## **2022 Impact Report** YOUR SUPPORT CHANGES LIVES

















### YOUR SUPPORT CHANGES LIVES — IMPACT REPORT 2022

Your support of Kessler Foundation helps people with disabilities maximize recovery, independence, and inclusion. Each day, Kessler Foundation researchers and grantmakers change lives, thanks to you.

Inside our Impact Report 2022, you'll find highlights of what you have made possible and stories of those whose lives you've changed. Your support enables our scientists to research groundbreaking rehabilitation interventions and helps our grantmakers create pathways to employment and independence. Your support changes lives.

With gratitude,



Rodaer DeRose President and CEO



Rodger DeRose and Michele Pignatello

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Michele Pignatello Vice President and Chief Development Officer

## You support. You heal. You inspire. YOU MAKE A DIFFERENCE. Your generosity helps people with disabilities maximize recovery, independence, and inclusion. Your support changes lives. **YOU CHANGE LIVES.** THANK YOU! **KESSLER**

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Carla Basante participates in of exercise on cognition and

Peii (Peggy) Chen, PhD, is developing home-based treatment for spatial neglect using the latest virtual reality technology.

Brian Sandroff. PhD and Ghaith Androwis, PhD, pool their expertise to find new ways to help people with MS maintain mobility, balance, and cognitive function.





Denise Krch. PhD. and Nancv Chiaravalloti, PhD, will use a new onsite laboratory to draw blood samples to determine new treatments.

William participates in a unique



Amanda Botticello, PhD, MPH, seeks the best ways to care for infants with neonatal abstinence syndrome

research to evaluate the impact mobility for people living with MS.





Steve Ascolese participates in research to retrain the brain and correct spatial neglect after stroke.

study to help teenagers and young adults living with autism spectrum disorder prepare for job interviews.



## YOUR SUPPORT RAISES EXPECTATIONS FOR RECOVERY AFTER SPINAL CORD INJURY

It is remarkable what the human body can achieve with access to groundbreaking research and the latest technology. At the Tim and Caroline Reynolds Center for Spinal Stimulation, Kessler Foundation researchers led by Gail F. Forrest, PhD, director, and Steven Kirshblum, MD, co-director, are harnessing the power of electrical stimulation to help restore function lost after spinal cord injury. By combining stimulation with intensive therapy, they are seeing dramatic gains, even among people living with spinal cord injury for many years.

Drs. Forrest and Kirshblum agree that your support has been critical to these advances. "With the help of the Reynolds family and many other donors, we have been able to expand our clinical research to enroll more individuals with spinal cord injury in our experimental studies and share our progress with the scientific community," explains Dr. Forrest.

People living with spinal cord injury in northern New Jersey have access to the Reynolds Center's innovative research studies. For others, participating in this research means traveling far from home. Thanks to the generosity of the Diamond Family in establishing the Kenny Diamond Memorial Fund, there is help for those who need temporary housing near Kessler Foundation while they participate in months-long studies.

At the Reynolds Center today, studies in spinal stimulation are translating into substantial improvements in function for individuals paralyzed by spinal cord injury, according to Dr. Forrest, a leader in the exploration of transcutaneous stimulation. For this approach, the stimulator is applied on the skin overlying the area of injury. While the stimulator is activated, the person can stand and walk. "Some individuals are able to move their limbs on their own after the stimulator is turned off—an exciting finding with tremendous implications for people living with spinal cord injury," she predicts. Stimulation can also improve trunk control and balance. "Being able to sit more comfortably for longer periods enhances wheelchair mobility and expands their ability to exercise and participate in therapy," adds Dr. Forrest.

Transcutaneous stimulation is restoring function to arms and hands, too. Increases in grip strength translate to greater independence in self-care and wheeled mobility, as well as other meaningful activities. "One participant delights in being able to throw a ball to his



Gail Forrest, PhD

child," notes Dr. Forrest, "and another relishes playing his piano again."

While gaining voluntary control over paralyzed or weakened limbs is a major focus of the Reynolds Center team, researchers are seeing improvements in other ways that are less well known. After spinal cord injury, many individuals lose control of their bladder and bowel, and their bodies are less able to respond to changes in blood pressure and temperature. "We are finding that stimulation improves some of these functions that are so important in daily life," says Dr. Forrest, "which has tremendous implications for the future of people with spinal cord injury and their caregivers."

This year, the Reynolds Center team expands its research to include epidural spinal stimulation, which involves surgically implanting a neurostimulator directly over the injured spinal cord. The procedure, developed at the University of Louisville, will be performed by neurosurgeon Robert Heary, MD, medical director of the Spine Program at Mountainside Medical Center in Mountainside, NJ.

Drs. Forrest and Kirshblum anticipate rapid progress in epidural stimulation research thanks to a major advance in stimulation technology made possible in part by support from an anonymous Kessler Foundation donor. A collaborative effort of Medtronic, Kessler Foundation, and the University of Louisville brings a remarkable tool to the forefront of stimulation technology. The Medtronic Stim X, a handheld tablet-type controller with



specialized capabilities to restore diverse kinds of function for individuals living with SCI. Participants implanted with epidural stimulators helped develop the new tablet, which gives them control over their own stimulation therapy. The Medtronic Stim X also records how participants use stimulation outside the clinical trial, providing researchers with valuable data about how individuals use epidural stimulation in their daily lives.

