

# kite works

2022 - 2023

Volume 3

Centennial and KITE

*reimagine*

what's possible

***In this Volume:***

**Research  
Designed to Hit  
a Nerve**

**How Cardiac  
Rehab gets to  
the Heart of the  
Matter**

**The Link between  
Breathlessness  
and Brainpower**

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## Note from KITE

Our story began in the summer of 2020. The world was battling the impacts of COVID-19. The health care sector was stretched thin, clinical staff were overwhelmed by unprecedented demands on the system, and much of the world was adjusting to life in lockdown.

Meanwhile, at the KITE Research Institute our teams soldiered on, deeply entrenched in a new rebranding campaign designed to share our bold, fresh new identity with a highly distracted world. As we introduced a series of inspirational “Stories Untold” (K for Knowledge), KITE experienced a serendipitous moment when our ambitions were met head-on by the aspirations of Centennial College’s Storyworks program.

The unexpected collision of healthcare research and the arts united market sectors that can often behave like oil and water. A new approach to healthcare-based storytelling bloomed (I for Innovation) and an opportunity for the creative students (T for Talent) at Centennial was born. The outcome is a mutually beneficial partnership that is helping tell unique and inspiring stories and create awareness and hope around the world (E for Everywhere).

Reimagining What’s Possible is exactly what happened back in 2020. If traditional approaches do not work, don’t be afraid to try something different. Try new things and embark on an unmapped journey with the confidence that there is something magical at the end of the road.

On behalf of everyone at KITE, we want to send a sincere thank you to all of the Storyworks students for your contributions, commitment, bravery, and for championing the “Stories Untold” series. Your contributions are inspiring the next generation of healthcare storytellers, and along the way you have become integral members of the KITE Community. Together we are helping to share new solutions with the communities we serve.

Thank you.

# Message from the Project Managers

Lesley Fullerton & Kyle Woolsey

To reimagine is to begin anew.

The KITE Research Institute's innovative work drives progress that inspires, empowers and unifies. KITE helps people reimagine what's possible for the future.

The Centennial College Communications and Professional Writing students who created this magazine wanted to reimagine their futures as well, and it was the realization of this shared connection that inspired the **reimagine** theme of *KITEworks* magazine, volume 3.

This project taught us many lessons and offered many insights of immeasurable value. We're grateful for the boundless support throughout, without which we wouldn't have been able to learn those lessons or

capture those insights.

Everyone at KITE was generous with their time, knowledge and guidance; our instructors supported us every step of the way and our tireless peers made us proud with their efforts and enthusiasm.

The stories in volume 3 of *KITEworks* magazine illustrate just a few of the ways KITE demonstrates what's possible through collaboration and dedication. The featured scientists, top in their fields, devote their lives to improving the quality of ours. It's a privilege to tell their stories.

We imagine the future. KITE reimagines it. Together we're limitless. Thank you to everyone involved in this project who helped us bring these stories to life anew.



## KITEWorks 22/23 Contributors

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COLLEGE

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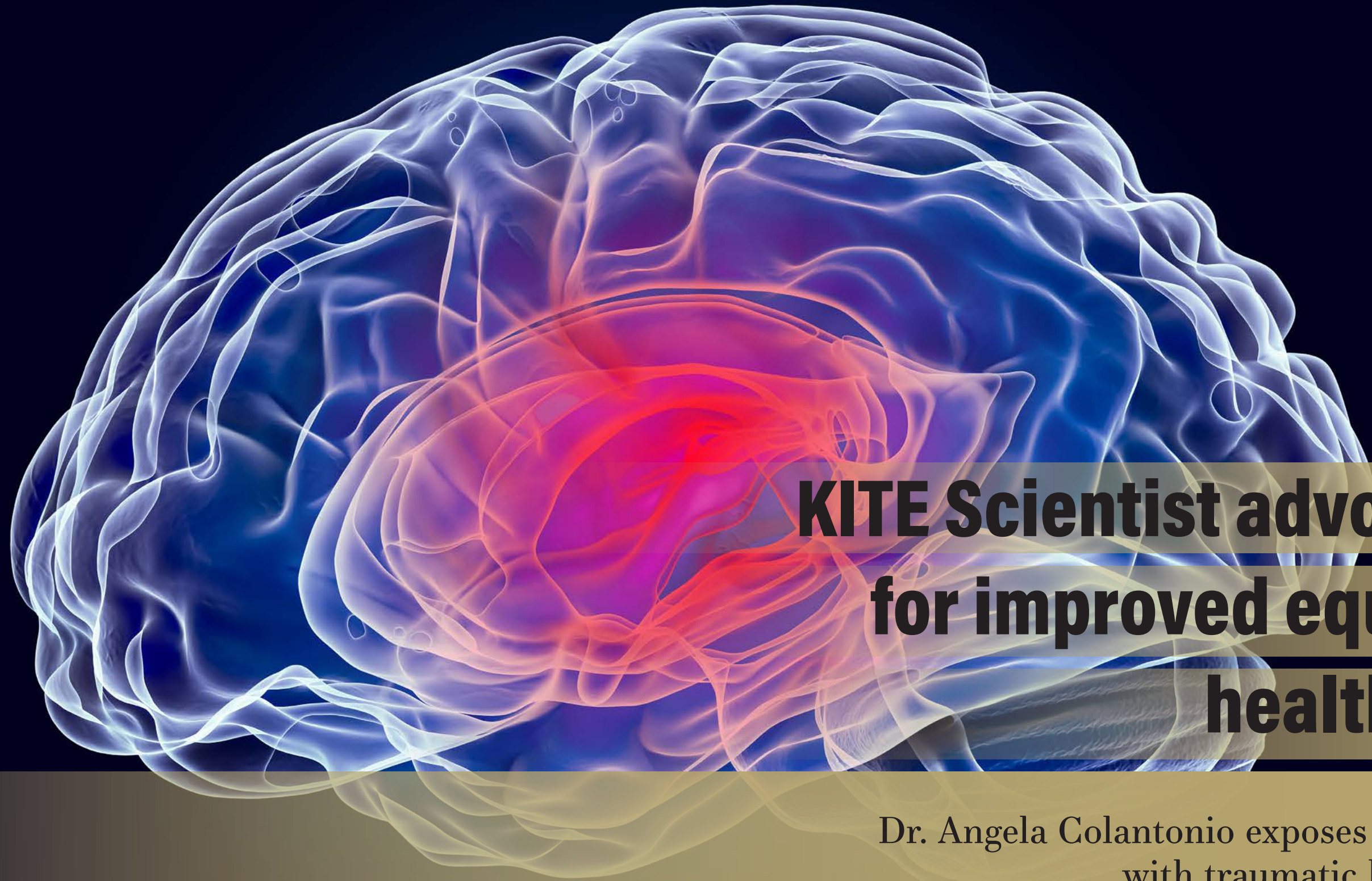
### Featured Scientists

Dr. Julio Furlan  
Dr. Sherry Grace  
Dr. Tracey Colella  
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Dr. Susan Marzolini  
Dr. Kei Masani  
Dr. Kristin Musselman  
Dr. Jose Zariffa  
Dr. Angela Colantonio  
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Rehana Yesmin

kite  UHN



# **KITE Scientist advocates for improved equity in health care**

Dr. Angela Colantonio exposes equity gaps  
with traumatic brain injury

Written by  
Tabitha Caswell

Edited by  
Kenzie Pascoe

Dr. Angela Colantonio is a researcher with ambitious goals: raise awareness of traumatic brain injury (TBI) and advocate for improved access to a high quality of care for survivors.

## What is her purpose? **Equity.**

In the early days of her career, while studying in the area of stroke, Dr. Colantonio was approached by a mentor who suggested examining links between brain injury and dementia, and she felt compelled to follow this lead.

“Regardless of this link, I found that in contrast to the enormous impact, or the potential for disability after a TBI, so little had been done in terms of looking at long-term outcomes and quality of life. And it affects people across the lifespan. I found it was a relatively unexplored area,” she says.

Dr. Colantonio became affiliated with Toronto Rehabilitation Institute in 2003 when she was awarded the Saunderson Family Chair in Acquired Brain Injury Research. Working out of the Acquired Brain Injury (ABI) Research Lab at The KITE Research Institute, Dr. Colantonio says she leads “an amazing team of scientists, clinicians, and trainees, in collaboration with fantastic stakeholders including persons with lived experience.”

In addition to her role at Toronto Rehab and KITE, Colantonio is also Director of the Rehabilitation Sciences Institute at the University of Toronto and a Professor in the Department of Occupational Science and Occupational Therapy as well as the Canada Research Chair (Tier 1) in Traumatic Brain Injury in Underserved Populations.



Earlier in her career, Dr. Colantonio and her team identified higher numbers of TBI in underserved populations, including individuals experiencing homelessness and incarceration. They also studied injuries in the workplace. Then they began to uncover a sex and gender gap. Dr. Colantonio suspected a TBI could directly impact the female reproductive system, but it was tough to find existing research related to the effects of TBI on a woman’s body. And so, it began. She and her team started collecting data through surveys, interviews, and data mining health record systems to expose this knowledge gap.

Dr. Colantonio says she and her award-winning team, along with many collaborators, have become “well-known trailblazers in the area of sex and gender considerations in brain injury.” Because of their work, we know that sex and gender can affect what happens within the context of care. And ironically, in a quest for equality, we must recognize that regardless of gender, male and female bodies are not created equal. And they are not given equal attention in the context of medical research. “For a long time, animal studies were largely done on male rodents,” she says.

It’s been argued that females should not be included in studies because their fluctuating hormones might skew the results and data. Dr. Colantonio points out that “only relatively recently have our federal agencies required researchers to address sex and gender considerations in their proposals. It’s just considered good science,” she says.

Dr. Colantonio explains that this results in a more personalized approach to rehabilitation for everyone because individual care is the best kind of care.

Dr. Colantonio agrees that awareness of TBI is on an upward trajectory with recent campaigns and media coverage about concussions in sports. She’s grateful for the attention, yet eager to expand.

“We do recognize the enormous amount of progress that’s been made in terms of brain injury and concussion awareness through sports,” she confirms. “But the general public needs to recognize that brain injuries occur in workplaces, and in underserved places as well.”

Race and other socioeconomic factors also contribute to the vast number of variables affecting the cause, severity, and outcome of a TBI. Symptoms may be ignored or dismissed by frontline workers, caregivers, and even patients. Due to this complicated web

of variables, every TBI is unique — impossible to predict, tricky to detect, and a challenge to treat.

“It’s not a one-size-fits-all approach,” says Dr. Colantonio, “We need to be aware that no two brain injuries are alike, and there are different considerations.” To address this, the team sifts through data to find patterns and isolate shortfalls — not only in our healthcare system but also relevant to our workplaces and our homes.

The ABI team brings a major focus to intimate partner violence (IPV). Victims of IPV may not report an injury for many reasons including safety, shame, or fear. And when these victims do surface in emergency rooms or at the desks of social workers, providers may not be trained to notice quiet warning signs of TBI like confusion and forgetfulness. And many are not equipped to navigate the referral process.

In their initial surveys of frontline workers, the team found that although physical injuries from IPV are commonly made to the head, face, and neck, many providers reported a lack of awareness and education to investigate the signs. Successfully catching subtle symptoms, and knowing what to do next, could make a positive and profound impact on the long-term quality of life for these people. At this intersection of IPV and TBI, victims can fall through cracks in the system.

