

## YOUR SUPPORT CHANGES LIVES

Impact Report 2019

Your support of Kessler Foundation champions life-changing rehabilitation research and employment for people with disabilities.

You enable our scientists to explore groundbreaking rehabilitation interventions and help our grantmakers create pathways to employment and independence for people with disabilities.

Inside our Impact Report 2019, you will find highlights of what you have made possible and stories of lives you've changed. Because of your generosity, these lives—and the lives of many others with disabilities—can continue to unfold.

With gratitude,



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Rodger DeRose and Michele Pignatello



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Thanks to your support, Natalie Barrett (right) can get up from her wheelchair and walk.

# YOUR SUPPORT TRANSFORMS CARE AND RECOVERY FOR PEOPLE WITH SPINAL CORD INJURY

Not long ago, recovery from spinal cord injury was a dream simply not thought possible. Individuals paralyzed by SCI benefited from advances in modern medical and surgical care, but the pace of progress was painfully slow when it came to restoring function. Today, thanks to your support, the increasing pace of this research is more promising than ever. Breakthroughs in spinal stimulation are making the dream of recovery more than just a possibility. Now, we can envision a future in which the dream becomes a reality.



Natalie Barrett with staff from the Center for Spinal Stimulation.

With support from Tim and Caroline Reynolds, and donors like you, Kessler Foundation established the Center for Spinal Stimulation to provide scientists with the resources to investigate how applying electrical stimulation to the spinal cord, combined with intensive physical therapy, can help individuals, like Natalie Barrett, regain mobility and function and live more independently.

To accelerate discoveries, this groundbreaking Center is bringing together the nation's leading experts in two promising experimental methods of spinal stimulation—transcutaneous and epidural. In transcutaneous stimulation, an electrical stimulator is placed on the skin overlying the damaged cord. In epidural stimulation, a stimulator is surgically implanted directly on the surface of the cord. Stimulating the cord activates the nerve centers and pathways turned off by trauma, reawakening the ability of the cord to conduct impulses to paralyzed muscles. Studying both methods positions the Center for Spinal Stimulation at the forefront of research and holds the promise to transform care and recovery for people with SCI.

Leading the new Center are director Gail Forrest, PhD, and co-director Steven Kirshblum, MD. Dr. Forrest is an expert in the emerging field of neuromodulation—the science behind the reawakening of the spinal cord. She is the Foundation's principal scientist in mobility research in spinal cord injury. Dr. Kirshblum is senior medical officer and director of spinal cord injury rehabilitation at Kessler Institute for Rehabilitation, chair of physical medicine and rehabilitation at Rutgers New Jersey Medical School, and Kessler Foundation's chief medical officer. He is internationally known for his expertise in spinal cord injury care, education, and research.

"The potential for restoration of function is quite dramatic," says Dr. Forrest, referring to recent findings of the Center's main collaborators based at the University of Louisville and UCLA. "With a combination of epidural stimulation and intensive physical therapy, four people with long-term paralysis regained the ability to stand and move their legs during stimulation, and two regained some ability to move on their own," she notes. "We are seeing other effects, as well, including improvements in bowel and bladder function, better temperature regulation, and benefits to cardiovascular and respiratory function. These exciting early results, and the continued support of our donors, inspire us to work even harder to build this line of research."

Scientists and therapists already are making progress at Kessler Foundation's West Orange location, where transcutaneous stimulation is combined with robotic-assisted walking to improve mobility. To provide the space needed for testing, training, and follow-up for long-term studies, construction of a major expansion is underway that, within a year, will allow more people in need to enroll in this experimental research.

Initially, Kessler Foundation's Center for Spinal Stimulation will provide intensive training and follow-up for individuals with epidural stimulators implanted by the University of Louisville team. By developing the capability for surgical implantation in New Jersey with neurosurgeon Robert Heary, MD, the Center will complete the spectrum of resources to advance stimulation research to the next level.

"We have much to learn about how stimulation affects the injured spinal cord," says Dr. Kirshblum. "With your support, this Center will enable us to learn how to maximize the gains in function," he predicts, "but more importantly, how to translate those gains into greater independence for the community of individuals living with spinal cord injury."