"Using this one controller, individuals can direct stimulation to move their limbs, empty their bladder, and control their blood pressure and breathing," explains Dr. Forrest. "And because the tablet can be used with limited hand function, they are gaining independence from family and caregivers." Dr. Kirshblum adds, "The team is currently working on Stim X version 2, which promises even more functionality."

The Reynolds Center will be the first facility on the East Coast to study both types of spinal stimulation. "By broadening the scope of our research in spinal stimulation, we will contribute to global efforts to revolutionize the outlook for people with spinal cord injury. With the continued support of our donors, we will transform the world's longstanding view of spinal cord injury as an incurable condition," concludes Dr. Kirshblum.

## Diamond Family Supports People with SCI to Honor Their Late Son Kenny

The Kenny Diamond Memorial Fund to support research in spinal cord injury at Kessler Foundation was established by the Diamond family to honor their son Kenny who passed away after living for more than two years with widespread cancer and a spinal cord tumor. When Kenny's paralysis made it too difficult for his parents to care for him at home, Kenny was admitted to Kessler Institute for Rehabilitation, where he received exceptional care until he passed away.

"We are grateful for the care Kenny received. We created the memorial fund to support SCI research," says Dr. Martin Diamond, Kenny's father. "Research is pivotal to advance treatments, technologies and cures. We chose to support SCI research," Dr. Diamond explains, "because of Kenny's unique situation with spinal paralysis and to help advance rehabilitation research for all people living with SCI."

Proceeds from The Kenny Diamond Memorial Fund will be targeted to defray housing costs for those patients needing financial assistance to enable participation in spinal implantation research at Kessler Foundation's Tim and Carolyn Reynolds Center for Spinal Stimulation.

Kenny's younger brother, Jeff, adds, "A weight was lifted from my parents' shoulders when Kenny was admitted to Kessler Institute. They knew he would receive expert care while adapting to life with paralysis. However, Kenny passed away after only six weeks in the hospital. We chose to establish the fund to support others who wish to participate in SCI research but lack the means to join an extensive study."

"Kenny had a big heart. He would be pleased about helping others with SCI," says Kenny's mom Shirley. "The Kenny Diamond Memorial Fund is a way to share a piece of Kenny's heart and for his family to show their gratitude.



Jeff Diamond, Kenny Diamond holding his young niece, and Dr. Martin Diamond.



Learn more about The Kenny Diamond Memorial Fund.

## YOUR SUPPORT ADVANCES EXPLORATIONS OF BRAIN NEUROPLASTICITY

Historically, it was believed that the brain stopped growing after childhood. We now know the contrary to be true. Neuroscience has confirmed that our brains change throughout our lives, from birth to death. The brain's ability to rewire its circuitry and make adaptive changes, known as neuroplasticity, is why recovery after injury is possible.

But much about neuroplasticity is not well understood. Thanks to your support, Kessler Foundation researchers are asking questions and pursuing answers. Using the functional magnetic resonance imaging (fMRI) and real-time neurofeedback capabilities of the Rocco Ortenzio Neuroimaging Center, they are conducting several novel pilot studies. Funded by the David F. Bolger Trust, these studies will help researchers understand how and where adaptions take place in the brain and correlate such changes to shifts in behavior and function.

### Identifying a Biomarker for Fatigue

Individuals who have sustained traumatic brain injury or stroke frequently rate fatigue to be their most troubling symptom, imposing limits on their ability to care for themselves, reengage with friends and family, and return to work.

Glenn Wylie, DPhil, director of the Ortenzio Center, and Olga Boukrina, PhD, senior research scientist in the Center for Stroke Rehabilitation Research at Kessler Foundation, are examining a biomarker for fatigue in people with stroke. "Sometimes after stroke people feel much more fatigued, and this dramatically increases their subjective experience of effort when performing mental tasks, which in turn affects their ability to participate in rehabilitation," says Dr. Boukrina. "We want to understand how fatigue is expressed in the brain," she adds.

"Our prior research shows that the basal ganglia plays a significant role in fatigue," explains Dr. Wylie. "This is a part of the brain where stroke damage can have significant effects on muscle control, vision, sense of touch, perception, and judgment," he adds.



Olga Boukrina, PhD, Jeanne Zanca, MPT, PhD, and Glenn Wylie, DPhil

To learn if there is a correlation between fatigue and the basal ganglia, the team is inducing fatigue in three groups—individuals with stroke with direct damage to the basal ganglia, individuals with stroke elsewhere in the brain, and individuals who have not experienced stroke.

"This study will allow us to identify the network of brain areas associated with fatigue. With this understanding, we then can turn to the important work of alleviating fatigue," concludes Dr. Boukrina.

### **Understanding Fatigue Across** the Lifecycle

Dr. Wylie is conducting another pilot study of cognitive fatigue—in older adults. While it may seem intuitive to assume that fatigue worsens with age, initial study data suggest otherwise. His team is examining both state fatiguein the moment—and trait fatigue—over an extended period-across different ages. Data collected so far show older individuals report comparable levels of fatigue over a longer period (e.g., two weeks), but experience less fatigue accomplishing immediate tasks. The initial data show the opposite to be true with younger participants who become more fatigued doing immediate tasks. Dr. Wylie and his team are now testing a sample of individuals over 65 years old to see if this same pattern is maintained as age increases.

"Investigating fatigue across the lifespan represents a unique window into the differences among all age groups," says Dr. Wylie. "Understanding how state and trait fatigue change over the lifecycle is a critical first step towards developing appropriate interventions for each group," he adds.