**“We need to be aware that no two brain injuries are alike.”**

**Dr. Colantonio's team, in collaboration with many stakeholders, has mobilized to prevent this from happening. Here are some areas where they are leading the way together:**

In 2016, the team co-organized Battered and brain injured: identifying and supporting brain injured women survivors of intimate partner violence, the first workshop of its kind in Canada, bringing the world of TBI and IPV together.

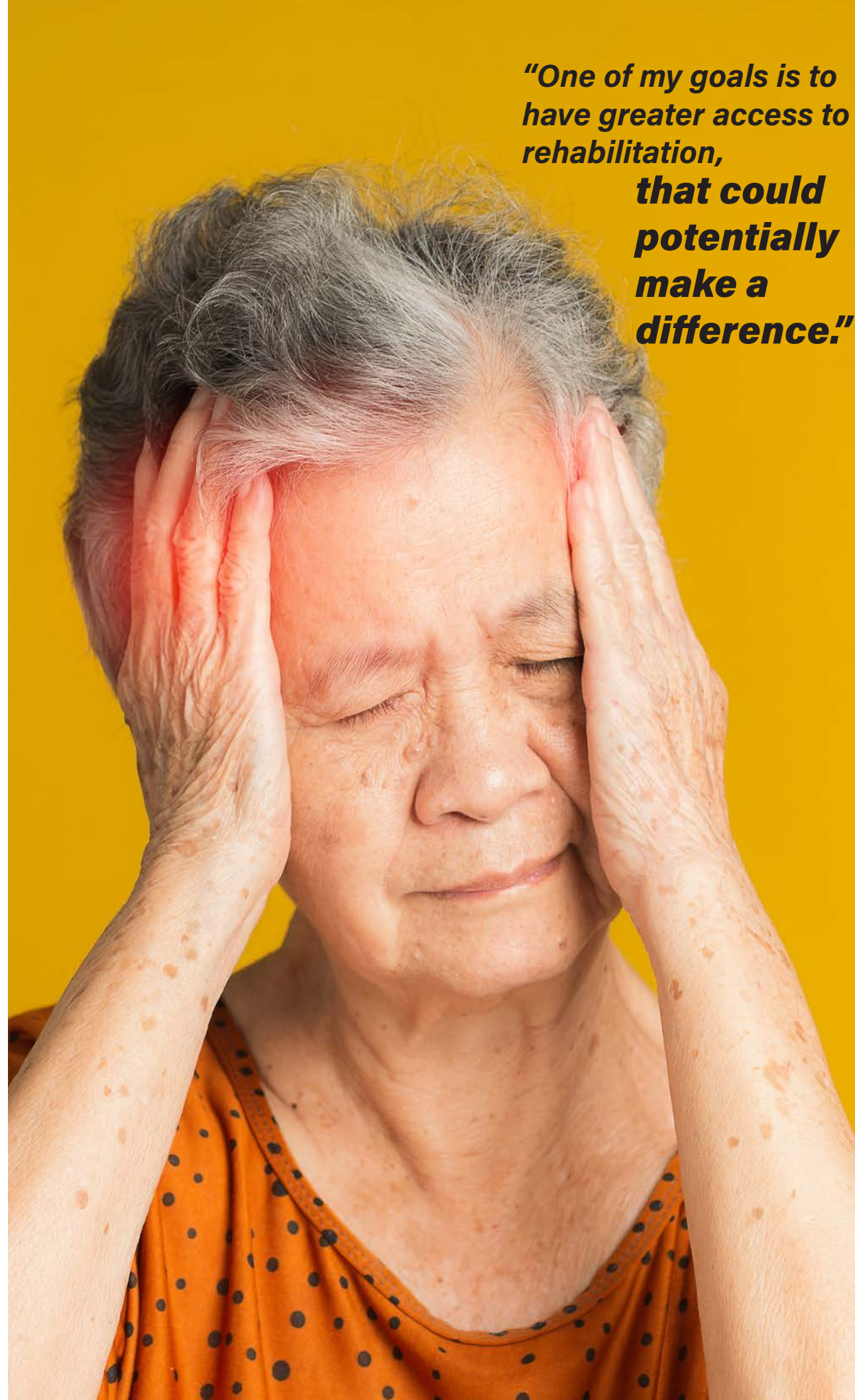
In 2019, Dr. Colantonio was invited to speak at the 80th Canadian Psychological Association National Convention in Halifax where she delivered a talk called Beyond football: intimate partner violence.

In 2022 Dr. Colantonio moderated the ACRM 2022 Chautauqua Symposium of experts, titled Intimate Partner Violence and Brain Injury: What every rehabilitation provider should know.

The team developed a toolkit called Abused & Brain Injured, Understanding the Intersection of Intimate Partner Violence and Traumatic Brain Injury, providing information and recommendations to frontline workers so they can give better trauma-informed care.

In early 2022, Dr. Colantonio and her team started the Traumatic Brain Injury: Addressing Inequities Speaker Series to increase awareness of TBI in underserved populations and as an avenue for explaining research findings. The series features talks and discussions on research, intervention, and policy updates relevant to TBI, underserved populations and inequities.

***“One of my goals is to have greater access to rehabilitation, that could potentially make a difference.”***



Future talks are announced on Twitter. Previous talks, as well as resources like the ABI toolkit, along with a collection of other accessible educational materials like videos and brochures, are available on the ABI Research Lab website. There, patients, families, and caregivers can find resources to help them on their unique journeys.


“One of my goals is to have greater access to rehabilitation, where needed, that could potentially make a difference,” says Dr. Colantonio. “Ensuring that this work could lead to more people accessing services — services that are actually helpful — would be great.”

During her time at KITE, Dr. Colantonio has witnessed many aha moments. Survivors develop awareness that their troubling symptoms may be due to a brain injury, and aren't their fault. Providers come to the realization that their patients' or clients' symptoms and behaviours were not due to personal failures or lack of motivation, but because of an underlying neurological condition. This understanding brings with it an opening for accommodation and better communication between all stakeholders involved in the care process.

Dr. Colantonio points out they are still in the infancy stage of research into TBI. With every success, there is still much more to do, more to learn, and more ways to make a difference. Yet she remains focused on her goal.

“For me, it's very validating — in particular, with sex and gender — the intense gratitude and appreciation we've received, particularly from female survivors we've met,” she says. “If survivors say it's important, then that's the most important thing to me.”

If you or someone you know has experienced a brain injury, and you're unsure where to turn, please visit [this link](#) for access to a referral network for help.

A woman's silhouette is shown in profile, looking towards the left. Behind her head is a glowing, translucent brain scan image. A vibrant green waveform, resembling a neural signal or data graph, is overlaid on the brain scan and extends across the left side of the image. The background is dark, making the glowing elements stand out.

# **KITE scientist seeks to expedite therapies for people living with neurodegenerative diseases like ALS**

Photo by Luis Carillo

Dr. Yana Yunusova envisions a clinical experience in which novel technologies

Written by  
Kyle Woolsey

Edited by  
Kenzie Pascoe



*“We used to use our listening or visual observation skill to assess an individual. Now we can use technology.”*

## KITE Research Institute Senior Scientist Dr. Yana Yunusova has a unique appreciation of time.

“What’s my research lifespan versus somebody’s actual lifespan?” she asks herself. With such a stark perspective, Dr. Yunusova is driven to spend her time wisely.

Dr. Yunusova is a KITE Research Institute Senior Scientist and a Professor at the Department of Speech-Language Pathology at the University of Toronto. She specializes in neurodegenerative disorders affecting speech such as amyotrophic lateral sclerosis (ALS).

Time is precious for us all, but for people with ALS, time is priceless. The disease rapidly breaks down functions such as walking, speaking, and eventually breathing. According to Dr. Yunusova, people with ALS have an average lifespan of a mere two to five years. When ALS affects speech first, it’s closer to two. Dr. Yunusova wants that time to count as much as it can.

ALS is a disease that disrupts nervous system connections between muscles and the brain. Dr. Yunusova explains that many people afflicted with

ALS have difficulty controlling the muscles of the face, tongue, and larynx, which are all involved in speech. Her research program is currently dedicated to developing new technology-based assessments and treatments for people with these speech disorders.

Advancements in the realm of speech-language pathology over the past 18 years have been astounding, and Dr. Yunusova’s work has been an integral part of the progress. But it’s been a slow undertaking that only hindsight can illustrate. She reflects on the process, saying “Sometimes when you start something you think it’s only going to take a short time to arrive at this point, right? And then you realize you better wear your best boots because it’s going to take a very, very long walk to get there.”

## Listening to the Past

Dr. Yunusova earned her PhD in Speech Science in 2005. Back in the early 2000s, speech-language pathology researchers were focused on gaining knowledge and understanding of how we move the tongue, lips and jaw to produce speech and how various diseases affect these movements. Dr. Yunusova’s PhD dissertation was about understanding how patients with ALS and Parkinson’s disease articulate sounds. She and her colleagues’ work built an essential foundation of knowledge. From that foundation, she says that speech-language pathology researchers collectively transitioned to developing clinical applications of that knowledge.

Dr. Yunusova says that measurements of disease progression in motor speech disorders used to be entirely subjective, which by nature isn’t very accurate. But research efforts and technological progress have led to remarkable advancements in objective measurements. Now, sophisticated software and AI algorithms can listen to and observe a person speaking to measure their speech patterns and facial movements.

“In the past, it was simply a perceptual evaluation,” Dr. Yunusova explains. “We used to use our listening or visual observation skill to assess an individual. Now we can use technology. Now we can say, ‘Ok, I’m going to listen to your speech and measure how long it takes

or pauses that you take while speaking or what kinds of errors you make in speech.’ And now references are available for these kinds of objective measures and they’re becoming more and more common practice.”