*Natalie Barrett (center)* 

## BUILDING ON HER GAINS, NATALIE VOWS NEVER TO STOP

Paralyzed in a car accident four years ago, Natalie Barrett started on her road to recovery at Kessler Institute for Rehabilitation. By working hard in rehabilitation and participating in our groundbreaking research in robotics and transcutaneous spinal stimulation, made possible by your support, her life has changed dramatically. Natalie describes spinal stimulation as "a jump start, a charge that makes me go, and I want to go! My legs are stronger and easier to control. Now, I can stand and walk, and even talk at the same time."

Today, Natalie lives more independently. She's back to working full time in customer service at a pool company. She manages well at home, cooking for herself and caring for her dog, Dutchess, and planning a future with her fiancé, Bryan. Natalie plans to build upon her gains. "Whatever happens, I'll keep trying," she says. "I'll never stop."

## **YOUR SUPPORT EXPANDS** THE SCOPE OF REHABILITATION **AFTER SPINAL CORD INJURY**

While loss of mobility is readily recognized among individuals with spinal cord injury, other deficits are often overlooked. **Up to 60 percent of people with SCI also have cognitive impairment**—difficulties with memory and learning—that complicate their recovery, limit their progress during rehabilitation, and adversely affect their quality of life. With your support, Kessler Foundation scientists are combining their expertise to investigate disabilities that impact both mobility and cognition.

Your Support Changes Lives: Impact Report 2019



Thanks to you, James Quesada (left) learned techniques to improve his memory.

Recovery depends on learning many new skills—from the basics of self-care to using wheelchairs, robotics, modified vehicles, and other assistive devices—which is why your support of this new line of research is so important.

Nancy Chiaravalloti, PhD

"Spinal cord injury research typically focuses on mobility impairments," explains Trevor Dyson-Hudson, MD, director of the Foundation's Center for Spinal Cord Injury Research and co-director of the Northern New Jersey SCI Model System, "but it's critically important to address these less obvious barriers to recovery so individuals can achieve maximal independence."

Thanks to your support, Kessler Foundation has exceptional strengths in researching ways to treat both cognitive and physical disabilities. Tools developed by Kessler Foundation scientists to treat learning and memory problems in people with multiple sclerosis and traumatic brain injury are now being tested in individuals with spinal cord injury like James Quesada. "We are applying what we've learned about cognitive rehabilitation to this new population," reports Nancy Chiaravalloti, PhD, director of the Centers for Neuropsychology and Neuroscience Research, and Traumatic Brain Injury Research, and director of the Northern New Jersey TBI Model System.

The rehabilitation process after spinal cord injury is learning intensive,"

Dr. Chiaravalloti explains. "Recovery depends on learning many new skills—from the basics of self-care to using wheelchairs, robotics, modified vehicles, and other assistive devices—which is why your support of this new line of research is so important."

The tools developed to treat people with multiple sclerosis and brain injury—the modified Story Memory Technique and Speed of Processing Training—are now being tested in individuals with spinal cord injury. Researchers measure participants' blood pressure, heart rate, respiratory rate, and brain blood flow. Low blood pressure, for example, is common after spinal cord injury and may contribute to cognitive problems. Medications that raise blood pressure are also being studied for their effects on learning and memory. "Finding a link between these measurements and cognitive problems will help us develop the most effective solutions for individuals with spinal cord injury," says Dr. Chiaravalloti.

Regaining their ability to learn and remember will have long-term effects," Dr. Chiaravalloti notes. "Improving these skills will improve their abilities to pursue opportunities for education and employment, and participate fully at home and in the community."

## IMPROVING HIS LEARNING AND MEMORY, JAMES ACHIEVES GREATER INDEPENDENCE

James Quesada sustained a high-level spinal cord injury five years ago in a motor vehicle accident and underwent rehabilitation at Kessler Institute for Rehabilitation. Through his participation in cognitive research at Kessler Foundation, made possible by your support, he learned he had memory difficulties and was selected to test the modified Story Memory Technique, a memory training treatment shown to improve memory in people with multiple sclerosis and traumatic brain injury.