### **Using Neurofeedback to Promote Beneficial Brain Plasticity**

In another pilot study, Dr. Boukrina is examining the use of an innovative technique called real-time fMRI neurofeedback to help stroke survivors overcome persistent reading and language deficits. This technology is applied to improve cerebral blood flow and neural activity in the left hemisphere of the brain. The left hemisphere is critical for the ability to speak, read, and write.

"Studies have shown that repeated efforts to self-regulate brain activity lead to learning-induced neural changes," Dr. Boukrina explains. With real-time fMRI and neurofeedback, participants learn to regulate their own brain activity by combining mental strategies with neurofeedback. While in the MRI scanner, they can see the changes taking place in their brain as they read, respond to verbal prompts, and perform motor imagerythey imagine moving their right hand to help activate the left side of the brain.



The brain's ability to rewire its circuitry and make adaptive changes, known as neuroplasticity, is why recovery after injury is possible.



Drs. Boukrina, Wylie, and Zanca explore neuroplasticity, thanks to your support.

Similarly, Jeanne Zanca, MPT, PhD, senior research scientist in the Center for Spinal Cord Injury Research, is piloting a study aimed at empowering people with spinal cord injury to self-regulate chronic neuropathic pain using neurofeedback. Neuropathic pain is a common complication of spinal cord injury that limits many aspects of functioning, including mobility, cognition, sleep, relationships, employment, and community engagement.

Current approaches to neuropathic pain treatment—typically medication and surgery often come with unwanted side effects. And while these options can chip away at the pain, they can't eradicate it completely. People with spinal cord injury need options to manage their remaining pain and reduce its interference with daily life.

By comparing the brain activity of people with spinal cord injury to that of their uninjured peers, Dr. Zanca seeks to identify the specific network of brain areas that contribute to the pain experience and to provide feedback

to help individuals self-regulate their pain. "While in the MRI scanner, participants are guided to identify their own best painminimizing strategies—focused breathing, picturing themselves in a favorite location and neurofeedback lets them know if they are succeeding," Dr. Zanca explains.

"Neurofeedback empowers individuals to find the best strategies to alleviate their chronic pain. It gives them control," she concludes.



Listen to Drs. Boukrina, Wylie, and Zanca discuss the correlations of changes in the brain to changes in behavior and function.

## YOUR SUPPORT PREPARES ADOLESCENTS WITH AUTISM FOR THE WORKFORCE USING POSITIVE PSYCHOLOGY

We all remember these moments—our first job, our first time living away from our parents, our first paycheck. The transition from adolescence to young adulthood is a difficult but critical time. For youth on the autism spectrum this time is even more challenging. An abundance of research indicates that they are more likely than their peers to experience low selfesteem, lack of confidence, and low motivation. Historically, interventions for kids on the spectrum have been deficit-based—focused on fixing what is deficient—or wrong—in a person. Across a lifetime, an individual with autism is told repeatedly what they should not do and cannot do.

Thanks to your support, Helen M. Genova, PhD, associate director of Kessler Foundation's Center for Autism Research, is developing and testing innovative solutions to help adolescents on the autism spectrum improve awareness of their own personal strengths and their ability to advocate for themselves across multiple contexts-school, relationships, job interviews, and employment. Dr. Genova's approach is based in positive psychology—focused on improving wellness by cultivating strengths, as opposed to fixing weaknesses. "Evidencebased tools that take this approach in autism are not in common use. With your support, my team and I are working to change this," says Dr. Genova.



Helen M. Genova, PhD, is developing innovative solutions to help adolescents on the autism spectrum improve awareness of their own personal strengths.

"Dr. Genova's approach is based in positive psychology—focused on improving wellness by cultivating strengths, as opposed to fixing weaknesses." For youth on the autism spectrum, a big challenge is getting and maintaining employment. Your support enabled Dr. Genova and her team to first develop and evaluate a positive psychology intervention, KF-STRIDE *Into the Interview!*, a web-based tool to improve job interview skills by teaching youth on the spectrum about their strengths and how to convey them to future employers. Dr. Genova has found KF-STRIDE *Into the Interview!* to be effective in improving interview skills and strength identification. Plus, the kids who've participated have reported that it was enjoyable and helpful.

Now, with a new grant from the Alfiero and Lucia Palestroni Foundation, Dr. Genova is developing and testing an app to complement KF-STRIDE *Into the Interview!* The app will prompt users to record how they used their strengths on a daily basis, helping to build on what they've learned and use it in daily life.

Once they've obtained a position, individuals on the autism spectrum can have significant difficulty maintaining a job and communicating with colleagues. With new support from the Dean Janeway Endowment Fund at the New Jersey Health Foundation, Wakefern Food Corporation, and two anonymous donors, Dr. Genova is also developing and testing KF-STRIDE *Into Work!* This new intervention will assist young adults with autism identify their job-applicable assets and talents to enhance work satisfaction, productivity, and well-being. KF-STRIDE *Into Work!* will teach individuals strength-based strategies to apply when stressed, frustrated, or overwhelmed. "Many employment interventions teach the same skills to everyone, even though autism is a spectrum and people with autism have different abilities and skills," says Dr. Genova, adding, "Our interventions take an individualized approach based on the unique strengths of each person."

"The support of our donors has been critical in helping us move these promising programs forward. Because of you, the future for people on the spectrum looks brighter. We are expanding our work using the latest technology to offer a wide range of training for transition-age youth so they can maximize their independence and inclusion," says Dr. Genova.



