Cord Injury Medicine fellow, Dr. Philippines Cabahug, will begin treating patients as a full-time faculty physician. She is an outstanding physician, well respected by her peers, and will be a wonderful addition to the team. The addition of Dr. Cabahug will provide an opportunity to schedule more patients, and we will also have the ability to see more urgent cases in a timely manner. We are all very excited to have Dr. Cabahug join the ICSCI team full time!

We are also expanding and improving our care center team and operations. The goal is to provide the best possible service to our clients. Under the leadership of Stefanie Wollschlager, this new team will manage all day-to-day scheduling and care center operations. Joining the existing team are two recent hires. Ciara Williams joined ICSCI several months ago, and has done an excellent job getting to know the systems and our processes. We have already seen a positive impact since she was hired. More recently, we hired JaQuan Hamilton. He has been a member of the Kennedy Krieger staff in other capacities for several years. We are happy to have him join ICSCI as we continue to grow our programs.

Another consequence of our success has been the amount of therapy space we have available in the gym. While we all enjoy the energy and camaraderie that is evident in the gym, we must also recognize that if we intend to continue to expand, we will need to address the space situation very soon. The management team has been researching both short-term and long-term options for expansion. We have several promising options for each scenario and will provide updates as we solidify our plans.

In short, we are growing, and doing everything possible to continue our quest to improve as many lives as possible. Thank you for your continued support!

Tom Novotny
Director of Operations

Updates:

We have recently re-designed our patient satisfaction survey, and in addition to receiving it in your discharge packets at the end of your bout of care, you will see them in the lobby of the clinic, at the monthly Patient Q&A sessions, and in the monthly Regeneration Generation Support Group.

We also recently created a new, easier-to-remember URL for our online survey:

kennedykrieger.org/ICSCIPatientSurvey
A Word from the Director

physical and functional recovery in chronic spinal cord injury,” which was published online in March 2013 by the Journal of Spinal Cord Medicine. The study showed a correlation between FES and higher neurological function scores, higher quadriceps muscle mass, and decreased intra/inter-muscular fat compared to the control group. The second study, authored by Devin Gary, Misti Malone, Anna Miglioretti, Thierry Houdayer, John McDonald et al. and titled “Neuronal Activity Promotes Myelination via cAMP Pathway” and published by Glia in June 2013, was a basic science study that demonstrated that session number and frequency of applied electrical stimulation had a direct impact on activity-dependent myelination of axons.

We have seen in the clinic and in our scientific studies that functional electrical stimulation (FES), a key component of ABRT, combined with leg and arm cycle ergometry promotes recovery and overall health. As a part of our continued ABRT research, members of our team are now focused on investigating and developing a more efficient universal external FES system. Current FES systems utilize self-adhesive electrodes that must be placed manually, which can be time consuming and lead to inaccurate choices in electrode size or placement. A universal, wearable, easy-to-use FES system could potentially activate every muscle in an arm or leg by utilizing a “virtual” stimulation field of electrodes that could reposition the stimulated area without the user having to move the electrodes. While this is a long-term project, we are optimistic and excited about continuing this endeavor.

As always, we are committed to staying in the forefront of spinal cord injury treatment and research.

John W. McDonald, III, MD, PhD
Executive Director, International Center for Spinal Cord Injury at Kennedy Krieger Institute

For more information about our research, visit spinalcordrecovery.org.

Adaptive Skiing

Colorado. Five patients from the ICSCI and their families were sponsored for the week-long trip, along with Dr. Becker, Dr. Sadowsky, and Dr. Adam Kaplan, a Johns Hopkins psychiatrist.

Each of the five adults who went on the ski trip had a different type of spinal cord injury, from transverse myelitis to life-threatening tumors to a traumatic spinal cord injury, and had different requirements for the adaptive equipment needed. On the first day of the trip, the Adaptive Sports Center team outfitted patients with outriggers and either a mono- or bi-ski with seats molded to fit their bodies. Then everyone, including family members, received personal skiing instruction twice a day for five days. By the end of the trip, patients were skiing independently or tethered to an instructor, and one had even pushed off from the ski lift independently!