The challenges of the training appealed to James. "It's just as important to train your brain as it is to train your muscles," he asserts. James likened the training to brain games that, with repetition over the weeks of the study, improved his ability to remember. "Learning the technique has definitely been helpful," he emphasizes. "I learned to group things I need to remember to make it easier to recall them later."



A.M. Barrett, MD (left) and stroke survivor Kevin Mullins (right)

## YOUR SUPPORT IMPROVES OUTLOOK FOR STROKE SURVIVORS

Every year, more than 650,000 Americans face the challenges of recovering from stroke. Many have spatial neglect, a hidden disability that complicates rehabilitation, hinders recovery, and increases the risks for injury and prolonged hospitalization.

Thanks to your generosity, Kessler Foundation's stroke rehabilitation research team, led by director A.M. Barrett, MD, focuses on finding effective ways to diagnose and treat spatial neglect. With support from The Wallerstein Foundation for Geriatric Life Improvement, the Charles and Ann Serraino Foundation, and donors like you, the team's research advances are raising the standard for rehabilitative care in the U.S. and other countries—improving the outlook for stroke survivors and their caregivers.

We are pleased to partner with Kessler Foundation to help stroke survivors remain active and productive members of our communities.

Joanne Serraino, president of the Serraino Foundation

More than a dozen rehabilitation facilities across the U.S. have adopted Kessler Foundation's spatial neglect assessment and treatment protocols—the Kessler Foundation Neglect Assessment Process (KF-NAP<sup>TM</sup>) and the Kessler Foundation Prism Adaptation Treatment (KF-PAT<sup>TM</sup>). "We know that people with spatial neglect like Kevin Mullins can be successfully treated using these tools," notes Dr. Barrett, "and their caregivers benefit as well. The next step is to document the impact of treating spatial neglect on their ability to function independently—at home, in their communities, and the workplace."

More than half of stroke survivors have this disabling complication, but few get the care they need. Now, with help from the Serraino Foundation, the research team is collecting and analyzing data about stroke survivors who receive spatial neglect care—whether they return home, how often they experience complications such as falls, and the costs of their rehabilitation. "By showing improved quality, reduced costs, and better outcomes, we can influence more rehabilitation facilities to consider KF-NAP<sup>TM</sup> and KF-PAT<sup>TM</sup> the standard of care for stroke survivors," Dr. Barrett emphasizes, "and convince third-party payers that reimbursement is warranted."

The Serraino Foundation is committed to funding projects that improve quality of life for seniors. "This research upholds the vision of my father, Charles, for better access to quality care," says Joanne Serraino, president of the Serraino Foundation. "We are pleased to partner with Kessler Foundation to help stroke survivors remain active and productive members of our communities."



Kevin Mullins (right) receiving the Kessler Foundation Prism Adaptation Treatment, thanks to your support.

## KEVIN ACCELERATES HIS RECOVERY WITH THE RIGHT DIAGNOSIS AND TREATMENT

When financial advisor Kevin Mullins, married and father of two, had a stroke, he experienced weakness on his left side and difficulty with balance and speech. Kevin was unaware that he also had a hidden disability called spatial neglect. During his rehabilitation at Kessler Institute. occupational therapists suspected that the stroke had affected his internal "GPS" and diagnosed this hidden disability using the Kessler Foundation Neglect Assessment Process (KF-NAP™) made possible by your support.

"People visited me, and if they were on my left, I simply didn't recognize that they were in the room. I had to be reminded they were there," Kevin recalls. "Then, I learned I had spatial neglect."

Because of you, therapists administered the Kessler Foundation Prism Adaptation Treatment (KF-PAT<sup>TM</sup>), a low-cost therapy that retrains the brain. Wearing specialized prism goggles for 10 sessions under supervision of a trained therapist helped Kevin regain awareness of his environment, improving his participation in rehabilitation and the pace of his recovery.



Tammy Quasius, who lives with MS, returned to work as a laboratory manager, thanks to your support.

# YOUR SUPPORT HELPS PEOPLE WITH MS STAY EMPLOYED

Multiple sclerosis is the leading cause of disability in middle-aged working adults. Because the disease is unpredictable and symptoms vary from person to person, many struggle to remain in the workforce and feel they have no choice but to leave.