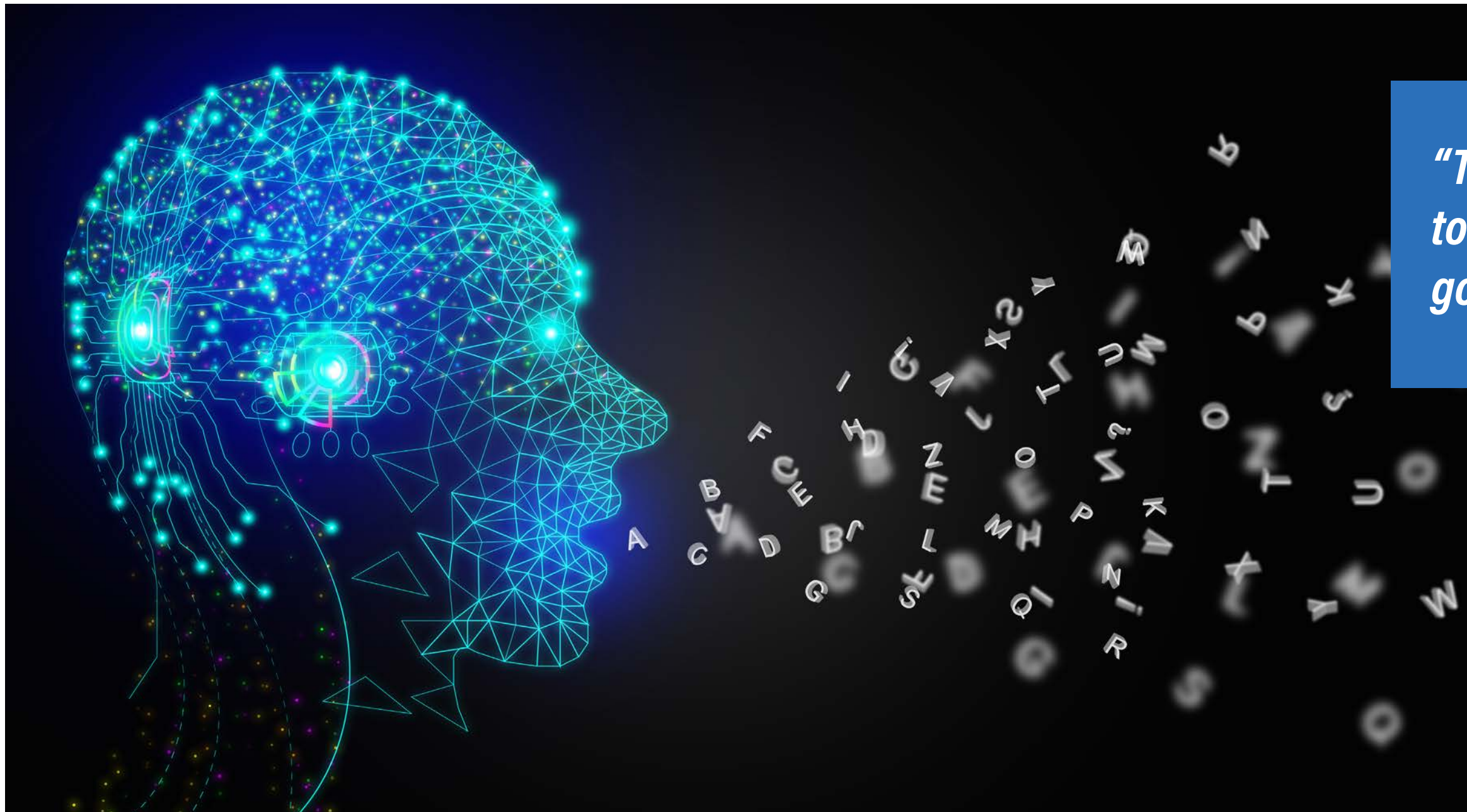
Dr. Yunusova sees incredible potential for applying new technologies to support both patients and clinicians, which she believes is her responsibility as a researcher. She wants to make the process as smooth, easy and productive as possible for people on both sides of the clinical coin.

Those with neurodegenerative diseases suffer from the slow speed of assessment and diagnosis, especially compared to the rapid speed of disease progression. When ALS affects speech first, Dr. Yunusova says it takes twelve months on average to diagnose. The devastating speed of ALS and the slowness of diagnosis is difficult to reconcile.

With the frustration of slow assessment and diagnosis, it’s a challenging process for clinicians as well. Dr. Yunusova talks about the importance of supporting them because of how difficult and exhausting clinical work is. “How we help clinicians make their lives easier is as important as how we help patients to live the best possible lives with the issues they’re experiencing,” she says.







***“Technology is the means to the goal - it is not the goal itself.”*** ←

### *Speaking to the Future*

Automating the assessment process would be a time-saving leap forward for both patients and clinicians. Dr. Yunusova believes this modernization can also create space to reimagine clinical relationships. If assessment could occur outside the clinical office, a patient could bring automated assessment results to their clinician to interpret for a diagnosis. The relationship could transform from one bogged down by assessment to one centred on action and results. Together, the patient and clinician could develop disease management strategies and focus on improving the patient’s daily functioning.

Dr. Yunusova envisions a clinical experience in which

novel technologies support communication, engagement and meaningful interactions. She sees these technologies as tools to improve the experience, saying “Technology is the means to the goal – it’s not the goal itself. It’s about how we harness the technologies to make a change in how we support clinical practice, both for clinicians and their patients.”

With Dr. Yunusova’s vision for the future, the question becomes how to make it a reality. Automating the assessment process will require well-trained artificial intelligence systems. To build those systems, machine learning algorithms require very large and widely accessible databases of objective measurements. “That’s why right now a lot of what we do is really in the

research realm,” Dr. Yunusova says. “Because we’re not quite yet at the point where a single lab could have access to databases of different speech disorders. Those databases have to be built on very similar types of tasks administered in very similar ways so that the algorithms can be well-trained.”

Once automated assessment systems are viable beyond research labs, Dr. Yunusova sees another barrier in proving their usability to clinicians. “The question is: are we ready to formulate the reasons that our technology is at such a level that clinicians would find it usable?” she asks. “Can it seamlessly interact with their existing clinical practices?”

### *Arriving on Time*

Modernizing clinical practices as Dr. Yunusova envisions is an enormous task. She explains that clinicians need compelling reasons to adopt new approaches and that demonstrating those reasons will require more years of work and collaboration with research fields focused on usability and implementation. But she believes that with the progress that has already been made, it’s not a question of if but when this modernization will occur.

During her research career, Dr. Yunusova says that speech-language pathology has gone from being overlooked by the medical field to being prominent in the conversation about the most important measures of neurodegenerative disease diagnosis and progression. The sensitivity of speech measurements is now recognized as similar to if not greater than other measures like walking or hand function. The efforts of Dr. Yunusova and her fellow researchers have put them on the map. Their next destination is in sight and only time will tell how they get there.

Reimagining the clinical experience will take dedication, patience and perseverance. But Dr. Yunusova is hopeful. “The research may not be affecting individual people yet beyond their understanding and awareness of the importance of tracking speech, but we are getting there,” she says. “We’re not quite there, but we will get there very soon, I believe.”

# How Cardiac Rehab gets to the Heart of the Matter

KITE Scientist Tracey Colella is determined to increase the reach and effectiveness of cardiac rehabilitation

Written by  
Paul Love

Edited by  
Naudya Prabudi



Like the lyrics of an angst-filled ballad, our hearts don't get enough attention in Canada, especially when it comes to recovery from a serious heart-related event. Some scientists and doctors are pushing for great change in that area, and one of its strongest advocates is KITE Research Institute scientist Dr. Tracey Colella.

Dr. Colella didn't always know she wanted to work in the realm of cardiac rehabilitation (CR), but she did know, at least as early as high school, that she wanted to be in healthcare. Her reason for focusing on the heart was personal.

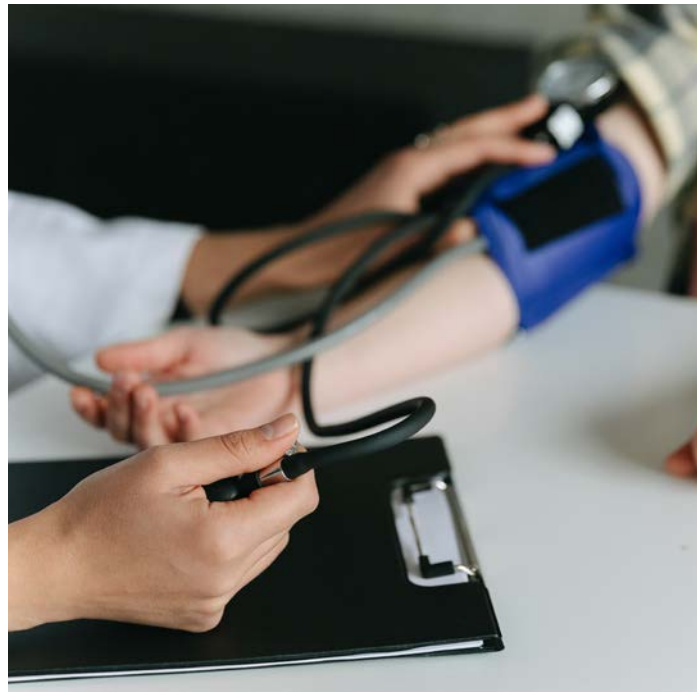
"I ended up getting into cardiovascular surgery and cardiology because my grandfather had a heart condition," she says. However, it was her time working at Sunnybrook Health Sciences Centre as a nurse practitioner that most profoundly influenced her career path.

"I ended up doing research on patient-oriented questions; patients were being discharged home within five days after having major open-heart surgery and feeling they were a bit lost to the system."

She noticed a pattern with the experiences of post-op patients and decided to do something about it.

"My colleague and I started a callback program because we had many callbacks from patients asking questions about recovery and some of the symptoms they were experiencing. Many of these questions could best be answered by other people who had been through this surgery; there's a history of research examining this idea of peer support," she says. "That's when I really became interested in the role of peer support in a patient's recovery."

Dr. Colella believes that one of the pillars of CR (and any kind of recovery for that matter) is peer support,



which is support from a person who has already lived through the experience of recovery – in this case, CR – offers informational and emotional support to that person. It is the emotional component particularly that she feels is fundamental to recovery.

"Someone like myself, a clinician or friends and family who haven't lived through this procedure or experience



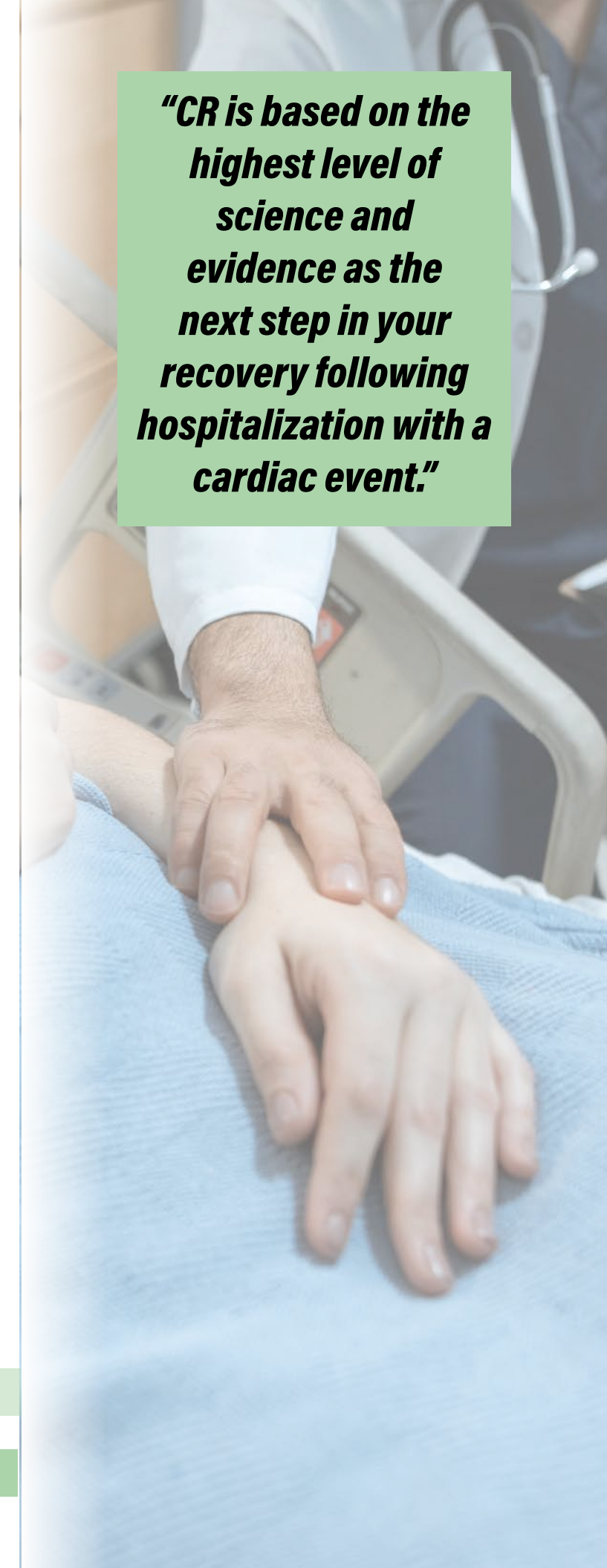
***"CR is based on the highest level of science and evidence as the next step in your recovery following hospitalization with a cardiac event."***

cannot truly understand every aspect of recovery. I can provide medical or clinical support for several issues, but when it comes to the understanding the personal experience of symptoms and the emotional challenges, it's someone who's been through this who can really help solidify that recovery and see people through to feeling better both mentally and physically."

