

## Personal Perspective: Disability, A Road Often Traveled... But Rarely Understood

Christopher Dixon, MA

As we travel down the road of life, we often must make our way around unexpected bends, and come upon obstacles that slow us down. Living with a disability throws some serious curves into your path, and it may be difficult to avoid potholes in the road. Most people don't realize the challenges that people with disabilities face on a daily basis – physically and emotionally. I've dealt with these difficulties, and have found my way around many problems.

I grew up in a small town in northern New Jersey, a happy and intelligent child who could do whatever any of the other children did: receive good grades, play sports, and make friends. My life was what most would call a 'normal' life. Around age nine, things changed. I still got good grades and made friends, but my walking changed... a genetic condition known as DYT1 dystonia had set in. This is a type of early onset neurological condition characterized by muscle contractions and irregular tremors. The first signs are difficulties with writing or walking, as in my case. I was no longer able to keep up with everyone. Life had changed; things were different. As a friend said, I'd have to get used to my 'new normal'.

At first, social events became more difficult to attend. Life became an endless trip to doctors' offices, and

my old friends didn't really stop by as often. I was unsure when the symptoms might end—if they would ever end. Watching others do things I was once able to do was the most frustrating part, especially activities where I excelled: running, shooting baskets, and hiking. I wondered whether I would ever be able to do these things again. But lost opportunities made room for new ones; I had more time to learn, study, and explore, and so I worked at sharpening my intellectual, problem-solving, and organizing skills. And I continued my way down life's road doing my best to avoid the bumps and curves—or just deal with them.



### IN THIS ISSUE

#### 3 Ask the Expert

An Interview with Rita Steindlberger

#### 4 Special Feature

Apps for Independence

#### 6 Nurses' Corner

Skin Care Tips for the At-Home Caregiver

Meet the Staff

Justin Stanley and Caitlin Denzer-Weiler

#### 7 Researchers On the Move

Boston, Netherlands, Denver, Spain, Chicago

The biggest hurdles haven't been social limitations or medical issues, however. The greatest challenge for me and many others with disabilities is the issue of employment. In my case, I have a graduate degree in industrial and organizational psychology, and have much experience in workflow development, research analysis, and project management. Yet, I'm currently relegated to consulting part-time. As an educated, professionally qualified, willing worker, this situation makes little sense, but under-employment seems to be common in the population with disabilities.

Part of the problem is that many employers don't see people with disabilities as a viable resource. This is a mistake. More than 69% of Americans with disabilities are striving to work. According to Kessler Foundation's large national survey, they are actively seeking jobs or preparing for work by getting the education, training, and rehabilitation they need. Those who are working are looking for better jobs, or seeking more hours. These are people who are willing to go that extra mile to

(Continued on page 2)

(Continued from previous page)

get the job done; they're willing to explore the unknown and expand upon their current job parameters. Clearly, this vigorous and able population is ready to provide our society's labor needs.

We all need to work, to contribute to society, to feel that we're part of the whole. When someone is left behind and their talents are not used to the fullest, we all miss out on something very special... we don't achieve everything we could as a society. Whether your talents are in medicine, education, cooking, or psychology—we all can contribute something great and wonderful to society. Who knows? A talent that seems insignificant to you might someday change the world...or make a real difference in one person's life.

People with disabilities are talented members of our society, but many don't get the chance to show what they are capable of. Why? Very often, employers fear that employees with disabilities will cost the business more money, that they're not capable of doing the job properly, or they'll be unable to 'keep up'. But in fact, studies show that workplace accommodations

are generally minor and low cost, and many workers provide their own. Moreover, their performance in the workplace may exceed expectations. Studies show that productivity increases and turnover decreases when employers diversify their workplaces, changes that add to the bottom line.

Employees with disabilities are conscientious—showing up on time, asking for less vacation, and willing to stay late when needed. They often show more enthusiasm and engagement. They've proven to be a much needed reliable resource in a world where hiring the right person is often 'hit-or-miss'.

Although my employment struggles continue, I continue to write, and have returned to school to further my education in industrial and organizational psychology. And I recently married a very special woman who makes every day an adventure. I've decided that my disability isn't who I am, it's just one part of me—a part that has made my life difficult, but at the same time has taught me so much.

