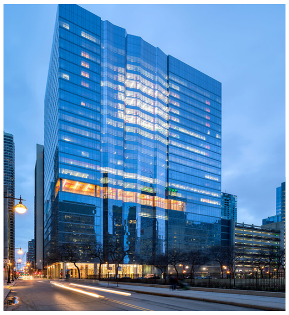
MRSCICS Matters

Summer Edition 2019


Shirley Ryan AbilityLab

Welcome to the Summer 2019 issue of MRSCICS Matters, the newsletter of the Midwest Regional Spinal Cord Injury Care System (MRSCICS) at the Shirley Ryan AbilityLab. In this issue you will read about adaptive sports, the Spinal Cord Injury Association of Illinois, risks of pressure sores, our former fellows' move to Michigan, and our new Beyond the Research video spotlight. Enjoy!

Inside

Beyond the Research: Video Series

Midwest Regional SCI Model System staff have launched a new video series that provides insights and inspiration for life after SCI. Kenneth Hill shares his story on perseverance, family, recreation, and the value of research in improving quality of life after SCI.


Kenneth Hill

View the full video here: https://www.youtube.com/watch?v=QVQxivgW9lU&feature=youtu.be

Are You Due For a National SCI Database Follow-Up Interview?

Are you approaching 1, 5, 10, 15, 20, 25, 30, 35, 40,45, or 50-year(s) since your injury? If so, you may be due for your next follow-up interview. Please contact Kayla Jones at 312-238-1624 or kjones05@sralab.org to schedule your interview. Your interview can be completed by phone, mail, or in-person.

The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) is a national leader in sponsoring research. NIDILRR is located in Washington, D.C., and is part of the Administration for Community Living at the U.S. Department of Health and Human Services.

NIDILRR
National Institute on Disability, Independent Living, and Rehabilitation Research

Adaptive Sports: Anyone Can Try

There are many lifestyle adjustments that come with the development of a spinal cord injury (SCI). One of these adjustment may be finding new and exciting activities to enjoy. Whether these activities are sedentary (sewing, drawing, reading, etc) or active/competitive such as adaptive sports, both can be highly beneficial to one's overall health. However, participating in adaptive sports goes far beyond the physical benefits they provide! For people with SCI, adaptive sports also provide the opportunity to form connections with others, learn new skills, and become a part of a community.

AWBA Players Celebrating

This was the mission of Richard Carlson when he created the American Wheelchair Bowling Association in 1962. Richard, a long time bowler wished to create a space where individuals with SCI could pursue their passion of bowling competitively while still being a part of the disability community. Since its founding, the AWBA has grown to provide 350 members with over 7 major tournaments annually throughout the country, with the National Championship being held every June. Members of AWBA have a diverse array of physical abilities and range from beginners to seasoned veteran bowlers from across the country.

We had a chance to speak with Kenneth Hill, avid wheelchair bowler and current Board of Director and Public Relations Chairman, about his experience with the association and how AWBA has changed his life for the better.

How did you become involved with the AWBA?

I began wheelchair bowling as a recreation sport to enjoy with my wife. Eventually I became more competitive and joined a local league bowling with standing bowlers. One day I came across an internet article of a wheelchair user named Walt Roy who bowled a 299 game in a tournament. I did more research on him and discovered he bowled in an organization called the American Wheelchair Bowling Association and this organization had tournaments across the country. I checked their tour schedule and went to watch a tournament in Las Vegas. And well 13 years later, I'm competing and serving on the Board of Director and Public Relations Chairman.

What has been your best experience working with the AWBA?

My experience has been nothing less than growing and learning. I have been given the privilege of serving others and sharing my experience in this sport with a population of wonderful people with diverse disabilities. I'm surrounded by people who are looking for a place to compete, meet new people, grow, and push themselves in areas they never considered possible. Working with the AWBA in Media and Public Relations put me in contact with people with greater influence in the sport of bowling and that has been personally beneficial to me.

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Adaptive Sports: Anyone Can Try

Since you've been associated with AWBA, what have been the significant benefits for AWBA members that you have witnessed?

The two main things would have to be camaraderie and personal growth. Many new wheelchair bowlers were living life alone, not able to find an avenue to meet people, participate, and belong to a community. The sport of bowling is social by nature and because of this, many new participants are excited by the community it brings into their lives, that the competitive aspect becomes secondary until they begin winning money!