One of the great by-products of peer support is that it often inspires the person who received the support to then become someone who offers it.

"These individuals often want to give back because someone helped them through a challenging time; this support can be cyclical and it's really inspiring." One of the main obstacles with the effectiveness of CR is the immense lack of awareness. Dr. Colella finds it frustrating that there's still some medical professionals unaware of the benefits of CR, which leads to many cardiac patients being discharged home without any idea as to what they should do to maintain recovery and prevent further cardiac issues.

"It's chronic disease self-management," she explains. "The patient needs to understand what has happened to them in order to know what they need to do to prevent a recurrence CR is not well-known, yet it has



such tremendous impacts on patients' quality of life and their future risk of disability or death."

Working with KITE, the facilities and the team at the Cardiovascular Prevention and Rehabilitation program led by Dr. Paul Oh, have been critical in Dr. Colella's research and the goal of increasing the effectiveness and reach of CR. Another key facilitator is involving patients as partners in the research team.

"We are fortunate to have a living lab in our CR program; we have patients coming in for program assessments, education, exercise, counselling and we're recruiting patients from our population, and that is so important – having patients involved in the research process helps to optimize improving the patients' journey. Thanks to KITE-UHN-Toronto Rehab we've had such strong support from that perspective."

The underrepresentation of women participating in CR is another challenge that Dr. Colella is targeting in her research. According to data from the Heart & Stroke Foundation of Canada, women are 50 per cent less likely than men to participate in cardiac rehabilitation. Dr. Colella stated that one of the main reasons is lack of referral and the misguided notion that women don't need rehab.

Another more challenging issue is how women tend to be caregivers more than men. As Dr. Colella put it, "Women tend to be . They often put others at the forefront instead of putting their own health first."

What are Dr. Colella and her colleagues doing to help ensure enrollment in CR increases for the people who need it? Filling the gap. According to Dr. Colella, the time between discharge from hospital and a CR program starting is about six to eight weeks.

To help patients navigate the void, Dr. Colella and her colleagues, including patient partners developed and are currently testing an interactive and educational application called MyCaRe, which stands for My Cardiac Recovery.

"MyCaRe is provided to patients upon discharge and are encouraged to monitor pain level, wounds, mood, heart rate, blood pressure, and patients input their information every day into this platform. They're given

***"The patient needs to understand what has happened to them in order to know what they need to do to prevent a recurrence."***

a Fitbit so we can also monitor their [physical] activity for six weeks in lead up to CR enrollment. Our team touches base with patients as needed to make sure everything is going well and if not, they can be referred back to the surgical clinic for assessment."

Feedback from patient volunteers thus far has been very good, she says.

As for the future of CR, it's all about virtual components, and taking personalization even further.

"One aspect of virtual CR research is focused on development of AI knowledge around personalizing our virtual care programs in order to optimize participation and prevent dropout. Working closely with biomedical engineers including Dr. Shehroz Khan, we're looking at how patients engage in CR, and whether we can identify when a patient becomes disengaged or at risk of program dropout. We're also developing an avatar that will facilitate exercises for patients in their homes."

Dr. Colella is on an important mission. She wants everyone to know that CR is not just an exercise program, and to understand how important it is to people who have had a heart-related event.

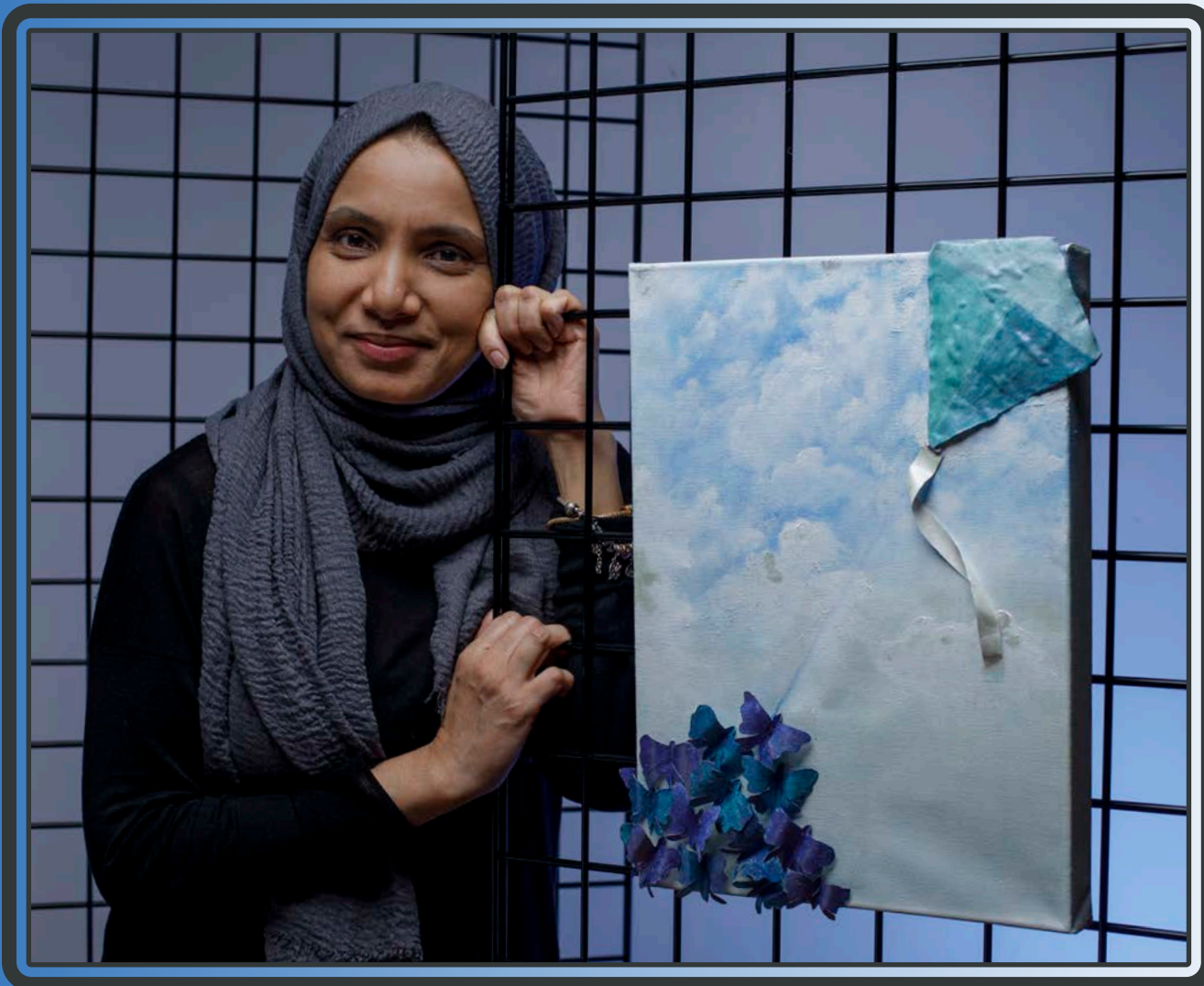
"CR is based on the highest level of science and evidence as the next step in recovery following hospitalization for a cardiac event. As natural as going to the hospital to get your procedure done, CR is key part of that next step in your continuum of care, and I honestly don't feel that this is well-publicized enough. CR makes a difference and improves life – not only quality of life but also years of life."



# HOPE

## takes flight

Written by  
Lesley Fullerton



# SPECIAL FEATURE

## *Aspiring artist Rehana Yasmin finds inspiration through KITE*

Since establishing a rewarding partnership in 2020, The KITE Research Institute and Centennial College have collaborated to tell the stories of our researchers and their exceptional work.

This year, we've broadened the way we tell these stories by including work created by a student in the Fine Arts Studio program.

Rehana Yesmin believes that art is the ultimate storyteller.

It's for this reason that Yesmin, a student in her final semester of the program, created "Hope" – a 3D artwork combining fabric, multimedia paper and acrylic elements on canvas.

"We can't share all of our feelings verbally, but we can share them through our art form. Art is a transformation of one's emotion," she says.

When Yesmin learned about KITE from one of her professors, she wanted to create something that would tell the research institute's story and share a visual

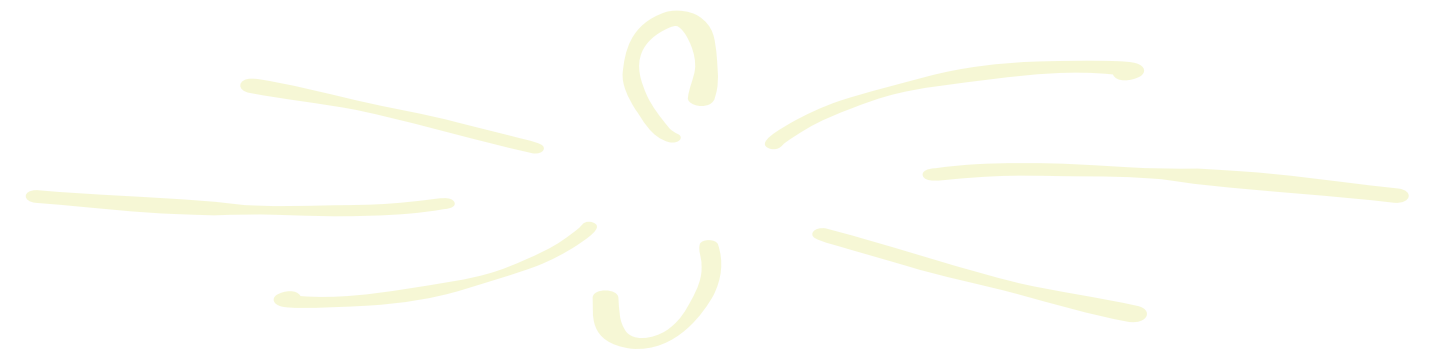
representation of the hope its scientists give to the world.

There was a time in Yesmin's life when she was confined to a wheelchair, unable to move for weeks. She required medical assistance to function in everyday life and remembers feeling helpless, which is why she can empathize with patients in need of KITE's innovations.

Yesmin believes that the world of art and the work being done at KITE have something in common – both have the power to take us places we never thought possible and help us reimagine a new way forward. "They can bring us out of the dark and into the light again," she says.

Yesmin knows from experience how important it is to move forward and upward, toward the light, and it is with this spirit that she created "Hope."

We look forward to continuing our relationship with more of these aspiring artists and exploring new opportunities for storytelling through fine arts.





# **Dr. Kei Masani: A Man of Science & Sports**

Taking a closer look into one KITE scientist's research in spinal cord injury and sports

Written by  
Maira Kabli

Edited by  
Connie Perez

## Movement. Like the stitches on a baseball, it's a thread woven through an ocean-spanning scientific and medical career.

"I'm ... a sports guy and my background belongs in physical education," says Dr. Kei Masani, a senior scientist at the KITE Research Institute and an associate professor at the University of Toronto's Institute of Biomedical Engineering specializing in research related to spinal cord injury (SCI). "In this sense, I believe I am a little unique."