Returning to my career is a dream come true. Kessler Foundation gave me the tools and confidence to pursue my dream and reclaim my power over the disease. Your support has changed my life and the lives of others with MS.

**Tammy Quasius** 



Lauren Strober, PhD

With your support, Kessler Foundation researcher Lauren Strober, PhD,
Senior Research Scientist, Center for
Neuropsychology and Neuroscience
Research, is exploring ways to help
people with MS, like Tammy Quasius,
stay employed, and Kessler Foundation
grantmakers are supporting programs to
help people with MS live to the fullest.

Dr. Strober identified factors contributing to unemployment in people with MS—fatigue, impairments in cognition and mobility, heat sensitivity, depression, and anxiety. She also learned that individuals with MS who continue to work face these same symptoms,

but demonstrate greater self-efficacy and coping skills that help them stay on the job.

Based on her findings, Dr. Strober is studying a wellness-based treatment she developed to address the factors that cause some to stop working. Research has shown that Dr. Strober's treatment helps people with MS stay employed by learning new coping skills, developing greater social support, and managing their symptoms better. The treatment offers strategies to reduce fatigue, anxiety, and depression, and improve processing speed and memory.

Your generosity makes this research possible and also supports important community initiatives such as the CentraState MS Wellness Program. The MS Wellness Program addresses common symptoms associated with the disease—fatigue, pain, depression, and avoidance of physical activity—in order to improve physical function, quality of life, and overall well-being for people with MS.



Tammy Quasius (center) with her family

## LIVING A FULL LIFE DESPITE MS, TAMMY RECLAIMS HER POWER

"Living with MS has its challenges, but it's brought many more blessings than curses," says Tammy Quasius, biologist, wife, and mother of two.

Tammy's symptoms began with fatigue, numbness, and trouble thinking and remembering. She suspected MS, but it took three years before she was diagnosed. Then, she worried. "How will I take care of my kids? Will I be able to work?"

Tammy set a goal of maintaining an active, healthy lifestyle. She learned about Kessler Foundation's MS research and participated in 11 studies—thanks to your support. She joined Dr. Lauren Strober's studies that were designed to build essential skills for succeeding in the workplace. "I learned new ways to organize information into lists and categories. This greatly improved my recall of names and words and my ability to complete tasks at work," Tammy notes.

Now, Tammy is back to work full time as a laboratory manager at Centenary University. "Returning to my career is a dream come true. Kessler Foundation gave me the tools and confidence to pursue my dream and reclaim my power over the disease," she asserts. "Your support has changed my life and the lives of others with MS."

## **YOUR SUPPORT CHANGES** THE LIVES **OF CHILDREN** WITH AUTISM AND ADHD

Since its opening in 2013, with support from the Rocco and Nancy Ortenzio Foundation, Select Medical, and donors like you, the research-dedicated Rocco Ortenzio Neuroimaging Center has accelerated the pace and broadened the scope of rehabilitation research at Kessler Foundation. Using the latest neuroimaging techniques, scientists have explored patterns of brain activity in adults with illnesses and injuries of the brain and spinal cord, developing new ways to restore function and improve quality of life. Now, with additional support from Children's Specialized Hospital, they are applying their knowledge to help children and adolescents with neurological disabilities.

Early, effective intervention for children with behavioral disorders will change the course of their lives. Thanks to the capabilities of the Ortenzio Neuroimaging Center, our collaboration with Children's Specialized Hospital, and the support of our donors, we are off to a solid start.

Helen Genova, PhD

"Researching behavioral disorders in children is an area of tremendous need and one where we can make a real difference" says Helen Genova, PhD, assistant director of the Center for Neuropsychology and Neuroscience Research at Kessler Foundation. "We know that children with autism or attention deficit hyperactivity disorder behave differently than their peers, but we can't explain why. Neuroimaging allows us to explore their brain activity—the first step in designing strategies to address behaviors that limit social and academic development."