*William Kendis practices his interview skills with Dr. Genova.* 

## William Lands a Summer Job

Potential employers often ask, "Why are you the right person for the job?" Practice and skill are needed to effectively communicate the best answer, especially if you live with autism like William Kendis.

William, who is 17 years old, participated in a unique 10-session online interview skills enhancement program being tested by Dr. Helen Genova and her team. The program helps teenagers and young adults on the spectrum identify their personal strengths and communicate them to potential employers.



William Kendis (right) and his mother, Lori Kendis (left).

"I think it's difficult for any young person to articulate their skills and strengths in a job interview," says Lori Kendis, William's mom. "For people with autism, anxiety about social interaction adds an extra layer of challenge to an already stressful situation," she explains.

Lori and William learned about Dr. Genova's research and they got involved. "I liked the online interview training sessions," says William of the first study he joined. "There was an animated interviewer, so I wasn't too nervous. Later, a real person helped me practice in pretend interviews—that was harder."

As William joined additional studies, Lori saw growth in her son's confidence. "Participating helped him identify his personality strengths. Creativity was one, which wasn't a surprise since he loves to draw," says Lori. "He then practiced communicating his strengths in mock interviews. Over time, I heard his confidence increase. I'm proud of him. His news skills already helped him get a summer job at our town pool," adds Lori.

William says he's grateful for Dr. Genova and her team. I also want to thank Kessler Foundation donors. I know you help make all this happen. One day, I'll interview for my first dream job. Thanks to you, I have a better chance at getting it!"



isten to a special message from. Villiam and Lori Kendis.

## YOUR SUPPORT CHARTS OPTIMAL PATHWAYS TO INDEPENDENCE USING BLOOD BIOMARKERS

Will I get better? When? How? All individuals faced with rehabilitation for disabling illnesses or injuries ask the same questions. Answering these questions has been a challenge for rehabilitation professionals who have had little scientific data to rely on for predicting recovery for individuals and charting their optimal pathways to independence.

Thanks to your support, these challenges will be overcome as blood-based biomarkers are incorporated in Kessler Foundation research. A new onsite laboratory for drawing blood samples, funded by a generous donation from Foundation Trustee Terri Goldberg and her husband, Michael, is enhancing the Foundation's research capabilities and accelerating the development of new treatments.

Biomarkers are measurable indicators of some biological state or condition that can indicate disease level or reflect future responsiveness to treatment. They may be imaging findings, behavioral or physiological changes, or substances detected in blood, saliva, and body tissues. Blood-based biomarkers, in particular, are playing an increasingly important role in research related to neurological illness and injuries.



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"A generous donation from Foundation Trustee Terri Goldberg and her husband, Michael, is enhancing the Foundation's research capabilities."

The first study to utilize the new laboratory is led by Denise Krch, PhD, senior research scientist in the Center for Traumatic Brain Injury Research. This multi-site federally funded study\* employs a unique holistic approach to improving the lives of people with traumatic brain injury and dementia and their caregivers. Researchers will use the new lab to draw blood to assess biomarkers present in moderate-to-severe traumatic brain injury, adding an important dimension to this study. "These biomarkers are strongly associated with the health-related quality of life for people with these disabling conditions," Dr. Krch explains.



Denise Krch, PhD and Nancy Chiaravalloti, PhD, will use a new onsite laboratory to draw blood samples to determine new treatments.

As major causes of long-term disability and caregiver burden, traumatic brain injury and dementia are targets for the innovative intervention being studied. A 12-week group-based treatment teaches long-lasting management skills to each individual and their caregiver. "The new lab enables us to easily screen participants for blood-based biomarkers, adding a potential diagnostic tool to our existing research protocol," she notes. "Identifying the biomarkers that correlate with treatment efficacy will help us determine the best way to implement this treatment approach," she adds. "The unique design of this intervention and the broad scope of this trial have the potential to transform how we manage traumatic brain injury and dementia in the future."

Known for their roles in diagnosing diseases and assessing health risks, biomarkers can also be useful for measuring responses to treatments. Identifying which individuals are likely to respond to an intervention is invaluable, according to Nancy Chiaravalloti, PhD, director of the Centers for Neuropsychology and Neuroscience Research, and Traumatic Brain Injury Research at Kessler Foundation. "Knowing in advance which treatments are likely to benefit each person will be a gamechanger. Selecting the most beneficial treatment will streamline their rehabilitation and increase their likelihood for recovery," she predicts. "Bringing new biomarkers into our research will provide the data we need to answer those important questions that every patient has."

\* U.S. Department of Defense, U.S. Army Medical Research & Development Command, Congressionally Directed Medical Research Programs (CDMRP), Peer Reviewed Alzheimer's Disease Research Program (PRARP) W81XWH-21-1-0743

## **Leader Mentors Next Generation**



Nancy Chiaravalloti, PhD

"Mentoring promising new researchers is one of the best parts of my job," says Dr. Chiaravalloti. "I aim to teach mentees the entire rehabilitation research process, from designing and leading studies to communicating findings to scientific and non-scientific audiences alike, so the impact of their research is felt by more people."

Dr. Chiaravalloti, who has mentored the next generation of rehabilitation research for 18 years, says contributions from mentees lead to more innovative research at Kessler Foundation. "I guide these new researchers to the next level, but mentees help us too, by inspiring new research paths."