Dr. Masani's current research is based in human movement from a neuromechanical perspective and focuses on developing therapeutic tools using functional electrical stimulation (FES) that can help a patient walk, stand, and perform adapted exercises with greater balance, specifically for those with SCI.

FES aids in patients' physical therapy and neuroplasticity by giving them the extra push they need, he explains. The idea is to combine multiple channels of electrical stimulation by placing electrodes on the targeted body part to create some functional movement, like reaching, grasping, walking or standing.

His work now, he says, focuses on incomplete spinal cord injury (iSCI), where a level of connection is present throughout the body but is damaged. Of those with a spinal cord injury, 80 per cent have iSCI.

In this state, standing up, moving the legs or maintaining balance is difficult, which is why patients fall a lot, he says.

"That's why in my projects, the big research goal is to improve their lower-level function by which they can improve their upright balance," Dr. Masani says. The work he's doing with FES, he says, "has a potential to increase standing balance for the iSCI population."

**"I'm thinking of ways of how my sports research can contribute to KITE!"**

### Dr. Masani's journey to KITE

Dr. Masani, a member of the American College of Sports Medicine and a baseball fan, along with colleagues at Tohoku University in Japan conducted the very first study investigating the effect of grip-enhancing agents on sliding friction between a baseball and a fingertip.

The study, published in *Communications Materials*, closely examined how the use of rosin powder and sticky substances changes the friction coefficient between a fingertip and the leather of a baseball.

These substances provide a firmer grasp of the ball, which is important in controlling the spin rate and accuracy of a pitch. The findings have the potential to significantly change how these substances are used in competitive baseball leagues.

Though baseball and sport more generally are not his specific focus now — most of his other research is focused on improving human mobility, specifically for those living with SCI — motion has been a constant in Dr. Masani's research.

"I was in the physical education field in Japan, where I was investigating the basic science of posture control, that is, how people stand up, maintain balance and walk", he explains.

Dr. Masani's research at the time examined issues with posture control — how people stand up, maintain balance and walk — among the elderly. He observed that as people got older, they would fall more, he says.

He also worked at developing methods that would help progress the movement of people at a more ordinary level of mobility to an athletic level. That research had applications elsewhere.

"I realized the same method and technique could be applicable to people that have a disability to get them to normality," he says. "So I applied the same technique of biomechanics on neurophysiology to help people with disabilities."

It was soon after receiving the Young Investigator Award from the Japanese Society of Biomechanics in the year 2000 that Masani made the trip to Canada,

where his career would take a pivotal turn that led to a new chapter in his research.

"I came to Canada (in 2003) interested in studying about functional electrical stimulation, which may be applicable for the problems in standing that the elderly people have," he says.

He stayed for a year, and that year, he says, changed his life.

"During that period, I saw lots of studies about SCI and found that my knowledge and technique could be applicable for helping people with SCI."

Today, Dr. Masani's research is an essential part of a larger project in progression, which involves the development of electrical stimulation within clothing.

### Aspiring projects for the future

Though his work on SCI and iSCI continues, an old love continues to pull at Dr. Masani.

"I'm also interested in researching injury prevention in sports, particularly baseball," he says. "I'm thinking of ways of how my sports research can contribute to KITE."

Maybe he'll turn his attention to injury prevention, rehabilitation or recovery from injury, he says.

"I think I can include this area of research as one of the next projects on my list." ♦





# **Dr. José Zariffa Research is Designed to Hit a Nerve**

*KITE scientist mines data in effort to improve  
the mobility of people living with disability*

**Written by**  
Kristen Charles-Vardon

**Edited by**  
Ranjeeta Dutta



Dr. José Zariffa strives to translate intricate data in an effort to develop solutions that can provide better treatments for people living with the effects of spinal cord injury (SCI) and strokes.

But ask Dr. Zariffa's kids about what their dad does as a rehabilitation engineer, and they might not be as fascinated. Not yet anyway.

"I don't know . . . if any kids are really impressed by their parents at that stage," he says about his 11- and 15-year-old children.

Dr. Zariffa, a Senior Scientist in the Neural Engineering and Therapeutics team at KITE and an Associate Professor at the Institute of Biomedical Engineering, University of Toronto, became attracted to biomedical engineering while completing his undergraduate degree in computer engineering.

Initially it was about "things that were cool and interesting," he says. His arrival at rehabilitation engineering happened over time, but he was able to bridge the technical skills and applications with a human element, although he claims there was no defining moment.

"You get exposed to different opportunities and different experiences and you learn about things that you didn't even know existed," he explains.

While he completed his PhD in electrical and biomedical engineering, he was "working in a rehab hospital with people with spinal cord injuries . . . that got me interested in the clinical aspects, the clinical applications," he continues. As a post-doctoral fellow, he interacted more with patients. "It was very meaningful and motivating," he recalls.

Today his research is focussed on upper limb function for those recovering after injuries to the nervous system. His team develops technologies for upper limb

***"The [neural] system is just so much more complicated and so different from anything that's man-made. That's what's so fascinating."***

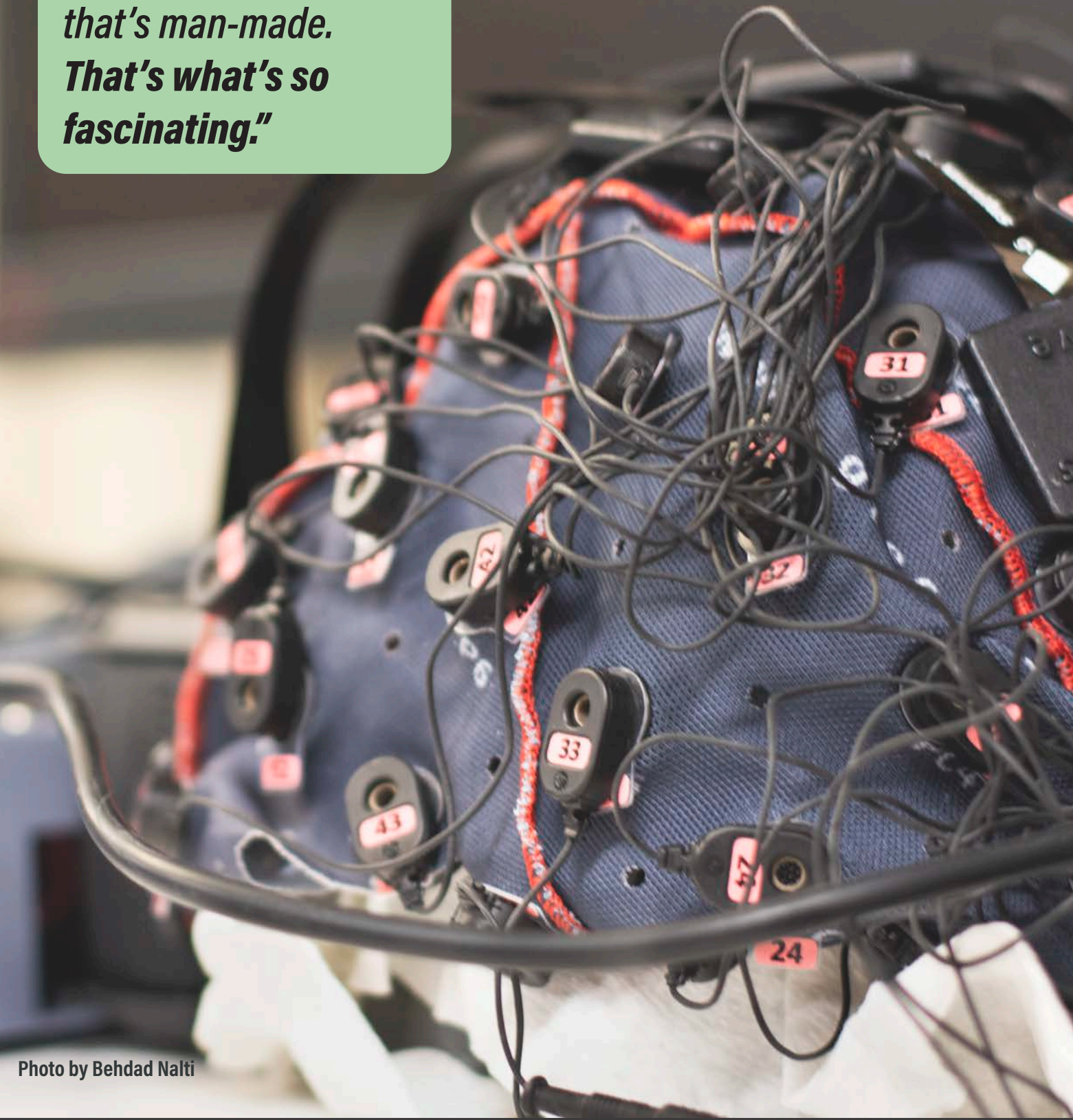


Photo by Behdad Nalti



neurorehabilitation, ranging from wearable technology for measuring hand function at home to neuroprosthetic systems for restoring function after paralysis.

"The [neural] system is just so much more complicated and so different from anything . . . that's man-made. That's what's so fascinating." He believes he's rambling, but the explanation he gives for this extraordinary and intriguing concept is vastly comprehensive. While his focus is the peripheral nervous system, the human element is entrenched in his research.

"Rehabilitation is really about getting people to go back to being able to do the things they want to do in their everyday life," he says.

Improving hand function is the primary goal for someone with a spinal cord injury. Therapists observe patients, but what they see in a controlled setting doesn't necessarily mimic what happens when patients are at home.

So, Dr. Zariffa and his team asked themselves, "How can we directly measure what's actually happening in their everyday life? And so, the goal there was to have a tool that could be used in research studies and in clinical trials to demonstrate that there was a benefit or there wasn't a benefit."

He and his team introduced wearable cameras as sensors that capture a patient's functions in their own

## ***“Rehabilitation is really about getting people to go back to being able to do the things they want to do in their everyday life.”***

environment. Taking advantage of easily accessible cameras, the team built software to analyze hand use. “We are at a point where we just finished one big study,” he explains. He and his team are still completing their assessments, but he says they have “the key findings to start moving that forward. So, if somebody wanted to use it in their research study, then we could do that now.” Dr. Zariffa and his team’s work then includes “developing partnerships with researchers who are interested in using these new tools,” he says.

He and his team believe they are a couple of years away from combining their data into a tool clinicians can use. They are interviewing clinicians and therapists to obtain their perspectives while analyzing how the information derived from the videos can be “summarized and presented to [the clinicians] to fit in their workflow and enable them to make use of it,” he says.

What clinicians and therapists acquire from this data can improve a patient’s therapy.

“We’ve built software that can be used to process the data and summarize it,” he continues. Once he and his team validate the information, Dr. Zariffa says, “Software is fairly easy to distribute and share.”

He admits it can be a bit frustrating to advance towards

a goal only to be stalled by the administrative process.

“On a systemic level, if you have an idea, you have to write a grant, wait for a decision, maybe you have to re-submit the grant,” he says. Once they receive approval and money, they must hire and train people and translate the research so it can be used by rehabilitation clinics. “That aspect can be a little bit draining on one’s patience for sure, but, you know, we try to keep moving . . . one foot in front of the other and just try to do our best to do good work and move as quickly as we can.”

Technology that can restore human movement is in our future, although Dr. Zariffa won’t commit to when this will happen.

“That’s certainly more of a long-term goal. I’m not going to give you a number. We’ve made some exciting progress.” However, Dr. Zariffa breaks down the complex into more comprehensible terms.