## HELPING CHILDREN WITH SPECIAL NEEDS FEEL COMFORTABLE DURING MRI

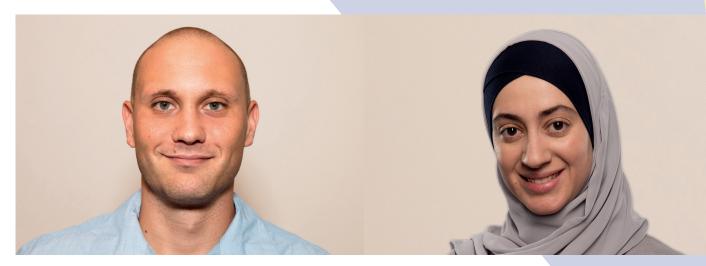
Collecting quality MRI scans is difficult in young participants with disabilities who often have trouble maintaining stillness and may feel anxious about being in the scanner. At Kessler Foundation, thanks to your support, scientists can prepare them by running a practice scan in an MRI simulator.



Helen Genova, PhD, helps a pediatric research participant in the MRI simulator.

The simulator mimics the sights,

sounds, and distractions of the actual experience. Preparing children in the MRI simulator increases the efficiency of the Ortenzio Neuroimaging Center, improves results, increases the pace of research, and minimizes stress on families, children, and research staff.



Anthony Juliano, PsyD (left) and Joman Natsheh, MD, PhD (right)

Researchers are using the specialized techniques available at the Ortenzio Neuroimaging Center, including functional MRI and structural imaging. Anthony Juliano, PsyD, a Kessler Foundation postdoctoral fellow funded by Children's Specialized Hospital, is comparing five to eight year olds with autism to their peers without autism. This pilot study is one of only a few examining this age group and is unique in its use of neuroimaging without medications or sedatives.

"Using neuroimaging to study young children is imperative," says Dr. Juliano. "Autism often becomes apparent around age two. Understanding brain activity at this early age will help us intervene before years of learning and social development are lost."

Joman Natsheh, PhD, also a Kessler Foundation postdoctoral fellow funded by Children's Specialized Hospital, is applying the capabilities of the Ortenzio Neuroimaging Center to study the behavior of six to ten year olds who take medication for attention deficit hyperactivity disorder. Children with this disorder tend to behave in habitual patterns, rather than adjust their behavior situationally to achieve a goal. In Dr. Natsheh's study, children play a goal-oriented game in the MRI scanner, while scientists document their behavior and brain activity. According to Dr. Natsheh, correlating brain activity with behavior will help scientists develop interventions that encourage goal-directed behavior.

"Early, effective intervention for children with behavioral disorders will change the course of their lives. Thanks to the imaging capabilities of the Ortenzio Neuroimaging Center, our collaboration with Children's Specialized Hospital, and the support of our donors, we are off to a solid start," says Dr. Genova.

# YOUR SUPPORT MAKES EMPLOYMENT POSSIBLE FOR ADOLESCENTS WITH AUTISM

Finding and maintaining employment is a challenge faced by many individuals with autism spectrum disorder, particularly adolescents. As young people with ASD transition to adulthood, they have significantly low rates of employment. In the U.S., only 55 percent of adults with autism had worked at any point during the six years after high school. In contrast, 74 percent of young adults with other types of disabilities had some work experience.



With your support, Helen Genova, PhD, is investigating the effectiveness of virtual reality job interview training in adolescents with autism.

A person with ASD may have the skills and talent to succeed in the workplace, but social dysfunction hampers the ability to get a job. Fortunately, donors like you are helping with the important first step to gaining employment—successfully navigating the job interview.

Kessler Foundation researchers are investigating whether technology can help improve job interviewing skills. In a pilot study generously supported by the Reitman Foundation, researcher Helen Genova, PhD, is exploring the feasibility of using a software program based on virtual reality to improve job interviewing skills. The software was developed by scientists at the University of Michigan with funding from Kessler Foundation and donors like you.

In the study, students practice social engagement and interviewing skills with a computer-generated interviewer who provides immediate feedback. This safe environment reduces anxiety. "We know that when teenagers with ASD practice interviewing skills, they will likely improve and do better on their next interview," explains Dr. Genova. "While they can practice with teachers or therapists, it's not always convenient, and it can be costly. The virtual reality software allows them to practice as many times as they need, at their convenience, and with low cost."