Marshall Garber, 17, called the trip one of the best experiences of his life. “I’m just so overwhelmed with how awesome this place is…it’s hard to put it into words,” said Garber. “Skiing as therapy gives such a whole body workout and my core muscles have been pushed in ways that they haven’t been,” he explains. “It gives you a mental boost. It makes you feel so good that you were able to conquer that mountain and do what you’re able to.”

All the patients got to experience the thrill of skiing, an experience that might never have been possible if not for ICSCI doctors who believe in helping patients live life to the fullest. The ICSCI team looks forward to continuing this collaboration with Adaptive Sports Center next year.

“I want to come back,” says Garber. “I’m gonna come back…You can’t get a taste of this place and not want to come back.”

To view videos from the trip, visit http://vimeo.com/64924604 or youtu.be/ayYBdJaXdsc.
Spotlight on Research

The International Center for Spinal Cord Injury (ICSCI) is fortunate to have a dedicated group of basic science researchers investigating the potential means to cure paralysis. Their breakthroughs have significantly added to the spinal cord injury research field.

Review of Ongoing Cell-based Therapy Research: A Potential Treatment for Spinal Cord Injury

By Andrea Benedict, PhD

Clinical management of traumatic spinal cord injuries (SCI) is a major challenge in need of new options for treatment and therapy. When SCI occurs, there is immediate physical damage of tissue at the site of injury, followed by a cascade of events including hemorrhaging, inflammation, loss of the axonal covering called myelin (an insulating coating that controls the speed of electrical signals traveling along the axon) and the cells that produce myelin (oligodendrocytes), formation of scar tissue by reactive astrocytes, and dieback of axons that survived the initial injury. All of these factors contribute to an environment that limits cell survival and axonal growth.

Animal models of traumatic SCI have shown that the spinal cord attempts to reorganize and modify the axonal connections after injury. However, without interventions, this ability to change, regenerate, and reconfigure, referred to as spinal cord plasticity, falls short of meaningful functional and sensory recovery in the majority of SCI cases. These findings have set the stage for developing therapies that can enhance the adaptability and plasticity of the surviving spinal cord tissue to produce meaningful recovery. One such approach currently in pre-clinical and early clinical trials is the use of cellular transplants.

Stem cells and progenitor cells have received considerable scientific attention because of their potential to “differentiate,” or turn into diverse cell types, as well as retain the ability to undergo cell division. Cells, once transplanted into the injured spinal cord, may replace dead or damaged cells. Additionally, transplanted cells can create an environment supportive of axonal regeneration, enabling regenerating axons to cross the injury site. Some non-stem cells, such as Schwann cells and olfactory ensheathing cells, have also been shown to produce a permissive environment for axon regeneration. A relatively recent scientific breakthrough has allowed adult non-stem cells to be genetically reprogrammed to become “stem-like” cells. These cells, called induced pluripotent stem cells, provide the potential advantage of using patients’ own cells to generate stem cells that could be used in cell-based therapy, decreasing cell rejection and avoiding the need for suppressing the immune system. Pre-clinical studies have shown promising results in the ability of these cell transplants to provide scaffolding for spinal cord axons in the injury site, cover existing axons with myelin, and produce growth factors that act as cues for cell growth, differentiation, and survival.

All over the country, clinical trials of cell-based therapies for SCI are now underway to determine the safety and feasibility of cell transplantation into the spinal cords of SCI patients. One of these trials was the first FDA-approved clinical trial for human embryonic stem cell-derived oligodendrocyte progenitor cells, which actively recruited a small number of patients before being halted for financial reasons. No serious adverse events were detected in the small number of patients in this trial, but further study is needed to determine any potential benefit from cell-based treatment for SCI. The scientific community is optimistic and looking forward to the results of a second trial in which Schwann cells harvested from SCI patients are being transplanted into their own spinal cords one month after injury, and another trial in Switzerland in which human neural stem cells are being transplanted 3 to 12 months after injury. While pre-clinical experiments suggest that cell-based therapies have potential to produce beneficial outcomes, cell transplantation alone does not lead to complete motor or sensory recovery. Approaches that combine cell-based therapy with pharmacological agents, growth factors, electrical stimulation, and rehabilitation are currently being evaluated for their ability to further enhance recovery after SCI.