“We’ve had some success . . . new algorithms to decode the activity at the nerve and be able to more specifically monitor what’s happening in the nerve, like what messages are being carried in the nerve. But there are still a number of steps.”

Still, rudimentary prototypes do exist and there has

been some success.

“The elements are there,” he says.

However, the regulatory and commercialization pieces of the puzzle add a complex layer. He explains, “It’s not like the cameras. You can buy a camera and record video and that’s fine. Whereas [it’s different] if you’re talking about implanting custom circuits into the human body.”

For someone who devotes his days to deciphering complex information, he doesn’t forget the human element, and he recognizes the need to step away and disconnect. Having children has helped him establish better work-life balance. Without the break he would “lose creativity and flexibility,” he says. While he doesn’t get a lot of alone time, he relishes reading a good novel or watching an absorbing movie.

Dr. Zariffa offers a positive outlook that can be applied by anyone, including his own children one day.

“You have to be exposed to different ideas and learn as you go and understand what’s out there and follow a seam of things that you find interesting and meaningful.”





# **Clinician-scientist strives to Bridge the Gap in Spinal Cord Care**

Putting the patient first is paramount  
for Dr. Julio Furlan

Written by  
Sabrina Ramroop

Edited by  
Connie Perez



For neurologist and scientist Dr. Julio Furlan, patient needs are paramount. His patients are always front and centre.

“(Patients) bring to the table exactly what they need.” “I think it is really important for us to listen to them first,” says Furlan, who is a scientist at the KITE Research Institute, a staff neurologist at the Toronto Rehabilitation Institute, and an assistant professor at the University of Toronto.

Dr. Furlan’s research focuses on neurorehabilitation in relation to spinal cord injury (SCI), spinal cord disease (SCD), and traumatic brain injury. He studies various injuries and diseases that impact the spinal cord and examines how that affects a patient’s day-to-day life. There are plenty of gaps in the knowledge of spinal cord rehabilitation and he wants to know “what we can do to improve the medical practice for better quality of life and recovery of the patients.”



Dr. Furlan, who is originally from Sao Paolo, Brazil, has an extensive educational background, including a Doctor of Medicine, a PhD in Surgical Neuroanatomy, a Bachelor of Law, a Master’s in Business Administration, and a Master’s in Clinical Epidemiology.

One of the ways that Dr. Furlan approaches patient-focused research is by studying predictors of outcome.

“Predictors of outcome means what are the factors that can influence the results of recovery,” he says.

These factors include motor and sensory function to autonomic recovery, disability and functionality after recovery, and participation in social activities. Predictors of outcome can be broken down into two variables: non-modifiable and modifiable. These variables help identify which factors researchers can intervene with to provide aid in the recovery process.

Looking at non-modifiable variables is crucial for spinal cord recovery because it can help scientists and researchers understand how these factors impact the

***“There is a delay of diagnosis many times. So I try to increase awareness, and then try to learn more about what I can do for these patients in terms of treatment.”***

recovery process, if at all. Sometimes, this leads to uncovering other factors that can be modified.

“For example, (chronological) age has no major impact on the recovery process after spinal cord injury. And for that reason, you can actually study having more access to rehabilitation and resources for elderly patients as well as for younger patients, and that you can modify,” Dr. Furlan says.

Knowing that age has no significant impact on the recovery process can help shift the focus onto how to gain equal access to health care and rehabilitation services for elderly patients.

Another example of a modifiable variable is sleep apnea. Dr. Furlan has studied sleep apnea in patients with paraplegia (paralysis in the legs and lower body) and tetraplegia (paralysis in parts of the upper and lower body). His findings suggest that sleep apnea is common in paraplegic and tetraplegic patients.

“So imagine somebody who has a new spinal cord injury and has all these dramatic changes in their lives. They come into the rehabilitation centre, but they are (feeling) drowsy, fatigue, and they cannot participate in rehabilitation,” says Dr. Furlan.

Lack of sleep can impact a patients’ motivation to participate in their rehabilitation, he adds. Since lack of sleep can have such a huge impact on a patients’ recovery process and the time it takes to recover, patients are now screened for sleep apnea. By treating sleep apnea, patients now experience a “reduction of anxiety, fatigue, they are more alert during the day, (and) they can participate more than before.”

In addition to studying predictors of outcome, Dr. Furlan studies spinal cord diseases that often get overlooked. One spinal cord disease that he is currently studying is degenerative cervical myelopathy (DCM). DCM occurs when the spinal cord becomes compressed – a common disease that happens with aging.



A patient uses their sleep apnea mask.



Dr. Furlan is part of an international organization called RECODE-DCM, short for Research Objectives and Common Data Elements for Degenerative Cervical Myelopathy.

“I’ve been involved in an international group now to increase the awareness of this disease because...not many people actually are thought to have this problem (but it’s a) number one cause of spinal cord injury on the cervical level,” says Dr. Furlan. “There is a delay of a diagnosis many times. So I try to increase awareness, and then try to learn more about what I can do for these patients in terms of treatment.”

Not only does Dr. Furlan advocate for spreading awareness and receiving proper treatment, but he’s also interested in making treatment and rehabilitation affordable. Given his education in business administration, Dr. Furlan is curious about how to improve the accessibility and cost of rehabilitation and exploring different ways to make it more affordable.

He explains, “spinal cord injury, fortunately, is not as common as other neurological disorders...but the economic impact is very large, and for families, it’s quite

a burden.”

For this reason, he tries to identify which areas of rehabilitation are more costly and determine how to reduce those costs.

An example of this is Dr. Furlan’s analysis on the cost of rehabilitation for elderly patients. Seeing as age has no impact on a patient’s recovery, Dr. Furlan says, “I started looking into the cost and (found that)...basically the cost is not that much larger.”

“It’s less costly than maintaining (elderly patients) in acute care for prolonged periods of time than waiting for a nursing home, or somewhere else where they will not have any chance to recover.”

Approaching healthcare from a cost standpoint helps continue to remove barriers for treatment and ensure that patients are getting the treatment they need.

Dr. Furlan’s work illustrates the work being done to help remove barriers to health care, ensure that patients receive the treatment they need, and keep patient’s needs at its core.





## **KITE Scientist Seeks to Develop Stroke Rehab Solution Tailored to Women**

Dr. Susan Marzolini found that women are less likely than men to access programs despite strokes occurring at the same rate

Written by  
Lesley Fullerton

Edited by  
Connie Perez

After having a sudden stroke in early 2019, Carmen Z. worried she may never regain the strength and mobility she'd once taken for granted.

Eager to do whatever she could to help advance her recovery, Carmen, a former patient at the Toronto Rehabilitation Institute, volunteered to participate in an exercise-based stroke rehab study, led by Dr. Susan Marzolini.

Four years after her stroke, things are improving for Carmen and she's more optimistic. She credits many of the gains she's made to the exercise Dr. Marzolini prescribed during the study – programming she continues to use today.

“Physical activity has helped me obtain some control over my situation. I think programs like these are so important for both mental and physical health,” she says.

Unfortunately, Carmen is an outlier.

According to Dr. Marzolini, a clinician scientist at The KITE Research Institute, most women who have a stroke don't participate in the exercise-based rehab programming they need.

But she's determined to change that.

Dr. Marzolini, also a registered kinesiologist and former professional basketball player, has spent more than three decades working in the field of cardiovascular rehabilitation and research. Most of this time has been dedicated to examining the effects that exercise can have on the health-related outcomes of those who suffer from cardiovascular disease or have had a stroke.

Early in her career, she observed that cardiac patients weren't being prescribed strength training as part of their rehab programs - something Dr. Marzolini believed they could benefit from. She decided to test her theory and conducted studies to measure the outcomes of



cardiac patients who participated in resistance training rehab programs versus those who didn't.

The answer was clear - to really help these individuals, strength exercises needed to be part of the solution. Her findings earned her the approval to develop a successful training program that now prescribes resistance training to almost 2,000 cardiac patients each year.

At the same time, Dr. Marzolini, also a practicing clinician, started seeing more stroke patients in her caseload. Having witnessed the success of the cardiac training program, she, along with Dr. Paul Oh, Medical Director of the Cardiovascular Prevention and Rehabilitation Program at UHN, decided to develop



**“The answer was clear - to really help these individuals, strength exercises needed to be part of the solution.”**

a similar program model for stroke rehab. After modifying the cardiac program's resistance and aerobic training components, Dr. Marzolini demonstrated the effectiveness of this type of training again through her research – this time with stroke patients.

But something was missing.

“I started to notice that half as many women were taking part in the program, despite suffering strokes at the same rate as men,” Dr. Marzolini says. Knowing how patient outcomes could be transformed by programs like these, she was troubled to see so few women participating. So why is it that they're less likely than their male counterparts to get the care they need?

According to Dr. Marzolini, there's a myriad of reasons. “To begin with, women have a different recovery profile and, they're on average, six years older than men when they have a stroke, making them more vulnerable from the beginning. They tend to experience greater pain, more depressive symptoms, poorer functional recovery and often suffer chronic and overwhelming fatigue.”

There are also reasons unrelated to physical health, Dr. Marzolini explains.

“They tend to have fewer socioeconomic resources available to them, often live alone and sometimes have difficulty accessing transportation. Those who fall victim to stroke in their younger years may be saddled with dual caregiver responsibilities - looking after both their children and aging parents. All these factors can

make participating in a rehab program more difficult.”

However, Dr. Marzolini believes she and her colleagues can work around many of these barriers by borrowing new findings from the field of cardiovascular rehab and recovery.

In November 2022, Dr. Marzolini and an international committee of seven other female experts in the field of cardiovascular health, published *Women-Focused Cardiovascular Rehabilitation: An International Council of Cardiovascular Prevention and Rehabilitation Clinical Practice Guideline*.

“As a group of women, we put our heads together with a common goal of finding ways for other women to get the benefits of cardiac rehab. We each had a role to play and were supportive of one another throughout the process. It was an incredible collaboration to be part of,” says Dr. Marzolini.

Under the leadership of Dr. Sherry Grace, a fellow KITE researcher, and expert in the field, the team worked together to create the guideline that instructs clinicians on how to best care for female cardiac patients and deliver women-focused programming. Its 15 recommendations include best practices for referring female patients to rehab and emphasize the importance of identifying how, and in what settings, programs can be delivered to help women feel more comfortable participating.

Included in these recommendations was the first

guideline for women with a stroke diagnosis participating in cardiovascular rehabilitation. Dr. Marzolini points out that we will be able to build on that guideline, but we need to know more about women's stroke recovery.

Unfortunately, it's an area that's been understudied, because, as with rehab programs, participation by women in stroke research is minimal. According to Dr. Marzolini, women have been shown to represent as little as 17 per cent of participants in some clinical trials, which makes identifying stroke-specific rehab recommendations difficult.

"Right now, some study results aren't generalizable because we don't have equal participation from women. We can't tailor solutions to them without knowing what will be most effective," she says.

But a new research study, *EMPOW-HER*, is seeking to solve that problem. Spearheaded by fellow KITE researcher and Toronto Rehab Medical Director Dr. Mark Bayley, the study will be led by Dr. Marzolini and her colleague, Dr. Shannon MacDonald.

*EMPOW-HER* is hoping to uncover what prevents women from getting involved in stroke research and what can be done to increase their participation. If the project is successful, it will teach researchers like Dr. Marzolini how to recruit more women for their studies and will



***“Women have been shown to represent as little as 17 percent of participants in some clinical trials.”***

bring them one step closer to providing rehab tailored to them.