AWBA 2nd Annual Midwestern Invitational team

What does this organization mean to you? To its members?

For me it means service. The ability to be able to meet and serve others. To help them to consider the possibility of participating in competitive sports. To build community in the lives of people, at the bowling alley as well as in their personal lives. So when difficult times come around, we have those who can come around to support and encourage the heart of those in need. This is the beautiful side of the AWBA, I have seen members lose health, family members, and sometimes simply hope, and as a community of bowlers we come along side to encourage, pray, or just sit with them. It's the privilege we have living our lives together around the sport of bowling.

Annual events?

We had the 2nd Annual Midwestern Invitational May 23-26 at Bowlero in Romeoville Illinois. We had bowlers from around the country competing in 3 divisions for prize money and trophies. On Friday May 24th, we had our community fundraiser where people can come out and bowl with the competition bowlers in the "Up/Down" event. All proceeds go to support the local chapter of Paralyzed Veterans of America.

For more information visit: https://awba.org/

Skin Care & Pressure Sores: Causes and Risks of Pressure

What do I need to know?

People with SCI are at high risk for pressure sores. Up to eighty percent of people with SCI will have a pressure sore in their lifetime. Thirty percent will have more than one pressure sore. Most pressure sores are preventable.

Pressure sores can be life threatening. Some possible problems are: Infections can grow and spread to the blood, heart, and bone. Prolonged bed rest needed for healing can keep you out of work, school and social activities for months.

Because you move less when healing a pressure sore, you are at higher risk for respiratory problems and urinary tract infections. Treatment can be very costly in lost wages or extra medical expenses.

What is a pressure sore?

A pressure sore (also called a pressure ulcer, decubitus ulcer, decubiti (plural), bedsore or skin breakdown) is an area of the skin or underlying tissue (muscle, bone) that is damaged due to loss of blood flow to the area. Blood flow to the skin keeps it alive and healthy. If the skin does not get blood, it will die.

Why do pressure sores happen?

Normally the nerves send messages of pain or discomfort to your brain to let you know when to move to relieve pressure, stay away from hot surfaces, or shift your weight. After injury, with little or no feeling, you have no warning signs to tell you that you have been in one position too long and that something is pressing against your skin causing it harm.

How do pressure sores happen?

Too much pressure on the skin for too long, such as sitting or lying too long in one position. The extended pressure cuts off the blood supply to the skin, leading to tissue damage, skin breakdown and a pressure sore.

Also common high-pressure situations like shearing, when the skin moves one way and the bone underneath it moves another way can cause pressure sores. This can result from slouching while sitting, sitting at a 45 angle (as in bed), or sliding during a transfer instead of lifting your body. Shearing can also happen during spasms.

Other common causes are:

- Trauma of any kind (cuts, bumps, burns, scrapes, rubbing); Abrasion or friction: Cut or scratch; Sliding across sheets or transfer board with bare skin.
- Bump or fall: Bumping toes into doorways; Bumping your buttocks off the tire during transfers; Bumping knees.

What puts me at risk of getting a pressure sore?

Being over- or underweight. When you are underweight, you have less natural padding to protect your body areas. But when you are overweight, it is harder to shift your weight and do pressure reliefs, and all that fat uses oxygen and nutrients that could be nourishing your skin. Loss of muscle mass can also effect the risk of getting a pressure sore.

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Skin Care & Pressure Sores: Causes and Risks of Pressure Cont.

Other risks include:

- Illness or poor overall health. This includes fevers, infections (such as Urinary Tract Infections), poor nutrition, and chronic diseases such as diabetes.
- Diabetes, high blood pressure and high cholesterol decrease circulation. If you have these diseases, pay particular attention to your feet and ankles.
- Blood flow to the paralyzed limbs decreases and the skin does not heal well if there is poor circulation.
- Moisture. Wet skin (from urine, stool, sweat, water) is more likely to break down.
- Aging causes skin to become thinner, dryer, and more fragile. You may need to adjust your pressure relief schedule or switch to a different type of cushion when you get older.
- Previous skin breakdown. Scar tissue is more fragile than normal skin.
- Spasticity can cause your arms or legs to bump against an object, or rub against a surface.