At the ICSCI, our research program focuses on understanding the biological effects of traumatic SCI and using the latest scientific tools to help advance potential therapies. One of our research areas focuses on the combination of human embryonic stem cell–derived oligodendrocyte progenitor cell transplantation and functional electrical stimulation (FES) after SCI. We are currently evaluating whether FES provided after cells were transplanted into the injured spinal cord can lead to increased oligodendrocyte progenitor cell survival and differentiation into mature cells that can rewrap the axons with myelin. The future of stem cell and non-stem cell–based therapies alone or in combination with other therapies has great potential for increasing recovery after traumatic SCI, and we are excited to be at the forefront of discovery!

If you are interested in a lab tour, please contact your therapist or Robin Locks at locks@kennedykrieger.org or 443-923-7965.
Welcome to the Advocacy Spot! Here we will aim to keep you abreast of today’s hot topics in legislation that will impact access to services, equipment, and other aspects of healthcare. By keeping you informed, we hope to motivate you to advocate, promoting change and protecting your right to quality care. On a daily basis, healthcare providers are advocating for you; however, your voices and your stories will make the greatest impact.

By Erin Michael, PT, DPT, ATP/SMS, and Kristin Sternowski, PT, DPT

In this issue, we focus on legislation that creates a spending cap on therapy services and another that could potentially improve your access to customized wheelchairs. Though both items are directed at the Medicare program, they affect each and every one of you, because Medicare is the “trend setter.” Eventually, other insurers will follow suit.

**Therapy Cap:**

Under the Balanced Budget Act of 1997, Medicare placed a limit or “cap” on the amount spent on skilled outpatient physical, occupational, and speech therapy each calendar year. Currently, there is an exceptions process that allows therapists to document a medical necessity for continued therapy beyond this cap. On December 31, 2013, the act that allows this exceptions process will expire, and patients will again be subject to the cap on rehabilitation services. This change will eliminate the exceptions used by many in our clinic who benefit from the intensive treatments provided by activity-based restorative therapy—treatments that go beyond Medicare’s therapy cap. Several congressmen have proposed “The Medicare Access to Rehabilitation Services Act” (H.R. 713/S. 367), which would eliminate this therapy cap once and for all. Patients and therapists are encouraged to contact their representatives in Congress and educate them on the importance of rehabilitation to improve the quality of life for those with spinal cord injuries.

Visit [http://capwiz.com/amerpta/home](http://capwiz.com/amerpta/home) and click on “Stop the Therapy Cap!”

**Complex Rehabilitation Technology (CRT):**

Currently, highly customized, configurable manual and power wheelchairs, adaptive seating and positioning systems, and other specialized equipment, such as standers and gait trainers (equipment known as CRT), are included in the same category as standard durable medical equipment (DME). This DME category does not account for the complex and unique nature of this equipment, the level of technology utilized, the full range of services furnished by DME vendors, or the skills and time needed by the therapist and vendor to appropriately evaluate a patient’s complex rehabilitation needs. Coverage for DME is constantly being cut, and without segregation of CRT from the DME category, access to this equipment is threatened. Product choice will be limited, and service to repair or maintain this equipment may be limited or unavailable. On March 7, 2013, Reps. Joe Crowley (NY-14) and Jim Sensenbrenner (WI-5) announced the re-introduction of the “Ensuring Access to Quality Complex Rehabilitation Technology Act” (H.R. 942). In addition, Senators Chuck Schumer (D-NY) and Thad Cochran (R-MS) have introduced a companion bill in the Senate, S.948. The senate bill only has one additional senator signed on, so we need you to reach out to your senators and ask them to sign on! This legislation will help ensure that people with disabilities or severe medical conditions are able to access the highly specialized medical equipment that meets their needs and improves their function day-to-day. Patients and therapists are encouraged to contact their representatives in Congress and educate them on the importance of custom wheelchairs and devices, and how they improve the quality of life and independence of those with spinal cord injury and paralysis.