With support from the Hearst Foundations, Dr. Chiaravalloti has mentored three Hearst Fellows. The first, Silvana Costa, PhD, launched two studies during her fellowship to examine the impact of cognitive rehabilitation in MS using neuroimaging. Dr. Costa, now a Kessler Foundation research scientist, leads the Neuropsychology of Eye Movements Laboratory and aspires to contribute significantly to the treatment and early intervention of cognitive deficits, improving quality of life among those who live with MS and other neurological conditions. Katie Lancaster, PhD, the second Hearst Fellow, designed a study to test an intervention for people with MS based on a newly identified form of emotion regulation—the social regulation of emotion. Current Hearst Fellow Aubree Alexander, PhD, is designing new cognitive rehabilitation techniques and evaluating their impact on daily functioning.

Dr. Chiaravalloti notes that while each of the Hearst Fellows is extremely different in background and experience, they are similar in their commitment to research and bringing improved treatments to people with disabilities.

"New lines of research, such as blood biomarking that could potentially better characterize dementia and cognitive decline, are the future," says Dr. Chiaravalloti. "Thanks to Terri and Michael Goldberg, and support from donors like you, the future is happening now at Kessler Foundation. The next generation of mentees will continue to spark innovation, improve treatments, and help people with disabilities live to the fullest," she concludes.

# YOUR SUPPORT HARNESSES THE POWER OF EXERCISE TO TRANSFORM MS TREATMENT

Living with multiple sclerosis is a challenge for individuals, their families, and their care partners. While disease-modifying therapies can slow the progression of MS, none of the available medications are effective in treating its wide range of debilitating symptoms. This is a major problem for people with MS, especially those with symptoms that affect their abilities to work, attend school, and care for their families.

With your support, Kessler Foundation researchers are pooling their expertise to find new ways to help individuals maintain their physical mobility, balance, and cognitive function, and cope with the fatigue and depression that often accompany MS. To address the wide array of physical and cognitive symptoms, scientists are testing a holistic approach based on exercise interventions, according to Brian Sandroff, PhD, director of the Exercise Neurorehabilitation Laboratory in the Center for Neuropsychology and Neuroscience Research.

"Incorporating exercise rehabilitation in treatment plans has the potential to transform MS care," he predicts. "But first, we need to establish that exercise is effective for treating MS and determine how to prescribe exercise to get the best results." Several MS exercise studies are underway at the Foundation— Project EXACT focuses on the effects of



Brian Sandroff, PhD, and Ghaith Androwis, PhD, pool their expertise to find new ways to help people with MS maintain mobility, balance, and cognitive function.

aerobic exercise on cognition, mobility, and the brain, and Project CogEx looks at the benefits of combined aerobic exercise and cognitive rehabilitation in progressive MS. Another exercise study is breaking new ground by applying robotic technology, thanks to the generous support of Joy and Avi Avidan.

In this ongoing experimental study, research participants walk in a wearable robot—the Ekso NR—that enables them to significantly increase their walking exercise, reaching levels that can improve their mobility and cognition, according to lead investigator, Ghaith Androwis, PhD, research scientist and director of the Rehabilitation Robotics and Research Laboratory in the Center for Mobility and Rehabilitation Engineering Research.

This randomized controlled pilot study, the first of its kind in MS, compared the effects of robotic exoskeleton-assisted exercise training with conventional gait training. Results generated international media interest following publication in medical literature. "Not only did we see large improvements in mobility and cognitive processing speed after a short course of robotic exercise training," reports Dr. Androwis, "these improvements correlated with positive changes in the brain seen on neuroimaging."

"Seeing these improvements is very exciting," comments Dr. Sandroff. "It's clear that exercise is a powerful behavior that involves many brain regions and networks. Our results show that by harnessing that power, individuals with MS may regain both physical and cognitive



function. Another important future direction in this area involves the consideration of exercise as a therapy that can potentially induce remyelination in people with MS," he adds.

To build on the overwhelming success of the initial trial, the research team is seeking funding for a larger randomized clinical trial. The goal is to determine the immediate and long-term effects of an extended course of robot-assisted training intervention and establish guidelines for clinical applications. "Based on our initial results, we're optimistic that this approach may be superior to the current standard of care," says Dr. Androwis.

Improving the standard of care will mean countering the sedentary lifestyles of most people with MS. "Shifting people to active lifestyles will be a challenge," cautions Dr. Sandroff. "Health care providers will need to act as agents of change." He envisions the Foundation's exercise rehabilitation research culminating in a toolkit for clinicians. "This would contain the resources needed for tailoring exercise protocols for patients with MS, setting individualized goals, and monitoring their transition to active lifestyles that improve their function and quality of life," he concludes.

## By Participating in MS Research, Carla Adapts and Gives Back

Carla Basante lives with multiple sclerosis and is a longtime participant in Kessler Foundation research to help people living with MS remain engaged in their communities, workplaces, and homes.

Carla has participated in 12 research studies. Her latest examined the effects of exercise on mobility and cognition while wearing a robotic exoskeleton. "The exoskeleton is an amazing piece of technology," says Carla. "Wearing it improved my balance, stance, gait, and posture—all areas which can decline with MS."



Carla Basante participates in research to evaluate the impact of exercise on cognition and mobility for people living with MS.

Carla remembers how hard she worked, physically and cognitively, in the exoskeleton. "You can't take your next step until your balance, stance, gait, and posture are in sync. I felt like my brain might explode as I worked to position my body correctly for every step. At the end of a session, I was exhausted, but I also felt strengthened and empowered."