This software already has shown benefits in adults with ASD and other disabilities, resulting in improved interview skills and higher employment rates. "Our study will help us understand if this tool is effective in adolescents," notes Dr. Genova.

With early support from the Reitman Foundation and donors like you, our researchers have leveraged this pilot study to garner funding from the New Jersey Governor's Council for Medical Research and Treatment of Autism for the next phase of research. The implications are exciting, says Dr. Genova. "If this intervention is effective, and these teenagers with ASD improve interviewing skills, this intervention could potentially be implemented in high school, ultimately improving employment outcomes for people with ASD."

While they can practice with teachers or therapists, it's not always convenient, and it can be costly. The virtual reality software allows them to practice as many times as they need, at their convenience, and with low cost.

Helen Genova, PhD



Jack Fanous (far right) assists Elaine Katz (left of Jack) of Kessler Foundation with the ribbon-cutting during the opening ceremony of the Jackson Drysdale Veterans Center at the GI Go Fund in Newark, NJ.

## YOUR SUPPORT HELPS VETERAN ENTREPRENEURS GROW

Imagine the frustration of serving your country, then returning home to find that you can't get a job. This is a reality for many veterans, and the challenge is even greater for veterans with disabilities. Your support helps veterans with disabilities transition to the civilian workforce and gain meaningful employment.

Thanks to donors like you, Kessler Foundation is a sponsor of the Jackson Drysdale Veterans Center, New Jersey's first one-stop center offering assistance with employment and entrepreneurship. The Center, located in downtown Newark, provides onsite and online job training and mentoring to prepare veterans for corporate positions. Veteran entrepreneurs like Justin Constantine, Lieutenant Colonel United States Marine Corps (Ret.), can access support services at the Drysdale Center to grow an idea from concept, to start-up, to established business.

"Helping veterans with disabilities transition to the workplace is a priority," says Elaine E. Katz, MS, CCC-SLP, senior vice president of Grants and Communications at Kessler Foundation. "We were pleased to partner with Panasonic, Prudential, and Job Path to launch the Drysdale Center."

The Drysdale Center, supported by GI Go Fund, Kessler Foundation and donors like you, was years in the making, starting with a pilot program in which 30 veterans with disabilities were trained for work-at-home jobs as customer service representatives for PSE&G.

"Our pilot program grew into a state-of-the-art facility, helping many veterans and their families. This would not have happened without the support of Kessler Foundation and its donors," says Jack Fanous, executive director, GI Go Fund.



#### Justin Constantine, Lt Col USMC (Ret.)

## PAVING THE WAY FOR FELLOW VETS, JUSTIN HELPS OTHERS ACHIEVE THEIR DREAMS

Justin Constantine, Lt Col USMC (Ret.), joined the Marines as a law student and served on active duty as a Judge Advocate General military law officer. Deployed to Iraq as a reservist in 2006, he was shot in the head by a sniper and sustained serious injuries, including a traumatic brain injury.

After a long recovery, Justin practiced as an attorney in government service. He dreamed of starting a business to help other veterans gain employment and achieve their dreams. Justin was one of the first veteran entrepreneurs

to utilize the Jackson Drysdale Veterans Center incubator space. "It's my way of giving back," he says. "I want employers to understand the business case for hiring veterans—not because it's patriotic but because we bring a lot to the table." Now, Justin is a motivational speaker, author, and veteran employment expert—paving the way for his fellow vets.



## ONLY ABILITIES MATTER

## AT STROLL 'N ROLL

Last September, our 17th Annual Kessler Foundation Stroll 'N Roll set new records once again. More than 600 people of all ages and abilities gathered in Verona Park in New Jersey for this community event, raising more than \$168,000—the most ever—to advance rehabilitation research and employment for people with disabilities.

Each year, Stroll 'N Roll demonstrates that only abilities matter.



## KESSLER SOCIETY GIVING THAT CHANGES LIVES

As a Kessler Society member, you provide our scientists and grantmakers with critical resources to propel new research discoveries and fund 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.



Henry H. Kessler, MD, PhD, founder of Kessler Institute for Rehabilitation

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