Visit [access2crt.org](http://access2crt.org) and click on the “contact congress” link.

We encourage you to visit the websites we have included here to become more informed and learn how easy it is to reach out to your congressmen and -women! You can play a significant role in educating others on how therapy services and custom equipment improve your lives. Stay tuned for continued updates on these bills, as well as additional legislation that may affect access to care and services.
Sign up now for Kennedy Krieger Institute’s Baltimore Running Festival Charity Team!

Saturday, October 12, 2013 • M&T Bank Stadium
kennedykrieger.org/BaltimoreMarathon

Join Team Kennedy Krieger.
Whether it’s the Kids Fun Run, 5k, Team Relay, or half or full marathon, we’ve got space for you!
By registering for the Kennedy Krieger Charity Team, you are agreeing to raise $250 for our spinal cord injury program and the training needs of patients with disabilities who participate in the event.

Sign up now and receive:
• Free registration
• Free carb-loading pasta party catered by Sabatino’s the evening before the race
• Kennedy Krieger Institute Under Armour team shirt
• Participant goodie bag with all kinds of cool free stuff
• Access to the team tent to secure your belongings during the race
• Morning coffee and breakfast, and post-race snacks and refreshments

Become a Kennedy Krieger Virtual Racer!
Can’t make it to the race, but still want to support Kennedy Krieger? Choose the “Virtual Racer” option during registration, and enjoy the perks of being on our team without having to race. By registering to be a “Virtual Racer” you are agreeing to raise $100 for Kennedy Krieger Institute. See our website for more information.

Registration is open to everyone!
For more information or to register online, visit kennedykrieger.org/BaltimoreMarathon. Questions? Contact us at events@kennedykrieger.org or 443-923-7300.
Employee Profile

Research Employee Profile:

Visar Belegu, PhD, Faculty Research Associate

As the son of two dual MD/PhD doctors, Visar Belegu, PhD, may have seemed destined to be a scientist in his home country of Kosovo. But Dr. Belegu’s life took a few twists and turns before he became one of the first ICSCI employees hired in 2005.

In 1993, as a young teenager, Belegu came to the United States as a foreign exchange student. “In Europe, addresses end in the country name, so when I read my [foreign exchange student] forms that listed ‘City: Grove City,’ and ‘State: OK,’ I assumed ‘OK’ meant the word ‘okay’ and that my paperwork looked fine,” recalls Dr. Belegu. “I didn’t know I was going to Oklahoma until I arrived in the United States.”

Belegu graduated from high school and was accepted to Northeastern State University, where he received a bachelor of science degree in biology with a cellular emphasis and a minor in chemistry. Unsure what to do next, Belegu followed the advice of a university professor who encouraged young Belegu to continue his studies and enter a PhD program.

In 2003, as he was finishing his PhD in biochemistry and molecular biology, Belegu lined up several interviews with labs all over the country. His first interview was with Dr. John W. McDonald, then director of the Spinal Cord Injury program at Washington University in St. Louis, Missouri. Convinced he had found the right laboratory, Belegu cancelled all of his other interviews. Within months, Dr. McDonald announced his plan to move his clinic and laboratory to Kennedy Krieger Institute and Johns Hopkins University to start the ICSCI. Dr. Belegu joined ICSCI as a post-doctoral graduate trainee and became one of the first employees of the new center.

According to Dr. Belegu, Dr. McDonald not only emphasizes to the ICSCI laboratory the importance of identifying the key issues to study, but also finding the right way to study those problems. Dr. Belegu concludes that “It’s easy to learn one technique of research and apply that to everything you do. It is not easy to learn new techniques or study an old problem in a new way.”

