ISSUE # 1
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## **Newsletter**





### Walk 4 PICS 2024 Recap

Thank you to everyone around the world who walked for Post-Intensive Care Syndrome during the month of September. In total, close to 1,000 people walked to raise awareness of PICS and celebrate survivorship, either at one of 14 host sites or at home with family or friends.

#### Nashville, TN Walk

This year's Nashville Walk was hosted by Vanderbilt University Medical Center and the VA Tennessee Valley Healthcare System. Although it was a rainy day on September 28th in Nashville, over 80 people, their families, and pets walked!

Dr. Pratik welcomed and thanked everyone for coming out to walk and explained why it is important to be an advocate for PICS.

A special thanks to survivor, Rich Campbell, who set up a video call with other ICU survivors who couldn't make it to the Nashville, walk. This enabled survivors from California all the way to Denmark to participate.

At the Nashville Walk, two individuals received the first annual Richard Langford Service Award - Carolyn Rogers, a PICS Survivor and Jenna MacDonald, the CIBS Center social worker.

The Rev. Richard Langford was a survivor of critical illness who was part of the CIBS post-ICU community for many years.

He was known for his southern charm. During his time with the CIBS community, Richard encouraged and served his fellow survivors regardless of how he was feeling, and he inspired others to do the same. Richard passed away September 29, 2023.

This newsletter is survivor-created and is part of our advocacy and education efforts. To get involved with PICS advocacy, please reach out to us via the email address at the bottom of this newsletter. Also, if you would like to nominate a survivor or provider for us to spotlight in a future issue, let us know. Thanks for your support!

### In this newsletter you can expect:

Walk 4 PICS 2024 Recap

Walk 4 PICS 2025

Mindfulness and Wellness

PICS Provider Spotlight

Stories of Impact

Walk for PACS Team

### **Newsletter Insights**



#### **Exciting News!**

The date for Walk 4 PICS 2025 is Saturday, September 27th.

If you would like to host a walk or donate to WALK4PICS 2025, please visit the link below.

Walk4PICS.com/#join



# Resource Corner with survivor Barbara VanMeter-Nivens

Free Zoom Laughter Yoga

Two 25 min sessions/week Tuesday 7:30-8pm EST Fridays 11:30-12pm EST

Each session includes a gentle warm-up, laughter yoga exercises, breathing exercises, and a cooldown. After all, laughter is the best medicine!

<u>CelesteGreeneLaughs.com</u>

# PICS Post-Intensive Care Syndrome

#### What is PICS?

More than five million patients are admitted annually to U.S. intensive care units (Society for Critical Care Medicine). With advances in modern medicine, approximately 70 percent of these individuals survive (Pandharipande et al., 2013).

Of those who survive their critical illness, many experience Post-Intensive Care Syndrome (PICS), a collection of new or worsening impairments in the cognitive, physical or mental health realm. Long-term cognitive impairment and other individual factors play a role in long-term outcomes.

## windthluss

Mindfulness is a technique that involves being aware of your thoughts, feelings, and surroundings during the present moment non-judgmentally. It can help people deflect unwanted habits and responses by learning to observe their experiences without reacting to them.

Below are a few characteristics of mindfulness:

Present Centered: Involves being fully attentive to what is happening in the present, and learning not to rehash the past or imagine future events

Compassionate: Involves allowing experiences to naturally rise and fall without avoidance or reactivity

We will go into more depth in future newsletters about the practice of mindfulness.



The CIBS Center at Vanderbilt University Medical Center in Nashville, Tennessee, supports patients recovering from critical illness, particularly those with Post-Intensive Care Syndrome (PICS) and Long COVID (LC), through specialized research and clinical care. Known for its pioneering work on brain dysfunction and cognitive health after ICU stays, the center offers vital support groups to help patients and families navigate the challenges of recovery and improve long-term survivorship outcomes.

Learn more at ICUDelirium.org

#### What is PICS-p?

Many children are impacted by Post-Intensive Care Syndrome in Pediatrics (PICS-p), and their journeys to recovery and healing can be equally challenging.

Family members and caregivers also shoulder the hardship of PICS, with some loved ones experiencing PICS-Family (PICS-f). Common symptoms of PICS-f include anxiety, depression and PTSD.

### PICS Provider Spotlight

Brian C. Peach, PhD, RN, CCRN, Assistant Professor





# Your career spans over 17 years in critical care nursing. How has this experience influenced your focus on PICS and ICU delirium in your research?

Working as an ICU nurse, reading critical care publications, and attending conferences stirred my interest in ICU delirium and PICS research. I've always loved being an ICU nurse—the opportunity to save lives or help people pass peacefully is incredibly meaningful. However, what every ICU nurse ultimately wants, and what I want, is for patients to have a good quality of life afterward.

Years ago at a conference where Brenda Pun was speaking alongside a survivor, I learned for the first time how many ICU patients develop life-altering cognitive and mental health conditions after critical illness. This inspired in me a passion to improve patient outcomes beyond the ICU.