For more information, contact the Midwest Regional Spinal Cord Injury Care system at 312-238-2802 or eanderson@sralab.org

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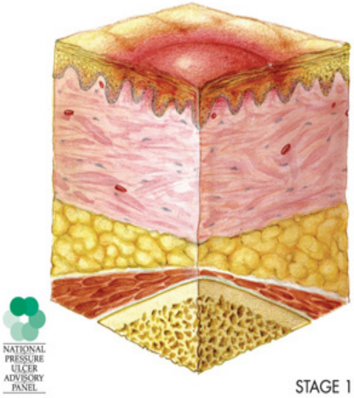
Know The Signs: Four Stages of Pressure Sores



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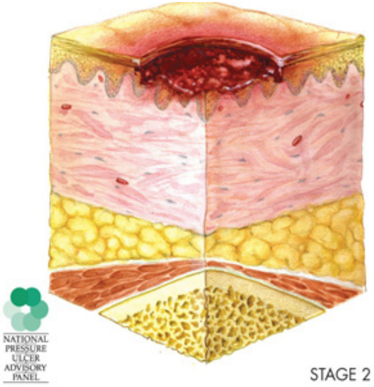

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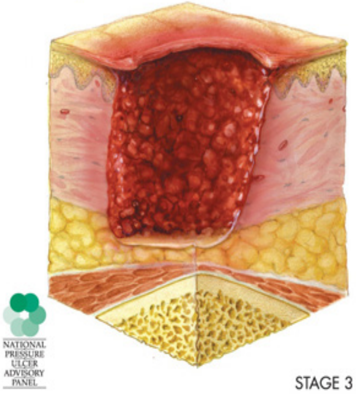

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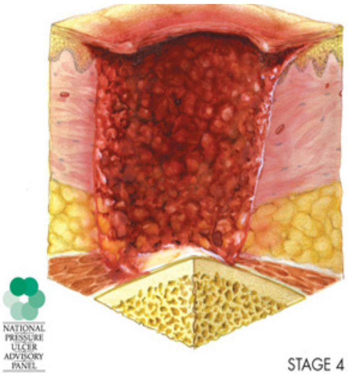

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Get Connected: Spinal Cord InjuryAssociation of Illinois

Adjusting to life after a spinal cord injury (SCI) can be difficult before leaving the hospital. Although hospitals try to prepare their patients as much as possible, there's only so much information that can be remembered during this time. The Spinal Cord Injury Association of Illinois (SCIA) is a great program to get connected with in order to stay up to date on the latest information about life with an SCI. Since its founding in 1979, the mission of the SCIA has been "to serve as a comprehensive resource center for individuals who have been personally affected by paralysis, those working in related fields, and other interested persons." This non-profit organization provides important information and support resources for people who have spinal cord injuries and their family members.

Not only does the SCIA help people with an SCI find the information they need, they are also involved in educating the community and helping people get more out of life. The SCIA runs a program called THINK FIRST with the goal to prevent brain and spinal cord injuries. For no charge, a speaker will come and teach children to think carefully about safety and how to prevent injuries. The presenters speak about their personal experience with their injury while educating them about precautionary measures. THINK FIRST is a national program, and has been well received by both teachers and students and won many awards.

Many areas of life can change after an SCI, and because of that, a large range of topics are covered on the SCIA website:
- Transportation
- Accessible rental properties
- Home modifications – such as building lifts and ramps

There are also links to organizations that explain how to find trained animal companions, flyers for community events, and where to go to get involved with the many sports and recreation activities that are available for people with SCIs. There are also places to go to learn more about topics related to living with an SCI that include:
- Bowel and bladder management
- Pain management
- Skin care
- Sexual functioning.

While many of these topics are discussed in the hospital, these resources are helpful for family members to learn more about the process of adjusting to an SCI, and they are great resources to use to see if more information is needed on each topic. You can also learn how to apply for disability benefits and keep up-to-date on legislation and policy in Illinois that involves the SCI community.

Membership is free for people with an SCI and their family members. Signing up for their newsletter is a great way to keep up with events. If you want more information please visit the SCIA website at **https://sci-illinois.org/**

Spinal
Cord
Injury
Association
of Illinois

Jessica Pruente: Former Pediatric Fellow Makes Big Move to Michigan


Jessica Pruente, MD

In 2005 Jessica Pruente was a high school student in the small town of Marquette, Michigan, who needed a summer job. She landed a challenging one--as a counselor at a summer camp for children with physical disabilities. Pruente found herself taking care of five little boys with spastic quadriplegic cerebral palsy. Despite the fact that the boys used wheelchairs to get around, they went camping, boating and fishing in between sessions of physical, occupational and speech therapy.