## Are you interested in participating in Traumatic Brain Injury research?



Kessler Foundation is looking for persons with TBI  
to participate in research studies in the following areas:



scan for info

- Problem Solving     Processing Speed Difficulties  
 Emotional Processing in TBI     Quality of Life (for Caregivers)

For more information, please contact:

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# ASK THE EXPERT:

## An Interview with Rita Steindlberger of the Brain Injury Alliance of New Jersey

TBI News & Views talked with Rita Steindlberger about her leadership of the Brain Injury Alliance of New Jersey (the Alliance) - the primary source of information, advocacy, and support for people with brain injury and their families in New Jersey.

### Q: Tell us a little bit about your background and what you were doing before you became president and CEO of the Alliance?

A: I started my professional career working for the City of New York as a housing policy analyst, and then moved to a non-profit that developed supportive housing and services for people who were homeless and diagnosed with serious mental illness. It was there that I became involved with a project that located housing with supports for people with traumatic brain injuries. I joined the Alliance 15 years ago as a part-time outreach specialist, moved up to oversee programs and operations, and began my current role last February.



Rita Steindlberger, MS,  
is the new president and CEO of  
the Alliance.

### Q: What motivated you to choose this career path?

A: After working in housing policy and research, I quickly realized I was more drawn to the issues of providing services and supports. I was moved and inspired by the struggles and successes of those we were working to help, and wanted to be more directly involved. Brain injury was particularly interesting to me because its effects are so varied and complex, which means that designing and delivering services is challenging and thought-provoking. In my current role, I have the privilege of meeting and interacting with many individuals with brain injury and their families, and it's this contact and collaboration that keeps me motivated to press forward with the work of the Alliance to ensure we have the best possible services and supports in place. I consider myself fortunate to work in a field I love, among so many talented professionals with the shared goal of improving the quality of life for people impacted by brain injury.

### Q: What's your vision for the Alliance?

A: I plan to cast a very wide net, ensuring that every person in the state of New Jersey who has sustained a brain injury and is in need of services and supports is aware that we're here and ready to help. This means our staff will be out in the field every day in every conceivable setting to spread the word. We envision the Alliance will rapidly adapt to the ever-evolving needs and issues that arise in the brain injury field by adjusting our services and supports in response—including our direct support services, educational offerings, and prevention initiatives. As a non-profit, funding is always an issue. We're actively planning and implementing strategies to increase our donor base and strengthen our partnerships with other organizations that support individuals with brain injury, so that we have the capacity to expand our services going forward.

### Q: How can people find more information about the Alliance and its programs, services, or resources?

A: People can call our Information and Resources Helpline at 800-669-4323, or go to our website, [www.bianj.org](http://www.bianj.org), which provides an overview of our programs and services, and has articles on and links to an expansive range of topics related to brain injury. Our staff are out in the community every day, and we're happy to respond to requests for presentations on a wide variety of topics related to brain injury, including prevention, education, and an overview of our services and supports.

**IN THE NEWS...** Nancy Chiaravalloti, PhD, was among top experts at TEDxHerndon where she presented her popular TED talk: "Techniques to Enhance Learning and Memory". Search YouTube for Nancy D. Chiaravalloti | TEDxHerndon.

Our most popular podcast is Dr. Chiaravalloti's interview on Dan Raviv's Weekend RoundUp on CBS radio. Listen on SoundCloud by searching "Nancy Chiaravalloti, PhD, Concussions: What Parents, Athletes Should Know".



# APPS for Independence



By Pam Tamulevicius, MS, CCC-SLP  
and Kelly Hontz, MSR, CCC-SLP

Smart phones and tablets can be lifesavers for persons who have experienced a brain injury.

Given the steady advances in mobile technology and its growing use in rehabilitation, researchers are studying how to match the device to the need, by taking into consideration the size and operating system of a device, along with its accessories, such as speakers and

keyboards. Many devices have accessibility features such as adjustments to touchscreen sensitivity, low vision options, and text-to-speech.

A diverse group of patients and families at Kessler Institute for Rehabilitation have successfully used these applications to continue safely practicing therapeutic techniques at home.

## Communication and Comprehension



**Audible**  
IOS devices and Android

Provides audio books (some are free) for those who may have difficulty reading.



**Heads Up**  
IOS devices and Android. \$0.99

Playing charades is an enjoyable and amusing way to facilitate language development.