He reflects, “When I came here to ICSCI, there was a minimalist approach to science in general. It was the time of the Human Genome Project, and the science community was focused on breaking everything down to the smallest components, but things are changing. As we attempt to translate our discoveries into therapies and cures, biomedical sciences have had to become more integrative.” He explains that his own work is a reflection of those changes. While much of his research involves basic science study of molecules and proteins that can only be seen through powerful microscopes or measured in color changes, he is also involved in human clinical advanced imaging studies of the brain and spinal cord. His team recently published an article titled “Extensive neurological recovery from a complete spinal cord injury: a case report and hypothesis on the role of cortical plasticity” in the Frontiers in Human Neuroscience journal in June 2013. Using advanced imaging techniques, Dr. Belegu and his team discovered structural and functional changes in the central nervous system of a patient with chronic cervical traumatic SCI who suffered a complete loss of motor and sensory function below the injury for six weeks post-injury but experienced a progressive neurological recovery that continued for 17 years. The study is the first to provide a comprehensive description of the structural and functional changes in a patient using advanced imaging techniques.

Dr. Belegu is convinced that integration and collaborations are essential in science now. “It’s important to work with a great group of people, because you can never do it by yourself,” he notes. “At ICSCI, we are doing tissue culture studies, animal studies, and human studies. We really do integrated research here.”

Dr. Belegu believes it is important for scientists to actually meet patients. “They can tell you about the problems and medical complications associated with injury that we should be addressing in our research, things that I had never thought about.”

“Plus it is the motivation. Science is tough,” Dr. Belegu explains. “We fail most of the time. Experiments may not work or projects can fall apart. Being around patients and the clinic is a good reminder of why we are doing it.”
Josh Basile, one of the very first patients at the International Center for Spinal Cord Injury (ICSCI), graduated from the David A. Clark School of Law on Saturday, May 11, 2013.

Josh came to ICSCI after a body surfing accident caused a cervical and closed head injury that left him quadriplegic at age 19. Josh was initially evaluated and flown to Shock Trauma in Baltimore, and then went on to National Rehabilitation Hospital for his initial acute rehabilitation care. Josh continued his path of SCI rehabilitation at the ICSCI, starting in April 2005.

Despite his injury, Josh continued his education and went on to take college courses, first at Montgomery College and then at the University of Maryland, where he graduated in May 2010. He feels that his injury changed him for the better and allowed him to focus on things that would make a difference. As a communications major, he tried to strengthen his voice, and he felt that a law school education would get him to that next level. He chose the David A. Clark School of Law because of its focus on public interest, something that Josh loves.

While in law school, Josh gained valuable experience through internships and clerkships with judges, law firms, a senator, and the Department of Justice. While clerking for United States Senator Tom Harkin of Iowa, he was part of the Health, Education, Labor, and Pension Committee working on health and disability law, helping to write disability legislation and attending all of their disability committee hearings. His supervisor was Andrew Imparato, former president of the AAPD (American Association of People with Disabilities) and one of the best disability rights advocates in the country. While interning for the United States Attorney’s Office for the Eastern District of Virginia within their Civil Division, Josh experienced the fast-paced action of the fastest docket in the country, known as the “rocket docket.” As part of the internship, which he describes as “incredible,” he visited the CIA and the FBI in Quantico, and shared many amazing field trips and lunches with judges.

This past semester, Josh interned with Jack H. Olender and Associates, several years after receiving the Olender Foundation’s America’s Role Model 2006 Award for his courage and benevolence after his accident. The Olender foundation also awarded a grant in Joshua’s honor to the ICSCI, which Dr. John McDonald accepted on behalf of the Center.

After graduating from law school magna cum laude in May, Josh received the best gift a graduate could hope for—Mr. Olender offered Josh a job, and recently hired him on as a law clerk. When he passes the bar exam, he will be promoted to law associate. Josh is excited about this opportunity and looks forward to being mentored by Mr. Olender in his new position. It’s the start of a promising new future for Josh.
Q&A with Josh Basile

ICSCI: Who do you look up to?

JB: I look up to Patrick Rummerfield, because he gives me hope; my father, who is my best friend; and Mr. Jack Olender, for his lifelong pursuit of justice and his tireless efforts fighting for the catastrophically injured.

ICSCI: What are your three best qualities?

JB: Determination, empathetic voice, and creativity.

ICSCI: What drives your strong focus on education?