The coordination to walk correctly remained with Carla post training. "Back home, my muscle memory kicked in," she explains. "I found myself automatically working mentally and physically to ensure smoother steps as if I were still wearing the exoskeleton."

For Carla, research participation is key to improving her quality of life with MS, but it's also how she gives back. "I learn a lot from Kessler Foundation researchers on how to adapt, but the research that I participate in isn't just for me—it improves the lives of everyone living with MS. Thank you, donors, for your support of Kessler Foundation research to help all of us with MS live more fully."



Listen to a special message from Carla Basante.

## YOUR SUPPORT BRINGS VIRTUAL REALITY HOME FOR STROKE SURVIVORS

Imagine living each day completely unaware of one side of your body and personal space. You may shave or make-up only half your face, ignore anyone who approaches on one side, or step into street traffic because the redlight signal is on your affected side. You are completely unaware that anything is amiss.

These debilitating symptoms represent spatial neglect, a common complication of stroke that often escapes detection.

In comparison to the general population of individuals with stroke, those with spatial neglect experience slower physical and cognitive recovery, lower self-awareness of disability, and greater difficulty returning to their communities. The impact on patients ranges from diminished quality of life to serious injury. With your support, and that of the Wallerstein Foundation for Geriatric Life Improvement and the Charles and Ann Serraino Foundation, Kessler Foundation scientists have been leading research in this area since 2007, developing and testing tools proven to successfully identify and treat spatial neglect.

Thanks to a 2021 grant from The Healthcare Foundation of New Jersey, which was founded by the Jewish community, Kessler Foundation researchers are developing and testing the effectiveness of a portable, home-based therapy program for spatial neglect using the latest virtual reality technology.



*Peii (Peggy) Chen, PhD, is developing home-based treatment for spatial neglect using the latest virtual reality technology.* 



Listen to Dr. Peggy Chen discuss the prevalence of spatial neglect after stroke. The newly funded project is an extension of the ongoing effort of Peii (Peggy) Chen, PhD, senior research scientist at Kessler Foundation. Since 2017, Dr. Chen and her team have been testing and refining a clinic-based treatment for spatial neglect and developed the novel, immersive virtual reality treatment called the Kessler Foundation Spatial Retraining Therapy (KF-SRT<sup>™</sup>) System. With this clinic-based treatment, patients wearing head-mounted goggles and using hand-tracking technology engage in a variety of challenging motor tasks in a computer-generated environment.

A major limitation of the clinic-based treatment is that the equipment is expensive and not portable. Many individuals with spatial neglect are unable to travel to receive treatment while others can't afford outpatient therapy immediately after inpatient care and there is an urgent need for spatial neglect treatment after inpatient rehabilitation.

To make the treatment accessible and affordable, Dr. Chen and her team are modifying the clinic-based system for use in patients' homes. "Immersive virtual reality technology is a new paradigm for spatial neglect rehabilitation," explains Dr. Chen.

Indeed, with support from Kessler Foundation Trustee Michael Davis and his wife, Francine, Dr. Chen's colleagues, Olga Boukrina, PhD, senior research scientist, and Timothy Rich, PhD, OTR/L, postdoctoral fellow, are developing and testing an additional virtual reality treatment. This treatment addresses neglect dyslexia—an under-investigated reading deficit associated with spatial neglect.



Olga Boukrina, PhD, investigates how virtual reality can help stroke survivors reduce reading errors.

"At this time, no evidence-based treatment specific to neglect dyslexia exists," says Dr. Boukrina. The treatment consists of repetitive eye movement exercises with a more advanced virtual reality goggle that has eye tracking built in to improve reading ability and quality of life.

"The Davis's are helping us understand how poor eye movement contributes to reading errors and how best to use the eye-gaze data provided by the virtual reality treatment to help stroke survivors reduce reading errors," explains Dr. Boukrina.

"Your support brings the latest technologies to the forefront of stroke rehabilitation and provides stepping-stones to future advances," concludes Dr. Chen.

"Your support brings the latest technologies to the forefront of stroke rehabilitation and provides stepping-stones to future advances."

— Peii (Peggy) Chen, PhD

## Steve Makes Music Again After His Stroke

Steve Ascolese sustained a stroke in June 2020. Though not paralyzed, he lost use of his left arm, hand, and leg. "I had my stroke near the beginning of the pandemic. As part of my recovery, and to get fresh air, I'd make frequent trips in my power wheelchair throughout the neighborhood," says Steve.

Steve also had spatial neglect—an underdiagnosed effect of stroke—causing him to lose awareness of the surrounding space on his left side. "The spatial neglect prevented me from seeing the curb while directing my wheelchair. I came close to driving off the sidewalk many times," Steve recalls.

Steve's spatial neglect also made it impossible for him to read. "As an amateur musician, I was devastated that I couldn't read sheet music." When Steve heard about a Kessler Foundation study to test newly designed virtual reality treatment for correcting spatial neglect, he eagerly joined.

"I enjoyed the games and activities on the training modules; they were never boring," Steve reports. "I like that the modules can be used at home—that will save transportation time and cost."

"Thanks to your support of Kessler Foundation research, I've retrained my brain after stroke. My wheelchair travel around the neighborhood is safe and I can read and play music again. I'm grateful to be living more independently. You have my heartfelt thanks."



Steve Ascolese participates in research to retrain the brain and correct spatial neglect after stroke.