Through my experience in critical care, I've come to recognize how some practices, such as excessive sedation, contribute to these long-term problems. I emphasize to my UCF nursing students that ICU patients often have compromised liver and kidney function, organs critical for filtering medications. Administering heavy sedation to these patients can prolong drug effects, increasing the risk of delirium. Since delirium is strongly linked to long-term cognitive issues, understanding and addressing these factors is vital. My time in the ICU has given me the knowledge and insight to advocate for better practices to improve patients' long-term health.

#### Is it best to talk to patients about PICS on the CCU level or the step-down level?

I believe patients and families would likely benefit from early conversations about PICS. While critically ill patients may not retain the information, their family or friends can. As the delirium clears, these discussions become even more crucial. At the very least, these conversations should happen on the step-down or medsurg floor before discharge.

An informal social media survey I conducted revealed that patients and families feel blindsided by the cognitive and functional challenges they face post-ICU, such as difficulty cooking, reading, or working. They emphasized the need for more education in the hospital setting to prepare them for what lies ahead, as the hardest days are often after leaving the ICU.

# Do you have a specific moment or interaction in your career that reinforced the importance of addressing PICS?

There isn't one specific moment, but rather numerous experiences that have reinforced the importance of addressing PICS. Through my interviews with survivors, I've seen the significant challenges they face, and hearing their stories has deeply impacted me. While emotionally taxing, these conversations drive home the urgency of this work.

Seeing positive results from VR Exposure Therapy has been incredibly motivating, especially knowing it's helped some individuals turn their lives around. These moments—witnessing both the struggles and the improvements—are what keep me passionate about continuing this work.

### Do you plan on hosting WALK4PICS in Orlando, FL in 2025?

100 percent, yes!

# What are the primary goals of your research on PICS, and how do you see it impacting patient care?

The primary goal of my research on PICS is to move from collecting data to developing interventions that make a tangible difference in patients' lives. After gathering information on survivors' memories, triggers, and symptoms like PTSD, anxiety, and depression, I shifted focus to testing a therapy called Compressed Virtual Reality Exposure Therapy at UCF.

This therapy, delivered at the UCF RESTORES clinical research center and trauma therapy clinic, involves a trauma therapist helping patients process their ICU experiences and gently exposing them to the visual, sound, smell, and touch cues that trigger traumatic memories. The goal is desensitization, reducing strong emotional reactions to these triggers over 10 therapy sessions.

Preliminary results are promising, with nearly all participants showing significant improvement within 3 months. My aim as a researcher is to create interventions that reduce patients' recovery times and improve their quality of life.

# Have there been any significant findings in your research that you believe clinicians and families should know about?

Many clinicians do not know about PICS. It's crucial to raise awareness, and I hope my upcoming article in *The Nurse Practitioner* sparks conversations and reaches a broader audience through online databases.

Many clinicians are unaware of what survivors endure, including the triggers that affect them, and they aren't screening for these issues. Additionally, therapies like Compressed Virtual Reality Exposure Therapy show promise in addressing medical PTSD and could significantly help survivors in their recovery.

# How do you incorporate PICS advocacy into your role as a professor, both in your teaching and mentoring of students?

As a professor at UCF, I incorporate PICS advocacy through teaching, mentoring, and community engagement. In our critical care course, I include slides on ICU delirium and PICS to introduce students to these critical topics, ensuring they are aware of the challenges faced by survivors. I also mentor doctoral students in PICS-related research, guiding them through coauthoring papers and dissertation projects to further their expertise. Additionally, I've given talks at national conferences to educate the next generation of nursing professionals about PICS.

# What advice would you give new clinicians or researchers interested in working in critical care?

My advice is to begin by building a strong foundational knowledge of PICS, including its risk factors and existing research. Familiarize yourself with research from key institutions conducting PICS research such as VUMC, Johns Hopkins, Pittsburgh, UPenn, and BYU, and consider potential opportunities for collaboration. It's essential to read the current research to identify gaps, such as the best treatment methods for PICS and the connection between delirium and long-term cognitive or mental health challenges. For clinicians, attending conferences, participating in hospital talks, reading relevant journals, and engaging directly with patients to understand their experiences are valuable ways to deepen understanding and contribute to this field.



### Mike's Corner

"In the face of medical trauma, remember: Healing is a journey, not a race. Each day brings new strength, resilience, and hope. Trust yourself, lean on your support, don't be afraid to ask for help, and embrace the possibility of brighter tomorrows."



Mike is a critical care survivor and fierce PICS advocate.



### **PICS Impact Story:**

How Ron Jennings went from ICU/PICS Survivor to Hurricane Helene Survivor

This month we would like to spotlight PICS survivor Ron Jennings. He recently experienced a once in a 5,000 year flood in upper Appalachia, East TN.