According to Dr. Marzolini, work of this kind is encouraged at KITE, and the institute's director, Dr. Milos R. Popovic, has created a welcoming environment for sex and gender research. "He's so supportive of our work and women-led research in general," she says.

When asked what she would like to see come from her stroke research work one day, Dr. Marzolini was quick to answer.

"There are three things. First, I'd like to see modifications made to stroke rehab programs so that anyone who

needs exercise and secondary prevention treatment can receive it, regardless of mobility deficits. Right now, 35 per cent of cardiac rehab centres won't accept stroke patients because of their limitations and these individuals are left without options. There needs to be more funding and training so effective programs are in place to support them.

"Second, I hope there's greater awareness of sex and gender differences when it comes to treating stroke patients so they can get the care that accommodates their specific needs.


"And finally, I hope to see equal representation of men and women in stroke-related research studies, so we can continue to improve our rehab programs."

But seeing meaningful results from her work may take years, so staying motivated in the present is important. So, what gives her the greatest satisfaction in her day-to-day work?

"It's seeing how exercise affects people post-stroke. Just a little change can make a huge difference and mean so much to these men and women. It's inspiring to see them work so hard and feel more in control of their lives."







# **Dr. Kristin Musselman helps spinal cord patients chart a new path using neuroplasticity**

KITE clinician-scientist seeks to tailor each patient's rehabilitation plan to their unique needs.

Written by  
Jacob Lasby

Edited by  
Kenzie Pascoe

**You may not realize it, but right now, you are learning.**

Every experience you have leads to the possibility of your nervous system finding new routes to send information - a process known as *neuroplasticity*.

KITE Research Institute Scientist, Dr. Kristin Musselman describes this phenomenon as “always happening, to everyone, all the time.”

As the neurological basis for how we learn, understanding neuroplasticity is essential for Dr. Musselman’s work supporting individuals living with neurological diseases and spinal cord injuries who are working to regain motor skills.

When the nervous system is damaged, as is the case for patients with spinal injuries, the pathways that our nervous system previously used to send information may be obstructed. Dr. Musselman compares this to a damaged or blocked highway.

“When this occurs, you need to look at other highways or pathways to reach your end destination,” says Dr. Musselman.

And like a blocked highway, alternate routes may be slower, while still successfully delivering information to the right place. As a new path becomes more trafficked; however, the information using it becomes more accustomed to the trip and begins to move with more confidence and efficiency.

Dr. Musselman describes these alternate pathways as “redundancies”, and they come built into our nervous system specifically for the occasion when familiar pathways are no longer viable.

It is Dr. Musselman’s job as a physiotherapist to help our nervous system find these new pathways and assist the body through external stimulation. In relearning how to send the information to its destination, clinicians can help patients move a finger and even take a step.

Working as a part of the research team at KITE in addition to being an Assistant Professor in the Department of Physical Therapy at the University of Toronto, Dr. Musselman has an extensive list of resources available to her. Instead, she prefers to take a more familiar approach to her research and therapy at Toronto Rehab’s Lyndhurst Centre.

Focussing on the rehabilitation of individuals with neurological diseases and spinal cord injuries, Dr. Musselman works to create approachable, practical methods of treatment for clinicians and patients alike.

At Lyndhurst, Canada’s largest free-standing spinal injury rehab facility, she is surrounded by a wealth of patients and well-experienced clinicians. This environment allows Dr. Musselman to draw from a wide variety of sources and viewpoints when conducting her research and lets her tailor each patient’s rehabilitation plan to their unique needs.

Considering her many duties, which include supervising PhD students, writing grant proposals, participating in clinical trials, and conducting one-on-one therapy sessions, Lyndhurst is the perfect environment for Dr. Musselman to experience something new every day.

**“You need to look at other highways or pathways to reach your end destination.”**



Relearning how to move our bodies can be arduous, but the patient gets to determine what success in this process means. Dr. Musselman's research participants are highly self-motivated, but when the work becomes too daunting, her therapy background allows her to utilize techniques to maintain determination. In the future, Musselman hopes to make volunteer participation more accessible with forward-thinking research techniques and 3D motion capture technology.

Over the last decade, strides in 3D motion capture have allowed the imaging process to become far more manageable than it previously was. What was once a task that could take up to three hours to complete and require patients with already limited mobility to squeeze into restrictive clothing and wear cumbersome trackers has become drastically more efficient with depth sensors that facilitate the data collection. This approach would allow Dr. Musselman's research team to observe more natural movement patterns.

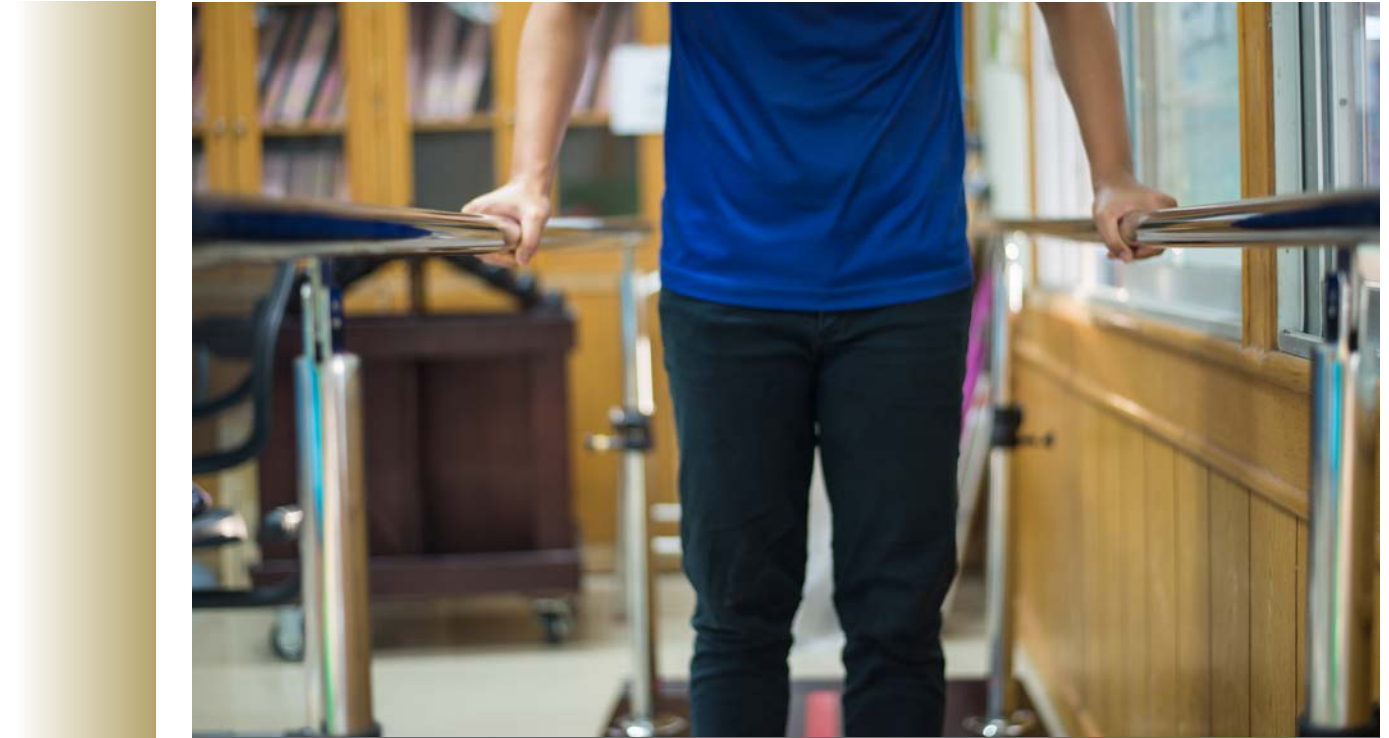
Though they have not yet acquired this technology at Lyndhurst, Dr. Musselman is very enthusiastic about the changes it would make for her research, primarily, the ease it would bring to volunteers who are currently hindered by their mobility and stamina. By trimming

down a three-hour process to one hour, patients would retain more energy and researchers could collect and analyze data from more participants.

A self-proclaimed, "person who likes new things", it is obvious as to why these technological jumps would excite the researcher. This glimpse into Dr. Musselman's inner workings also helps for further understanding into her excitement about a new project she will launch this year that will focus on the gaze of participants.

Predominantly, "the coordination between the visual input and the execution of the walking movement" for those with spinal cord injuries. The methodology will equip participants with gaze-tracking eyewear that will monitor eye movements throughout the day. This type of gaze behaviour research has not yet been conducted on populations with spinal cord injuries, and Dr. Musselman hopes that findings will allow for a greater understanding of how vision relates to balance; ultimately leading to fewer falls for injured individuals.

Currently, researchers know that vision is important to balance, but they are still investigating how our bodies use the information to maintain stability while walking. Dr. Musselman hopes that looking at the spinal cord




injured participants in this study will be "the missing piece in my understanding of how we should be approaching walking and balance rehabilitation in this population".

The study will look at injured and uninjured populations and try to determine the differences in how subjects use their gaze. Data collected from these tests will then be used to determine the likelihood of patients falling in real-world scenarios, which are difficult to recreate. Dr. Musselman also hopes the findings will provide new targets and insights into how to improve training methods for patients with spinal cord injuries who are seeking to regain mobility. Trials like these are another example of Dr. Musselman's accessible research ideology as the technology is relatively inexpensive and could be used in an everyday clinic.

In terms of next steps, Dr. Musselman is in discussion

with researchers in the Netherlands who are using depth cameras and projections to augment a subject's environment virtually. This technology is relatively inexpensive and allows researchers to track the relationship between vision and balance by studying a walker's gaze when objects appear in front of them, making participation more active and engaging.

Augmented reality movement studies also starkly contrast the often-unrealistic simulation of real-life walking that treadmills provide and create an exciting method of achieving more reliable results.

The "fun and engagement" factor is a balance that is tricky to find for therapists who still want to make relevant exercises for their patients; it is a hope of Dr. Musselman that this cheaper technology will breed more creative methods of gathering information that can be used in both clinics and research labs. 



# *Breathlessness and Brain Power:*

**KITE Scientist explores link  
between respiratory muscles  
and coordination**

Dr. Darlene Reid is helping patients with chronic respiratory conditions reimagine their lives with small improvement

Written by  
Janna Frith

Edited by  
Nadya Prabudi

Rifling a wrist shot over the goalie's shoulder.

Grabbing a cup of coffee.

Both require brain power to activate the muscles and limbs to move and coordinate. But for an individual with acute or chronic respiratory conditions experiencing breathlessness, picking up that coffee mug can use similar focus and energy as an athlete perfecting their skill.



It takes brain power to optimize physical activity ... it takes brain power for coordination.

This is something that fascinates Dr. W. Darlene Reid, a research scientist at The KITE Research Institute. With years of experience as a physical therapist, her long history of studying limb muscles led her to focus on understanding respiratory muscles and conditions, and how patients are impacted physically and cognitively.

“I see a lot of parallels between the physiology of athletes and the altered physiology of patients with chronic respiratory conditions,” she says. “When patients are doing daily activities that we take for granted, they’re actually working to maximal capacity.”

Dr. Reid says her journey into the field was a natural progression.

“I did a lot of sports in high school. In fact, what I remember most is what the gym looks like, not the library!” she says with a laugh. “When I first broke my leg, it was a physical therapist who helped me improve my function and mobility, causing me to think about the profession in a natural way.”