## YOUR SUPPORT BRIGHTENS THE FUTURE FOR NEWBORNS AFFECTED BY THE OPIOID CRISIS

Despite actions aimed at controlling the widespread use and abuse of opioids, the opioid crisis in the United States shows little sign of abating. As more infants are born addicted, there is new urgency to the pediatric rehabilitation research being conducted by Kessler Foundation in collaboration with Children's Specialized Hospital.

In 2019, with generous support from the Reitman Foundation, researchers at Kessler Foundation, led by Amanda Botticello, PhD, MPH, associate director of the Centers for Spinal Cord Injury Research and Outcomes & Assessment Research at Kessler Foundation, joined with rehabilitation professionals at Children's Specialized to study the impact of neonatal abstinence syndrome (NAS). Children's Specialized offers pediatric rehabilitation for newborns with NAS, the syndrome of acute withdrawal that affects newborns exposed to opioids before birth.

This initial funding from the Reitman Foundation enabled researchers to establish a registry of all infants admitted to inpatient rehabilitation for NAS at Children's Specialized, including data on timing of admission, types of withdrawal symptoms, response to weaning medications and therapies, type of drug exposure, and other treatment details. During pediatric rehabilitation, newborns receive specialized therapy while being gradually weaned off opiates in a calm environment. This novel registry is the foundation for research aimed at brighter futures for newborns treated for NAS, according to Jodi Zalewitz, MD, director of the Infant Toddler Team at Children's Specialized. "Despite decades of research, we still lack consensus on the best ways to identify and treat these high-risk infants," Dr. Zalewitz explains. "This registry is an important step toward reaching those goals."

Recognizing the urgent need to accelerate NAS research, the Reitman Foundation continued its support last year, enabling researchers to greatly expand the scope of their investigation. "We were able to enroll 30 more infants in our study," reports Dr. Botticello, "and begin collecting data from their outpatient follow-up visits."

Dr. Botticello anticipates that the Reitman Foundation funding will have substantial impact. "Increasing our sample size will strengthen our findings," she notes, "and being able to follow these children as they grow is an important step toward the larger longitudinal studies we need to fill the gaps in our knowledge of the impact of NAS."

The team is focusing on understanding how treatment affects the severe symptoms of withdrawal, which disrupt feeding, sleeping, and early development. "Ultimately, we want to understand risks for developmental delays, speech difficulties, and learning disabilities, as well as the need for referrals for mental health, behavioral, and school-readiness services," says Dr. Botticello.

Because of the combined support of the Reitman Foundation and Children's Specialized, the registry will be an ongoing source of data for finding the best ways to care for survivors of NAS. "The goal is to correlate the treatment they receive at Children's Specialized with how well they do during childhood and modify neonatal care to achieve the best outcomes," she explains. "Feeding difficulties, for example, are common among babies with NAS and may contribute to the social and emotional health issues that they experience later in life. The data we are collecting will help us research ways to refine the guidelines for feeding and nutrition to reduce the risk for those issues."

"The complex needs of these infants may persist into childhood, posing new challenges for the children, their caregivers, and educators," Dr. Botticello acknowledges. "The path ahead—complicated by the stigma surrounding drug use and mental illness demands enormous effort," she cautions, "but with the help of donors who care, we are headed in the right direction."

Drs. Botticello, Zalewitz, and the entire research team are dedicated to learning all they can about the consequences of NAS. "The advances we achieve through our partnership have the potential to impact pediatric rehabilitation on a much larger scale," they note. "Further research is critical—without it, these children may be left behind."

![](_page_11_Picture_12.jpeg)

Amanda Botticello, PhD, MPH, seeks the best ways to care for infants with neonatal abstinence syndrome.

## YOUR SUPPORT DEBUNKS MYTHS ABOUT COLLEGE-TO-WORK SUCCESSES FOR PEOPLE WITH DISABILITIES

Call it what you will, but assumptions and misconceptions about people with disabilities are common, especially when it comes to higher educational achievement and employment opportunities for graduates. For example, some traditional viewpoints claim that college isn't a good choice for people with disabilities; they can't perform as well as their peers; and they won't find jobs after graduation.

A Kessler Foundation survey—made possible by your support-handily debunked these unfounded theories. Survey results showed that employment for recent college graduates with disabilities is at almost the same rates as their peers without disabilities. The survey data collected will provide valueadded guidance points now and in the future for college students with disabilities, counselors, and educators.

"Kessler Foundation 2020 National Employment & Disability Survey: Recent College Graduates" conducted in partnership with the University of New Hampshire Institute on Disability was the third in a groundbreaking series of surveys aimed at gaining detailed information on the ways people with disabilities achieve inclusion in the workplace.

Recent college graduates with disabilities were as likely to be employed as their peers without disabilities, according to the survey, with 90 percent of each group holding jobs within five years of graduation. "This result clearly suggests that higher education pays off for people with disabilities," says John O'Neill, PhD, director of the Foundation's Center for Employment and Disability Research. "We also found that college students with disabilities preparing for careers were just as likely to engage in internships, paid employment, and career counseling services and benefit from them like their peers without disabilities," he adds.

More than 30 years after the passage of the Americans with Disabilities Act of 1990 (ADA), students with disabilities are reaping the benefits of higher education. The survey results reflect opportunities now open for people with disabilities because of the ADA. "The findings provide direction for youth with disabilities and their families, counselors, educators, and therapists dedicated to supporting them as they pursue careers and economic independence," O'Neill explains.

