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~ Save the Date ~

EMPOWERMENT RETREAT 2022

For Adults with Disabilities

September 16 - 18

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From The Desk Of *Roberta Kestenbaum*



Despite the continuing concerns about COVID-19 in 2022, the New Year is getting off to a great start for SBRN and our community. With the help of our volunteers, supporters and participants, we are initiating, modifying and continuing old and new programs and events. We hope you will join us in our endeavors.

Our new "**Health Conversations with Nurse Barbara**" is up and running. If you have questions about your or your family member's health and care, you can discuss your concerns one-on-one with our nurse, Barbara Dombroff, RN. This is an opportunity to prioritize your health and ask questions, discuss options and talk through your concerns.

We kicked off our new virtual series, "**Empowered Conversations: Virtual Speaker Series**" (previously the Virtual Empowerment Series – VES) in January. This program provides weekly interactive virtual one-hour workshops that explore living with disabilities in an open forum for sharing and asking questions of peers. Sessions are coordinated, facilitated and led by individuals who identify as having a disability. We are very grateful to the **Christopher and Dana Reeve Foundation** for supporting our program through a Quality of Life grant.

We are thrilled to announce our newest group: the "**Men's Virtual Chat**" for men with disabilities. This virtual peer-support group offers an opportunity to share thoughts, find resources and build community. The *Men's Virtual Chat* meet at 7:00 pm on the third Tuesday of each month. We also continue to host the longstanding "**Golden Girls**" for women with disabilities on the first Wednesday of each month, with a time change to 5:00 pm.

Save the Date! We are tentatively scheduling our annual **Empowerment Retreat** for adults with disabilities for September 16-18, 2022. More info will follow on whether the event will be virtual or a hybrid of virtual and in-person.

We are so appreciative of all the participants in our fundraising campaign with HundredX Causes. In this innovative program, participants shared their opinions on popular brands and companies and we received funds for each review. With over 900 opinions submitted, we raised over \$1,800! Thank you to all who took the time to share their thoughts.

Medical Trauma and PTSD: It's Real

If you search online for the term “Medical PTSD,” very little shows up. You may find some personal stories and a few definitions but not much information from the medical field. It has been studied a bit for cancer and heart patients but little has been done for people with chronic conditions and those who require multiple surgeries and hospital stays. Yet medical trauma does exist and many children and adults experience PTSD symptoms. Recognizing these experiences is important for healing and moving forward.



What are Medical PTSD and Medical Trauma?

Post-traumatic stress disorder (PTSD) is typically thought of as a response to specific trauma, such as abuse, natural disasters, violent crime, war and other frightening or dangerous experiences. But trauma can occur from medical settings or conditions as well. This can be in response to one-time discrete events such as a sudden illness or injury, receiving a frightening diagnosis, or having a complex surgery or procedure. It can also be the result of chronic illness, including living with scary or frustrating symptoms, continual invasive tests or procedures, difficult surgeries, bad side effects from medicines or even undiagnosed, worrying symptoms.

Medical trauma and medical PTSD (m-PTSD) are often used interchangeably, and though there is a lot of overlap, there are differences. Medical PTSD is a clinical diagnosis for certain symptoms that meet specific criteria. Medical trauma is not an official diagnosis – it’s a term that is used more broadly to refer to emotional reactions to medical illnesses, injuries and treatments. This trauma can lead to symptoms of PTSD, as well as other conditions such as depression and anxiety. Even if a person doesn’t meet the stringent criteria for PTSD, they may still be experiencing symptoms from the medical trauma. The concept of trauma is subjective so *if someone feels they have experienced trauma, then they have*, and their responses and symptoms are unique to them.



Medical trauma differs from other types in other ways as well. While other types of trauma arise from situations that you would usually want to avoid, medical treatment is generally necessary and it should be protecting patients’ health and well-being. (The hospital should be where you go to get better!) This oddity may help explain why this type of trauma is often less recognized. Medical trauma and its emotional reactions are often overlooked while healthcare providers focus on physical symptoms and healing. This is sometimes referred to as “disenfranchised trauma”, which means that the emotions are unacknowledged, and as a result, patients don’t receive any information on how to care for their reactions and feelings.