JB: The more you know, the more you can do. Education opens up so many doors for you. With the right mind and the right voice, anything is possible. I prefer to focus on what I can do, rather than what I cannot.

ICSCI: If you had three wishes, what would they be?

JB: 1) The ability to heal others and myself; 2) The ability to learn and retain information—wouldn’t it be great to have information downloaded into your brain like in the movie The Matrix?; 3) To one day have the opportunity to get married and have a beautiful family.

ICSCI: What would you like people to know about you?

JB: My injury definitely changed me, but I am still the same person. I loved life before my injury, and I still love life now—it’s just different. I love my Determined2heal work. I get calls from a new injured person or family member every week, and I enjoy helping with that. It’s really rewarding.

ICSCI: What do you like to do in your spare time?

JB: My favorite hobby is golfing, and second to that is bowling. I golf using a sling shot to hit the long ball and a device I created called the “pendulum putter.” For bowling, I use a special ramp and a weighted bowling ball that creates controlled spin depending on how I angle the ball before its release. I can bowl over 200. I also started doing eHarmony last summer, and have gone on lots of dates. It was pretty fun to know that the dating scene still exists. It was a lot easier than I thought it would be, because people are very receptive, and there is still a lot of love out there.

ICSCI: If you could write a message to each of your family members, and they could read it 20 years from now, what would it say?

JB: Thank you for never giving up on me and not leaving me, and always being by my side. I could have never done it without you! Dad, thank you for being my best friend, and pushing me to always be a better me. I love you!

“Hope through Motion” Around the World

Our patients and staff have made Hope through Motion t-shirts a common sight around Kennedy Krieger. But you’ve also carried our message of hope back to your homes, schools, and communities. Submit pictures of you out and about wearing your ICSCI Hope through Motion t-shirts to ICSCInews@kennedykrieger.org. Your picture could be in the next issue of Spinal Cord Injury Updates!

Let’s see Hope through Motion in action. Can you beat this issue’s pictures from Spain and Dubai?
Expanding Educational Program

Most people can agree that learning is a lifelong experience that goes well beyond our high school or college years. Continuing education is required for many professions and highly encouraged for those seeking to expand their own workplace or personal skills. At the International Center for Spinal Cord Injury (ICSCI), we not only encourage our employees to engage in continuing education, we provide in-service opportunities in order to further develop our staff’s knowledge base. Several years ago, ICSCI took the step to expand our educational program by developing an evidence-based Activity-Based Restorative Therapy (ABRT) curriculum training program, which we shared with Veterans Administration (VA) and military hospital physicians, therapists, nurses, and administrators. For the past five years, Dr. Albert Recio and Rebecca Martin, OTR/L, OTD, CPAM, spearheaded the project and developed a curriculum that utilizes a combination of both on-site and online learning platforms. Over the past four and a half years, the team has conducted symposiums, training sessions, and workshops in Seattle, Boston, Richmond, Baltimore, Washington, D.C., and Pittsburgh. At each session, the program has been well received across these “partner” sites, and in June 2012, the program culminated in an intensive week-long ABRT fellowship at ICSCI.

“Almost every week, we get calls from physicians and therapists all over the country who have questions about ABRT,” says Rebecca Martin, ICSCI manager of Clinical Education and Training. “They want to know how to do a specific type of therapy. They want advice on implementation. It was clear that the next step for ICSCI was to share our knowledge of ABRT beyond our own clinic.” This past February, our Activity-Based Restorative Therapy workshop, held in Seattle, had 50 participants including nurses, occupational therapists, physical therapists, exercise therapists, and administrators. “We look forward to expanding our workshop,” comments Martin. “It has been an overwhelming success.” In September, the team will travel to Nashville, Tennessee, to hold a two-day workshop in the basic and advanced principles of ABRT.

On June 17, 2013, our third annual Contemporary Trends in Spinal Cord Injury Management symposium was held in Baltimore with approximately 100 attendees. Bringing together the expertise of physicians, researchers, and therapists, this symposium focused on the latest spinal cord injury treatments and research. This year’s symposium featured renowned researchers and physical therapists Estelle C. Field-Fote, PhD, PT, FAPTA, and George Hornby, PhD, PT.