Survey results also suggest that community college, with its lower cost and ease of access, provides the first springboard to advanced education for about one in five recent college graduates with disabilities.

Yet challenges remain and many opportunities for improvement also emerged from the survey results. Recent graduates with disabilities were less likely to find work related to their college degree or hold permanent positions. Instead, they were more likely to work intermittently or on-call as consultants or freelancers.

**MYTH:** College students with disabilities are relegated to offices for students with disabilities and don't access career services that are available to general college population.

![](_page_12_Picture_9.jpeg)

TRUTH: College students with disabilities engage in academic and career preparation and internships with faculty advisors at least as much as college students without disabilities.

**MYTH:** People with disabilities do not want to work.

J

**TRUTH:** A college education pays off for people with disabilities among those who graduated in the past five years, 90 percent report holding jobs after college.

![](_page_12_Picture_15.jpeg)

A pre-screened national sample of 4,738 adults completed the survey, half of whom had at least one disability, and half without disabilities. All respondents were aged 20 to 35 and had graduated from college in the last five years with an associate degree or higher.

With your support, many more analyses are planned for these data, which will add to our understanding of factors contributing to the successful college-to-work transition of people with disabilities.

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## ONLY ABILITIES MATTER AT Strick References

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Last September, Kessler Foundation's annual signature event was a first—our first-ever hybrid Stroll 'N Roll, presented by Gibbons PC, Impossible Dream, and Pfizer. People of all ages and abilities gathered in Verona Park and in their own neighborhoods to prove that abilities are what matter. Together we raised a record-breaking \$205,000 to advance rehabilitation research and employment for people with disabilities. **The generosity of champions like you made this happen.** 

Inspiring leaders created teams of champions to give back and make a lasting impact. Our dedicated Stroll 'N Roll committee reached out to friends and family to make the event a success!

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Your Support Changes Lives: Impact Report 2022

## **KESSLER SOCIETY—GIVING THAT CHANGES LIVES**

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Henry H. Kessler, MD, PhD, founded Kessler Institute for Rehabilitation after serving in World War II.

As a Kessler Society member, you propel rehabilitation research discoveries and innovative employment initiatives. As a result, people with disabilities reimagine what's possible and realize the extraordinary. Year after year, you champion groundbreaking rehabilitation research and employment for people with disabilities—helping people take first steps, improve thinking and learning, and overcome obstacles to employment.

Kessler Society members honor Henry H. Kessler, MD, PhD, who founded Kessler Institute for Rehabilitation after serving in World War II. His vision was "...to treat the whole individual...to help him or her successfully regain physical, mental, social, vocational and economic usefulness to the fullest possible degree."

Today, Dr. Kessler's vision is reflected in the institutions that bear his name-Kessler Foundation and Kessler Institute for Rehabilitation, which consistently ranks as one of the best rehabilitation hospitals in the nation.

Our donors continue Dr. Kessler's legacy. Membership in the Kessler Society is extended to friends who make annual gifts totaling \$500 or more.

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\$100,000+	\$25,000 – \$99,000	\$10,000 – \$24,999
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Kessler Society members honor Dr. Kessler, pictured in 1955 at the Kessler Institute Children's Clinic.

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### In 2021, inspired leaders raised funds to champion research and employment for people with disabilities.

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## **Remembering Our Dear Friend and Colleague Gerard Malanga, MD**

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In mid-May, we lost our dear friend and colleague Gerard Malanga, MD, to cancer. Gerry—as he was known—was director of the New Jersey Regenerative Institute and visiting scientist at Kessler Foundation. He was also integral to the Derfner-Lieberman Regenerative Rehabilitation Research Laboratory at Kessler Foundation funded by Jay Lieberman of the Derfner Foundation. He worked closely with Trevor Dyson-Hudson, MD, and Nathan Hogaboom, PhD, co-directors of the Derfner-Lieberman Laboratory, to pioneer regenerative rehabilitation research.

Gerry was board certified in physical medicine and rehabilitation and the subspecialties of sports medicine and pain medicine. He specialized in nonsurgical and regenerative treatments of musculoskeletal disorders including injuries of the neck, back, shoulder, and knee. He lectured throughout the United States and internationally on topics related to sports medicine, orthopedics, and pain management. Fellows came from all over the world to train with him.

At Kessler Foundation, Gerry was known for his relentless dedication to some of the most complex medical challenges of medical rehabilitation. He understood that research drives advancements in clinical care and sought to translate findings from bench to bedside. Dedicated to his work, Gerry offered his wise counsel to the very end, saying it gave him energy for his fight.

"Gerry will be missed by all of us at Kessler Foundation. We will remember and be inspired by his compassion as we continue to pursue excellence in rehabilitation research," says Rodger DeRose, president and CEO.

## The Impact of Your Generosity

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\$25.000 Sponsors one research participant with spinal cord injury in a transcutaneous spinal stimulation study.

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\$2.500 Underwrites a functional MRI scan and its analysis to determine changes in the brain or spinal cord

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\$15,000 Sponsors one research participant with brain injury, stroke, or MS in a study to restore mobility using a robotic exoskeleton

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![](_page_17_Picture_29.jpeg)

\$5.000 Sponsors one research participant in a study to improve quality of life after spinal cord iniurv.

\$1.000 Covers the cost of one study's Institutional Review Board renewal.

![](_page_17_Picture_32.jpeg)

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