Causes and Triggers

Causes of medical trauma and m-PTSD are quite varied, ranging from living with challenging chronic issues to problematic interactions with medical professionals and difficult surgeries or procedures. Trauma can result from the actions (or inactions) of a provider or it can result from an experience or event that could not be prevented. How a person experiences and reacts to medical trauma differs for everyone and is based on factors such as the individuals' diagnoses, medical symptoms, past and current experiences and age.

Misunderstandings and lack of empathy can create trauma. Being ignored, not having your concerns validated or explained or not providing information on what to expect can lead to unwanted anxiety and symptoms of trauma. Concerns about finances, missing work and the recovery process can also be factors in experiencing trauma. Your past history can also affect the likelihood of experiencing symptoms.

A person who has experienced trauma in the past, including cumulative experiences throughout their life, is more likely to experience m-PTSD symptoms. Re-experiencing the trauma can be triggered by events such as entering a hospital or going for a procedure. It can also be triggered by little things such as scheduling an appointment or things that are not as obvious, such as bright lights or certain scents that are reminiscent of the hospital or other medical setting. Our bodies and brains remember the feelings and sensations that were experienced and later reactions can be triggered by similar sights and sounds.

Age can affect how a person interprets the event. While an adult might understand that the doctor is performing a difficult and possibly painful procedure to ultimately help, a child might not recognize that. For a child, it may be much more confusing and frightening. Subjective interpretations are important at all ages, but are particularly true for young children who don't understand the complexity of the situation.

The nature of medical trauma itself can also affect outcomes. Medical PTSD differs from other types in a few significant ways. Most types of trauma occur from external events (such as abuse, violence or surgical procedures), but m-PTSD can also stem from internal sources such as chronic illnesses or symptoms which are within the person and always there. This can be difficult because it may be important for people to remain highly aware of their physical symptoms and conditions to monitor their health, but this constant awareness can worsen m-PTSD symptoms. With chronic conditions, people can't "walk away" from their triggers. Similarly, because there often is not an endpoint to chronic conditions, it is more difficult to put the trauma "in the past" and instead much of the trauma is focused on the uncertainty of the future and how their condition will progress.



COVID-19 and Medical Trauma

The COVID-19 pandemic has increased situations that can result in trauma. Separating patients from their emotional support from friends, family or caretakers during appointments or procedures can increase the stress level, feelings of isolation and the likelihood of adverse reactions. Generalized anxiety over catching the illness also adds to the medical stress.

Signs and Symptoms of m-PTSD

Trauma responses are different for everyone, and may occur directly following the trauma or at a later time. Some common signs and symptoms of medical trauma and m-PTSD include:

- * **Re-experiencing the trauma**—This includes going over the details in your head as well as intrusive memories of the trauma. Memories may be fragmented or crystal clear and are often brought on by triggers.
- * **Avoidance** – People might avoid the people, places and things that remind them of the trauma as a way of trying to reduce anxiety; however, it may actually worsen anxiety as well as physical health. They may be more likely to avoid scheduling or going to doctors' appointments or procedures and may be more reluctant to take medications if they are reminders of their trauma.
- * **Hyperarousal** – This not only refers to intense awareness of body sensations and feelings, but can also be related to sleep problems and irritability. People may also experience physical arousal feelings such as heart-racing and sweating.
- * **Physical responses** – This could include numbness, nausea or indigestion, skin rashes, pain and other symptoms. PTSD can also make medical symptoms worse with the stress and anxiety affecting the body and its ability to heal.
- * **Behavioral/emotional changes** – Trauma can lead to self-harm, substance abuse or eating disorders or engaging in compulsive behaviors like working or exercising all the time. Some may experience panic attacks or feelings of anger or shame.



Healing

Determining how you will go about healing will depend on your own individual experiences, reactions and triggers. It's important to consider your full range of symptoms and address them both behaviorally and emotionally.

Emotional healing can take time and the process can be mentally painful at times, but talking through your feelings and thoughts with a trained therapist or with friends can make them feel less intense and more manageable.