She went on to obtain her Bachelor of Medical Rehabilitation at the University of Manitoba, where she wrote a research paper on respiratory muscles, an

early indicator of her work to come.

“I got interested in this because, as a physical therapist, I worked with people with chronic and acute respiratory conditions in the intensive care unit, on the wards and as outpatients,” shares Dr Reid with compassion in her voice. “I saw what a difference it made for them just to be able to walk to the store and buy a newspaper. That’s why I’ve worked in this area, and that’s pretty much why I’ve stayed in this area.”

“Examining respiratory muscle performance in patients with acute and chronic disease has led me into further research into breathlessness and how it impacts the mind and body coordination,” she says.

After completing her PhD at the University of British Columbia, Dr. Reid joined its faculty as a professor in the Department of Physical Therapy. She was there until 2014 when she relocated to Ontario. She began her tenure as chair of the Department of Physical Therapy at the University of Toronto in January 2015.



***“For me, it was very important to see the connection of my research to how it might improve the life of a person with either chronic respiratory disease or acute respiratory disease.”***

“I came here because of the research,” shares Dr. Reid. “I thought it would be great, and ... it’s phenomenal. The density of research, the proximity of the health facilities, and the opportunities to network and collaborate are phenomenal.”

It’s clear that collaboration and mentoring are two things Dr. Reid feels passionate about. “I still get excited working with research trainees,” she says smiling. “Watching them think, helping them understand and pointing in a particular direction and watching them run ... that, to me, is very exciting.”

At KITE, Dr. Reid has an integrated physiology lab where she and her colleagues examine very particular aspects of the respiratory muscles and how motor control is impacted. When someone is healthy, they can be in the lab for intensive studies for hours. But with Dr. Reid’s research, her patients are far from full health, so she ensures they are in and out of the lab within an hour and a half at the most.

With the use of non-invasive tools like functional near-infrared spectroscopy (fNIRS) and electromyography (EMG), they can see a patient’s brain activity and muscle activity by assessing the changes in blood flow and metabolism when asked to do a simple task like squeeze a ball or reach up and touch their nose. This allows Dr. Reid’s team to examine the capacity of muscles in people with acute or chronic lung disorders like exacerbations of the interstitial lung disease (ILD).

“Thinking about how the brain drives muscle activity will hopefully help improve the ability for people to

do physical activities or to get weaned off mechanical ventilators earlier,” she says. “For people with considerable disability without energy to do an extra rehabilitation regimen, a small improvement, if it’s targeted in the right way, can make a huge difference in their life.”

This is what motivates Dr. Reid in her continued research and work as an integrated physiologist: Helping patients with chronic respiratory conditions reimagine their lives with small improvements. She has worked on different kinds of research but always returns to respiratory muscles.

“For me, it was very important to see the connection of my research to how it might improve the life of a person with either chronic respiratory disease or acute respiratory disease.”

Recently, Dr. Reid has been zeroing in on breathlessness, known as dyspnea, a symptom caused by lung disorders like chronic obstructive pulmonary disease (COPD) and ILD. On a mission toward understanding how it affects patients cognitively and impacts their physical coordination, she hopes her research will produce a better appreciation of breathlessness in people suffering from lung disorders. Dr. Reid says she dreams for more than just awareness, but to also find ways to reduce the distressful sensation people feel and find ways to make physical activities easier despite breathlessness.

So, what does this kind of research look like? In the lab, individuals are attached to fNIRS tools to monitor brain activity as they do simple activities like spell



words backwards or walk back and forth – things many of us take for granted and do without thinking. Dr. Reid shares that in older individuals, neural activity decreased over just a 30-metre walk, showing that they didn’t need to really think about what they were doing. It came naturally without much effort. But for patients with COPD who experience breathlessness, their neural activity plateaued while doing the same exercises, showing evidence that it takes a lot more cognitive effort to perform routine activities.

For patients, research gives credibility to the difficulties they experience and helps clinicians understand their reality. It guides rehabilitation plans to build endurance, both physically and cognitively.

“By understanding the interaction between the mind,


physical ability, and the capacity to accomplish a task,” says Dr. Reid, “patients can be encouraged to simplify or set up routines that help them manage a fuller life, maintaining a level of independence.”

At KITE, being surrounded by people who think about rehabilitation has pushed Dr. Reid to think about her research in a different way. Now she focuses on asking: How can we help patients with acute and chronic lung disease? How can we reimagine activities to help patients maintain their level of independence?

Finding answers to these questions gets her fired up.

“This work isn’t for everyone,” Dr. Reid laughs. “But for me, to do clinical research is very rewarding. I’ve been doing it a long, long time and I still want to do it.”





# **Dr. Sherry Grace is on a mission to promote accessible cardiovascular rehabilitation**

Her research aims to overcome barriers to participation

Written by  
Nadine Ford

Edited by  
Ranjeeta Dutta



Cardiovascular disease is a leading cause of death and disability. It is well established that cardiac rehab is the best way to reduce risk, but far too few patients are getting the care they need.

KITE Research Institute Senior Scientist Prof. Sherry Grace is on a mission to change this.

“Cardiac rehabilitation is a holistic chronic disease management program that saves lives,” she says. Patients who participate in cardiac rehab are also less likely to be re-hospitalized. This reduces anxiety in families, but also frees up bed space to lower hospital wait times.

“When more patients are attending cardiac rehab, fewer will have health complications, which also means more of these patients can return to work and other valued life roles sooner,” Prof. Grace says. “This means better quality of life for patients, but also more taxpayer dollars can go towards improving our healthcare system overall.”

The first step in cardiac rehab is an assessment to get an understanding of a patient’s various clinical conditions, psychosocial status, and goals. During this assessment, the doctor will also look at medical risk factor management, like cholesterol and blood pressure, she says.

Then the patients start structured exercise, which they can perform under supervision or independently at home. Also included in the program are patient education for behaviour changes, and counselling for psychosocial well-being.

These programs last about five months on average, with patients coming to the site twice a week for an hour each time.

But according to research, cardiac rehab programs are used by too few patients, and even fewer of those who are marginalized, Prof. Grace says. This gap means patients and their families suffer, and results in higher



**“Cardiac rehabilitation is a holistic chronic disease management program that saves lives.”**

health care costs for society.

Prof. Grace has dedicated her career to improving access to cardiac rehab. Since completing her PhD, she has been working at University Health Network, joining Toronto Rehab’s KITE when they merged in 2011. In addition to her role at KITE, she is also a Professor in the Faculty of Health at York University.

Prof. Grace focuses her research on overcoming barriers to cardiac rehab participation, such as increasing program capacity, ensuring patients are referred, and that programs better engage patients.

For instance, Prof. Grace co-founded an international network of cardiac rehab champions and providers. Among their many activities, they audit the availability of rehab in relation to the burden of heart disease in every country of the world. Canada does quite well when we compare ourselves globally, she says, so we can share what is working here to promote rehab in areas where it is needed most. Prof. Grace also works with the World Health Organization to support cardiac rehab implementation in all member states.

But even where there are programs, patients need to be referred by a doctor first. So, to get started, “the best recommendation is for individuals to speak with their doctors to get a referral if they can – especially with cardiovascular rehabilitation being free in Ontario,” Prof. Grace says.



Prof. Grace's research has established the benefits of automatic cardiac rehabilitation referral, which leverages electronic medical records to identify every patient who would benefit from cardiac rehab while they're still in the hospital. Prof. Grace has worked to implement automatic referral at University Health Network, other centres in Canada, and recently with the U.S. Centers for Disease Control and Prevention.

If the patient can get a referral but faces a logistical barrier to attending sessions, there are remote offerings for most cardiac rehab programs. With the remote offerings, patients speak with their coordinator for about 15 minutes a week on the phone or online, and are supported to work through the full program on their own time.

For the patients opting for remote rehab, KITE's cardiovascular rehabilitation program has developed a "Cardiac College" online program. This can also help to

reach more patients, she says.

The Cardiac College program contains exercise videos and patient education that can be done at home. To increase accessibility, it is available in 10 languages, and is available and used around the world.

Although it varies by jurisdiction, Prof. Grace showed that on average, about 25 per cent of patients enroll in cardiac rehabilitation. With automatic referral, she demonstrated this can be increased to 70 per cent — and potentially even more since COVID-19, as remote programs are more widely available now.

But there is still more that needs to be done, she says.

"Ideally, every patient with a heart issue would be automatically referred to a cardiac rehabilitation program, no matter where they live," Prof. Grace says. "And, ideally, there would be accessible space for them in these programs, with trained staff providing care tailored to the patient's individual needs."



## A Note from the Editors

Connie Perez, Nadya Prabudi, Ranjeeta Dutta & Kenzie Pascoe

Editing is a rewarding experience; it allows writers to refine their work and ensure they communicate their message effectively. While some think it's easy, the real challenge emerges during hands-on revising. There are many layers to the editing process. While writing is a free-flowing, stream-of-consciousness technique, editing refines the flow of words, sentences and the holistic structure of a piece. An extra word or a misplaced comma can change the meaning entirely. As a result, editing requires critical thinking and attention to detail.

Teaming up with KITE was an honour for us. While working on the project, we enhanced our editing, communication and leadership skills. We learned to bolster and support each other's strengths and weaknesses. The following quote from Henry Ford best represents our team's experience: "Coming together is a beginning. Keeping together is progress. Working together is success."

The project's success would not have been possible without the valued support of KITE and our classmates, who skilfully took on the roles of project managers, writers and designers. We admire our colleagues' work. Their confidence inspired us to work hard to realize their collective vision for this publication. We know how important this project was for KITE and UHN and how much this project meant to each of us personally. We're also grateful to the Storyworks faculty, Jennifer McIlroy and Phil Alves, for helping us become better writers, editors, classmates and co-workers during this career-changing opportunity.

## A Note from the Designers

Shan Gibson, Sierra Van Arragon & Joshleen Marmol

We are using the skills we learned from a previous class to make a project that isn't just an assignment; it's a collective piece of work that will be seen by many people. We may have signed up for a writing program, but we now have a complete magazine as a design element for our portfolios - we also have a better understanding of what designers need to make beautiful work.

It's been a good challenge for us to take on - we worked well as a class together and it will be exciting to share the finished product! It's been amazing to work with such talented and cooperative classmates; our project managers did a great job keeping everyone on track, the writers wrote thoughtful pieces about their subjects, and the editors ensured that everything was cohesive and professional.

We are thankful for the opportunity to work with KITE and learning more about their inspiring work. And thank you to our instructors, Phil and Jen, for leading us through this process. We hope you enjoy reading this magazine!

# The Photographers

## Joseph Marranta

Joseph Marranta is the Coordinator of Centennial's Photography program and the mentor behind the scenes for students working on the KITEworks projects. His drive to reveal the stories people and nature don't say out loud is at the heart of his craft. For the cover photograph, his goal was to capture the cycle of active curiosity that leads to something re-imagined. "It starts with human observation, and then becomes a shared question, and then becomes a social vision. If it's the right vision, the cycle is never-ending and re-imagination becomes innovation."

**Bitá Sazegara** 

**Sara Delves** 

**Behdad Nalti** 

**Joseline Antonella Tucunango Almeida** 

**Luis Carrillo** 

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**49 Storyworks students** *and counting...*

A close-up, low-angle shot of a woman's face, looking upwards and to the right. Her hair is long and light brown, blowing in the wind, creating a sense of movement and energy. The lighting is dramatic, with strong highlights on her hair and face, set against a dark, blurred background.

# ***REIMAGINE***

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