**Language TherAppy**  
IOS devices and Free Lite version

Targets basic expression, comprehension, reading, and writing. Tracks progress, records data, and provides a cueing hierarchy.

## Cognition



**Calendar /Reminders**  
IOS devices and Android

Calendars, alarms, and written banners serve as reminders, aid information recall, and help track events, appointments, and holidays.



**Google Maps**  
IOS devices and Android

Provides basic search engine information and navigation to specified locations such as stores, clinics, and doctor's offices.



**ICE (In Case of Emergency)**  
IOS devices and Android—Free Lite Version

Allows for retrieval of essential medical information such as emergency contacts, medications, allergies, and past medical history.



**Spaced Retrieval Therapy**  
IOS devices, \$3.99

Builds memory and automatically adjusts the degree of difficulty according to skill level.



**Unus Tactus**  
IOS devices and Android, \$9.99

Provides easy dialing system for persons who may experience motor difficulties when using a smart phone. Contacts are transformed into a 4x4 grid with a photograph.

## Prevention



**Concussion Coach**  
IOS devices  
Free Application

Provides a portable self-assessment tool for monitoring symptoms of a concussion. Tracks progress over time and offers coping strategies.



**Fruit Ninja**  
IOS devices and Android  
Free Application

A fun and addictive way to improve the speed of fine motor movements by virtually slicing fruit with your fingers.



**Health IQ**  
IOS devices  
Free Application

Created by doctors and health experts to promote awareness; contains information on more than 300 health topics.



**Metronome**  
IOS devices and Android  
Free Application

The regular, repetitive sound of a metronome can help maintain normal cadence and sequencing while walking.

(Continued on page 5)



# Nurses' Corner: Skin Care Tips for the At-Home Caregiver

Daryl Blewett, RN, BSN, CRRN and Bonnie Tillman, RN, BSN, CRRN



Caregivers who are busy keeping track of medications, nutritional needs, and medical visits may be overlooking the basics of proper skin care. Keeping the skin intact, with no open areas, is an important task. Once skin breakdown occurs, healing can be a challenge. Knowing how to protect the skin and care for skin impairments is a priority.

The skin is the largest organ of the body and when caring for a person with a disability, considerable time and energy may be required to maintain its good health. Any changes in appearance, including redness, discoloration, rash, or abrasion, should be recognized as potential skin impairments. If not treated, the skin may blister or break, resulting in a wound with the potential for infection. Changes in the patient's functional status, decline in circulation, inadequate nutrition/hydration, incontinence, and medication side effects may contribute to the development of skin impairments. Diabetes and vascular disease are just two of the many health issues that can adversely affect wound healing.

To prevent skin impairment and enhance wound healing, patients may need help to:

- Stay hydrated – Drinking plenty of water optimizes skin health
- Bathe regularly – Bathing provides an opportunity to inspect the skin
- Keep skin clean and dry – Pay special attention to skin folds, under arms, and groin areas
- Weight shift often – At least every two hours
- Eat a healthy diet – If skin breakdown occurs, increasing protein intake will help with healing.
- Moisturize skin often – Use lotion on dry skin areas

Skin care should be a part of the caregiver's daily routine. Maintaining healthy, clean skin can decrease the risk of wounds, infections, and other problems that complicate caregiving. When questions arise about the care of a particular skin impairment, caregivers should contact the healthcare provider.

## MEET THE STAFF



Meet **Justin Stanley, BA**, research recruitment specialist at Kessler Foundation. Justin brings a broad range of patient-centered experience to his position. He worked at the Brain Injury Alliance of New Jersey (BIANJ) for seven years, first as an information and resource (I&R) specialist responsible for the Helpline, then as the I&R program coordinator. He formerly worked for the Epilepsy Foundation of New Jersey.

Justin is fascinated by how research can improve the lives of people with disabilities, particularly those recovering from stroke and traumatic brain injury. "At BIANJ, I was a cheerleader for research," Justin says. "I often guided Helpline callers to connect with clinical trials." According to Justin, participating in research can have a positive impact: "People affected by brain injury often feel a deep need to reconnect to the community, and participation in research can serve this need. They feel they're giving back, and being active and involved members of their own treatment team."