“We thoroughly believe that it is important not only to encourage our own staff to continually improve, learn, and evolve as practitioners, but to share what we do well with the rest of the rehabilitation community,” says Martin. “It is all about improving care for everyone with a spinal cord injury.”
Recent ICSCI Research and Professional Publications


Support Our Work

With your support, we are revolutionizing rehabilitation for patients with spinal cord injury and paralysis, offering something many of them have been told was lost forever: hope.

Dear John,

Every time I am discharged from therapy, I receive a patient satisfaction survey. My therapist tells me it’s important and that I should fill it out. I have never filled one out before. If I do, is it confidential? And, why is it important?

Signed,
Grateful Patient

Dear Grateful,

That’s a great question. Patient satisfaction is very important to the International Center for Spinal Cord Injury, and these patient satisfaction surveys are a vital tool that we use to evaluate our program and services. We encourage everyone (patients, family members, caregivers) to fill them out during their bout of care or appointments. Your feedback is always confidential. While many patients and family members write their names on their surveys, this is not required and you can remain anonymous. The individual surveys are read by non-clinical personnel and only the overall results are shared with the ICSCI team, not the individual surveys.

Comments and suggestions made by patients and caregivers in these surveys have had a direct impact on our program. In response to feedback regarding scheduling, we have recently re-structured and expanded our care center team. These changes will allow us to schedule and follow up with patients in a faster and more efficient manner. Feedback regarding space in the gym led us to purchase additional mats, and we are exploring several opportunities for expansion.

Your feedback drives our program and ensures that the whole ICSCI team is meeting and exceeding your needs and expectations.

Sincerely,
John

The team appreciates and encourages questions from employees, patients, family members, and all ICSCI supporters. Submissions may be sent to Dr. John W. McDonald, Executive Director of the International Center for Spinal Cord Injury, by e-mail to ICSCInews@kennedykrieger.org. Not all questions will be published due to space limitations, but unpublished questions will be answered by e-mail.
Our Center’s Seating Clinic

Achieving independent mobility and being able to access your environment can be difficult following a spinal cord injury or paralysis. For this reason, the Seating and Mobility Clinic within the International Center for Spinal Cord Injury (ICSCI) at Kennedy Krieger Institute provides comprehensive evaluations and fittings of wheelchairs and specialized seating systems to determine the best equipment to meet mobility and positioning needs.

“Selection of the appropriate wheelchair and seating system is an important process, especially when an individual depends on a wheelchair for mobility,” explains Erin Michael, PT, DPT, APT/SMS, an ICSCI seating and mobility specialist. Customized seating can improve not only independence with mobility, but also balance, independence with activities of daily living, comfort, protection of skin integrity, and safety. With the right equipment, patients can improve posture and control of head, trunk, and extremities; environmental access in the home and community; and protection of upper extremity joints.

The ICSCI Seating and Mobility Clinic is staffed by physical and occupational therapists who are certified Assistive Technology Professionals and Seating and Mobility Specialists by RESNA (Rehabilitation Engineering & Assistive Technology Society of North America), and have special training in seating issues and technologies.

Throughout the process, therapists work with the patient, their family, rehabilitation equipment specialists, and the rehabilitation team to identify the primary reasons for new equipment and the factors affecting a patient’s mobility and equipment needs, in order to recommend the most appropriate equipment to help meet the goals of the patient. These factors can range from musculoskeletal alignment and function to functional ability, such as the ability to self-propel. The team also considers transfer status, pain levels, status of current equipment, transportation considerations, and home accessibility needs. If necessary, they employ pressure mapping technology (PMT) as an evaluation tool to show actual pressure between a body surface and the seating system.

“Our Seating and Mobility Clinic is very patient-centered. The patients and their families are partners in the process,” explains Elizabeth Farrell, PT, DPT, APT, an ICSCI assistive technology professional. “Understanding that is essential to determining what equipment will best help the patient achieve their own personal and rehabilitative goals.”