Professional/clinical therapies: Therapists may recommend different therapies depending on your needs and their expertise, such as **cognitive processing therapy** which encourages you to challenge and modify unhelpful beliefs about your illness, or **acceptance and commitment therapy**, which uses mindfulness as a tool. Other therapies use mind-body approaches, self-talk, deep breathing, relaxation and self-care as techniques for healing.

Therapists can help you build coping strategies to help you feel less anxious and more in control. They can help you develop short- and long-term plans to get through any future medical events and cope with the aftermath. Therapists can also help you talk about your flashbacks and memories and re-frame them in a less threatening way.

Other ways to heal:

- User your allies and advocates to provide support both during and after the events that may lead to trauma. Bringing a family member or friend with you, or asking for a social worker or case manager, can lessen the potential for trauma by helping you advocate for what is best for you. If you are incapacitated, they can ensure that you get the physical and emotional care that you need.
- Attend support groups focused on self-care and stress management, particularly for those who have experienced medical trauma.
- Find your own form of stress relief, such as body movement through exercise or yoga, or self-expression through art, music or writing.

In sum, Medical Trauma and m-PTSD are real, even if they are often overlooked, and if you are experiencing symptoms that are affecting your life, you should seek help and support.



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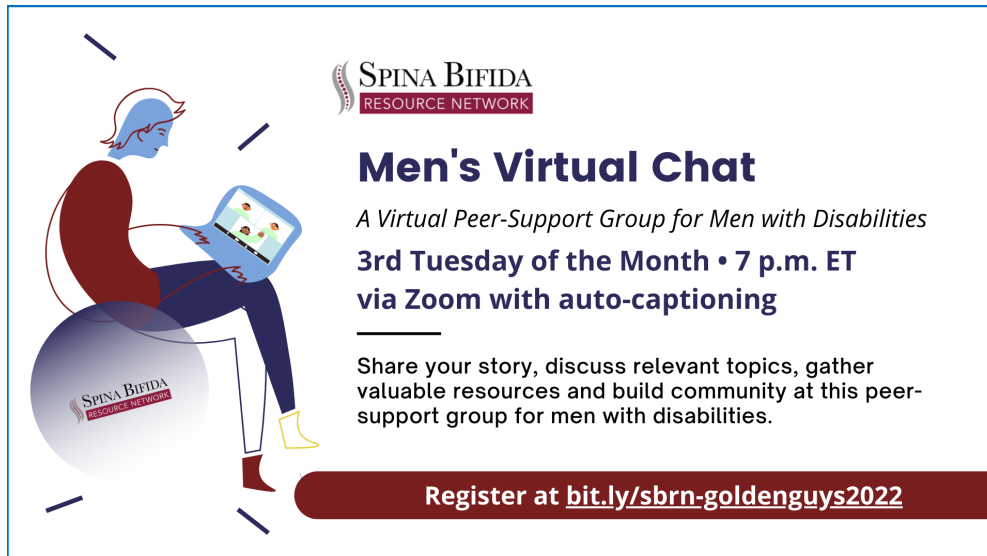
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This information is presented for the purpose of education and is not meant as a substitute for medical advice or care from a physician or other healthcare providers. Contact your healthcare provider with questions about care.

Introducing our New Virtual Group: The “Men’s Virtual Chat”

SBRN is excited to announce our new virtual peer-support group for men with disabilities. The "**Men’s Virtual Chat**" is a monthly tele-support group for men of all ages with spina bifida and other disabilities to discuss relevant topics such as social issues, relationships, medical services and anything else that's on their minds!

A graphic for the Men's Virtual Chat. On the left, a stylized illustration of a man with a blue head and red body is sitting on a large blue sphere, using a laptop. The Spina Bifida Resource Network logo is on the sphere. To the right, the text reads: "SPINA BIFIDA RESOURCE NETWORK", "Men's Virtual Chat", "A Virtual Peer-Support Group for Men with Disabilities", "3rd Tuesday of the Month • 7 p.m. ET", "via Zoom with auto-captioning", "Share your story, discuss relevant topics, gather valuable resources and build community at this peer-support group for men with disabilities.", and a red button with the text "Register at bit.ly/sbrn-goldenguys2022".