Justin has a degree in philosophy and is pursuing a masters in health psychology. His studies focus on the biological, psychological, and social factors of stress, as well as coping and caregiving after traumatic brain injury. He lives in Bound Brook with his wife and their dog, Frankie, a very friendly and enthusiastic chihuahua-dachshund mix.



Meet **Caitlin Denzer-Weiler, PT, DPT, NCS**, physical therapist and board-certified neurological clinical specialist at Kessler Institute for Rehabilitation. She has been at the Chester, NJ campus for five years.

Caitlin brings creativity to developing and administering treatment plans in the inpatient setting for patients with brain injury and stroke. She is also a faculty member in the Neurologic Physical Therapy Residency program, where she provides advanced learning opportunities for residents. Caitlin enjoys improving her own practice skills while facilitating the professional growth of others. She has aided in the development and implementation of various learning opportunities on the Chester campus, such as journal clubs, gait training labs, and department shadowing programs.

For the past two years, Caitlin has expanded her expertise through the use of animal-assisted therapy. She works with Frita, a Labrador-golden retriever mix trained as a facility dog by Canine Companions for Independence. Together they help patients improve their balance by walking on different surfaces, boost their tolerance for sitting or standing while playing fetch, and gain a greater range of motion using brushing techniques. Caitlin and Frita form a dynamic team that brings cheer to patients while motivating them to make the most of their therapy sessions.

# ON THE MOVE... Boston, Netherlands, Denver, Spain, and Chicago

## BOSTON...



Dr. Ekaterina Dobryakova



Angela Spirou

At the International Neuropsychological Society Conference in Boston, **Angela Spirou** and **Ekaterina Dobryakova, PhD**, presented their research on depression and motivation in individuals with traumatic brain injury (TBI). They found an association between high levels of depression and lower levels of overall motivation and drive—the persistent pursuit of desired goals. Their findings were further supported by functional neuroimaging data linking depressive symptomology and motivation in individuals with TBI.

**Denise Krch, PhD, Glenn Wylie, DPhil, and Nancy Chiaravalloti, PhD**, shared their TBI study showing increased vulnerability in a brain structure known as the sagittal stratum, a major system of fibers linking numerous brain regions, which is associated with performance on certain cognitive tests. This structure may be a useful biomarker for deficits in thinking and remembering in people with chronic TBI. Dr. Chiaravalloti and John DeLuca, PhD, explained their research linking neuroimaging findings with the effects of cognitive rehabilitation on brain function. Mounting evidence shows the efficacy of cognitive interventions for improving new learning and memory.



Dr. Denise Krch



Dr. Nancy Chiaravalloti



Dr. Glenn Wylie



Dr. John DeLuca

## NETHERLANDS...



Dr. Denise Krch

**Dr. Krch** and colleagues presented at the International Brain Injury Conference in the Netherlands. Their study showed academic achievement and cognitive leisure activities could make the brain more resistant to the effects of injury.

## NEW JERSEY... SPAIN... DENVER...



Dr. Anthony Lequerica

At the annual seminar of the Brain Injury Alliance of New Jersey, **Anthony Lequerica, PhD**, presented new findings on sleep disturbances that affect recovery after TBI. Dr. Lequerica

also joined colleagues from Spain, Portugal, and Latin America in Bilbao, Spain for the first ever IberoAmerican Neuropsychology Conference, where he presented a study on the Disability Rating Scale used in the rehabilitation of individuals with moderate to severe TBI. Attendees discussed cognitive rehabilitation programs that may be effective for U.S.-based Spanish-speakers who have had a TBI. At the American Psychological Association Conference in Denver, Colorado, Dr. Lequerica spoke about multicultural issues, health disparities, and the delivery of culturally competent services to individuals with TBI from diverse racial/ethnic backgrounds.

## CHICAGO...



Dr. Jeannie Lengenfelder



Dr. Yael Goverover



Chris Cagna



Angela Smith



Dr. Nancy Chiaravalloti

**Jeannie Lengenfelder, PhD, Yael Goverover, OT, PhD, Chris Cagna, Angela Smith, and Dr. Chiaravalloti** presented a poster on apathy and TBI at the American Congress of Rehabilitation Medicine in Chicago, Illinois. Of 50 individuals with TBI, 38% (19) had significant apathy that adversely affected their quality of life. This research suggests that screening for apathy after TBI could identify individuals who may benefit from an intervention incorporated into their overall treatment plan.



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