Pruente asked each of her campers to set a goal for the summer. One wanted to be able to make and toast s'mores without any assistance. Others wanted to improve their ability to walk. "They ended up creating social relationships that turned into life-long friendships," Pruente remembers. Her life was changed, too. Pruente decided to pursue a medical career in pediatric rehabilitation, a path that took her to Michigan State University for both college and medical school and eventually to the Shirley Ryan AbilityLab (SRALab) in Chicago for a two-year fellowship.

As Pruente, M.D., was making her rounds at the Shirley Ryan AbilityLab, she couldn't help noticing how many patients in the pediatric rehabilitation floor were children with gunshot wounds. "It was just so depressing to see these kids come in," Pruente says. "We wondered do they graduate from high school? Do they end up getting jobs and contributing to the workforce? On the rehab side, we can't necessarily prevent these injuries from happening. All we can do is help them rehab to their full potential and give them the resources and tools to reach it."

Pruente, 31, proposed a study looking at how child survivors of SCI were faring as adults, and the Craig H. Neilsen Foundation in Encino, California, agreed to fund the work. The task of identifying potential subjects was simplified because the SRALab has been tracking SCI survivors at five-year intervals as one of the nation's federally funded Spinal Cord Injury Model Systems.

While many SCI survivors had stopped responding to SRALab's follow-up surveys over the years, Pruente was able to find a pool of 44. Slightly less than half of them agreed to participate and have completed a 40-minute telephone survey about everything from their educational background to their mental health. The recruitment process is ongoing and Pruente hopes to recruit a total of 30.

So far, the news is better than Pruente expected. "Our interim analysis shows that most of the participants are enjoying really high levels of quality of life. That's really nice to see. The majority had at least a high school degree and quite a few had some college as well." Even more surprising, the group's depression and anxiety scores were close to U.S. population norms. In the areas of resilience and psychological trauma, their average scores tracked those with spinal cord injuries from other causes.

As a next step, Pruente is enrolling another group of SCI survivors who match the age, gender and degree of injuries of the gunshot survivors but who were not injured through violence. She is planning to compare outcomes between the two groups.

Pruente will be finishing her research and writing up her findings from Ann Arbor where she recently began a job as an Assistant Professor of Pediatric Rehabilitation Medicine at the University of Michigan. It's a respected program and it takes her back to Michigan where her parents still live. That was a "huge factor" in deciding to leave Chicago, she says.

Research Study for Persons with SCI

Evaluating the Utilization and Efficiency of Wearable Exoskeletons for SCI Rehabilitation

The Center for Rehabilitation Outcomes Research is conducting a study that explores opinions and experiences of persons with spinal cord injury (SCI) about the use of exoskeletons in therapy and the community.

*We are looking for veterans with exoskeleton experience.

Participants must meet the following criteria:
- Adults (18 and over)
- Must be able to speak and understand English
- Have a history of traumatic spinal cord injury at any level and severity.
- Are veterans of the United States Military

Participants in this study will:

- Attend a one-time focus group at the Shirley Ryan AbilityLab or remotely through secure video conference. The focus group will last approximately 120 minutes.

For additional information or you are interested in participating, please contact Rachel Bond at 312-238-3042 or rbond@sralab.org.

IRB Project #: STU00205146
Principal Investigator: Allen Heinemann
The Shirley Ryan AbilityLab is an academic affiliate of Northwestern University Feinberg School of Medicine.

We want to hear from you!

Interested in other SCI topics? Want to be the next "Beyond the Research: Video Series" guest? Want more information? Need to update your contact information? Want to receive this newsletter by email? Let us know. Contact Kayleigh Mann at 312-238-8256 or kmann@sralab.org

Want to get involved in research at SRALab?

Contact Emily Anderson at 312-238-1226 or eanderson@sralab.org to learn about the Center for Rehabilitation Outcomes Research's (CROR) registry. After you enroll in this registry, we will contact you about CROR's upcoming studies.

Visit https://www.sralab.org/search?content_type=clinical_trial for a list of Shirley Ryan AbilityLab's research studies and clinical trials.

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