SPINA BIFIDA
RESOURCE NETWORK

Men's Virtual Chat

A Virtual Peer-Support Group for Men with Disabilities

3rd Tuesday of the Month • 7 p.m. ET
via Zoom with auto-captioning

Share your story, discuss relevant topics, gather valuable resources and build community at this peer-support group for men with disabilities.

Register at bit.ly/sbrn-goldenguys2022

The group will meet online the 3rd Tuesday of each month at 7pm ET through Zoom. Participants can call in using a phone or join us from a laptop, desktop or tablet. There is no cost to participate (though you must register to receive the Zoom link.) Auto-captioning will be available.

We are happy to welcome **Steven Nguyen** as the facilitator of the Men’s Virtual Chat. Steven, 32, is a disability advocate and certified peer mentor. Living with spina bifida, Steven understands the daily struggles and barriers that people with disabilities face and works to promote inclusion and bring about positive changes in his community. A resident of New Orleans, LA, he serves/has served on many state councils and boards, most notably, the Louisiana Developmental Disabilities Council, The Louisiana Statewide Independent Living Council and Spina Bifida of Louisiana. Steven’s educational background is in computer information technology, and his hobbies include playing adaptive sports, traveling and spending time with family and friends. He always appreciates connecting with others, offering support and finding shared or new interests.



Share your story, gather valuable resources and make new friends while enjoying the convenience of connecting from home using your phone or computer.

Register here to receive the Zoom link: bit.ly/sbrn-goldenguys2022.

SBRN Receives a Quality of Life Grant from the Reeve Foundation

The Spina Bifida Resource Network (SBRN) is proud to announce that it has been awarded \$21,200 as part of the **Christopher & Dana Reeve Foundation National Paralysis Resource Center (NPRC)** 2021 Priority Impact Quality of Life grants. Seventeen grants totaling \$499,700 were awarded. The Quality of Life Grants Program supports nonprofit organizations that empower individuals living with paralysis. Since the Quality of Life Grants Program's inception, more than 3,490 grants totaling over \$36 million have been awarded. Funding for this program was made possible through a cooperative agreement with the Administration for Community Living (ACL grant #90PRRC0006-01-00). Grants are targeted to focus on high-priority issues to increase access to services and increase the independence or inclusion of people living with paralysis, their family members, and caregivers.

SBRN will use the grant to support our ***"Empowered Conversations: Virtual Speaker Series,"*** which provides weekly virtual one-hour workshops, coordinated and facilitated by individuals who identify as having a disability, that explore living with paralysis and disabilities in an open forum for sharing and asking questions of peers. This program provides adults with disabilities an interactive safe space for peer- and expert-led discussion, education and skill building to minimize social isolation during and beyond COVID and to optimize physical, social and emotional health and wellbeing.

"SBRN is very honored to receive this award for our Virtual Speaker Series. These funds will allow us to expand our options and support our speakers and facilitators. This program will empower participants to become changemakers in their own lives and communities, and will encourage them to live life without self-imposed limits. Thank you to the Reeve Foundation for their support in empowering individuals living with paralysis to live their best lives," said Roberta Kestenbaum, Executive Director of the Spina Bifida Resource Network.

From the Reeve Foundation:

The Christopher & Dana Reeve Foundation is dedicated to curing spinal cord injury by funding innovative research and improving the quality of life for individuals and families impacted by paralysis. By uniting the brightest minds in the field, we are working tirelessly to accelerate scientific discovery across the field of spinal cord research by investing in labs across the globe. Additionally, through a cooperative agreement with the Administration for Community Living, the Reeve Foundation's National Paralysis Resource Center (NPRC) promotes the health, well-being, and independence of people living with paralysis, providing comprehensive information, resources, and referral services assisting over 100,000 individuals and families since its launch in 2002. The Reeve Foundation is committed to elevating our community's voices and needs to achieve greater representation and independence. We meet all 20 of the Better Business Bureau's standards for charity accountability and hold the BBB's Charity Seal. For more information, please visit our website at www.ChristopherReeve.org or call 800-225-0292.