### What do you want people to know about you?

Hi, I'm Ron Jennings. I am 65 years old and live in a home my grandfather built in 1945 overlooking the Appalachian Mountains in upper East TN. I was an emcee for a Gospel Venue for about 10 years. I volunteer monthly helping with food distribution at a local church. I live with "Ugly" (that's her name), a 7lb Pomchi. She is my therapy dog and helps me with my PTSD. I recently went through devastating flooding due to Hurricane Helene. Flood waters reached over sixty feet and my community was wiped out by rainfall.

#### What sent you to the ICU?

In November 2011, my Cardiologist implanted a new pacemaker inside me to help with the blackout symptoms I was experiencing. A week later, the surgical site became infected. I started running a fever and my blood pressure dropped. I went to the ER where the doctors told me I was Septic. After being admitted to the ICU I died (the 1st of 3 times). I was then placed on a ventilator and the next morning went into emergency surgery to fix the broken wires. I was given a two percent chance of living and my family was encouraged to make funeral arrangements. By God's amazing grace I pulled through. I was in the ICU for 30 days, on a ventilator in a coma for 11 days and lost about 80 pounds. I walked out of the ICU on New Years Eve.

### What brought you to the ICU Support Group?

In 2019, I was diagnosed with PTSD from a near death experience. I had originally found a support group for Sepsis survivors on sepsis.org but I didn't feel like I was a good fit. I emailed my story to a board member of the Sepsis group and Dr. Carla Sevin at Vanderbilt. Dr. Sevin set me up with Dr. Jim Jackson, who had a support group for folks that had been in the ICU. After one visit (which I was terrified to join, because I felt like the folks in the group wouldn't have anything in common with me) I found a FAMILY, a family I didn't know I needed. This was in February of 2020 and I have been attending the ICU Survivors group every week since.

### How has being a member of the ICU Survivors Support group benefited you?

Before joining, I felt like I was lost in a very dry forest. I couldn't find my way home and I was dying of thirst. Imagine searching a dry creek bed filled with dry leaves. For some reason you reach down and turn over a rock about the size of a dinner plate and suddenly you see a wet spot. As you take your hand and start raking back wet leaves a trickle of water starts flowing, not much, but its enough to cup your hand and get a much needed refreshing taste of pure liquid refreshing HOPE, bring a spark of life to what seemed like inevitable misery.

Every week that I joined I would hear something that fit my situation like a glove. For me, hearing others talk about their experiences and daily setbacks and victories hit home.

Being part of this group literally saved my life in 2020. I had been diagnosed with an unerupted brain aneurysm during my annual checkup and my doctor said I needed surgery. I wanted a second opinion and told the ICU Survivors group about my diagnosis. Two members of the support group helped me travel over 300 miles to get to Vandy from my home so I could get a second opinion. Turns out I did not need that surgery and if I would've had the surgery I would have most likely died.

Lastly, I was raised believing any who sees a Psychologist is nuts. Having been diagnosed with PTSD, suffering from nightmares and feelings of impending doom, I knew I needed help but was ashamed to ask for it. When I heard that the Psychologist leading the ICU Survivors group sees a Psychologist regularly, I thought I would give it a try. It was LIFE CHANGING. I owe so much to this group. I have learned that if you need help, ASK.

### What made you want to be involved with advocacy work like WALK4PICS?

After being released from the ICU I suffered with many things and my PCP and specialists had no clue what was wrong. They would give me more pills and tell me to quit being so anxious. The diagnosis of PICS (Post Intensive Care Syndrome) answered all of my undiagnosed symptoms. Being educated about PICS has been life changing. I will admit, at first I was angry that my doctors had never mentioned anything close to PICS. I trusted them with my life and they literally didn't know such a disease exists, let alone how to treat it. It was from this frustration that I decided I wanted to help spread the word to others about PICS.

### What do you want others to know about PICS?

Long after you leave the ICU you will more than likely experience cognitive impairments. You may have been a multitasker before the critical illness and now you struggle to remember how to tie your shoes. If that is the case, it is OK. Give yourself some grace for it could take some time to adjust to the new you. One valued support group member likens the "new you" as version 2.0. So. I am now Ron 2.0. PICS Survivors may encounter other psychological struggles like anxiety, depression or PTSD. I would BEG anyone struggling with this to REACH OUT and don't be ashamed to ask for help. I still experience daily physical exhaustion and have to take twenty minute naps to "reset" my brain. We are all on a mission to teach the world about PICS. I plan on doing my best to WALK along side of them to help spread the word!





# **Thoughts from Spencer Freeman:**

#### Critical care survivor and patient advocate

During my recovery from critical illness, I discovered that small steps—like trying to walk each day or attempting something new—meant more than regaining strength. They brought smiles to my wife and mother, moments of light in the darkness they endured while I was sick. Watching their relief and joy reminded me of something profound: my survival wasn't just about me. Their suffering, their tireless care, had purpose, and giving it meaning became my greatest motivation.

Knowing how much they endured made me determined to get better physically, emotionally, and spiritually. It also inspired me to speak for others like me, patients and survivors of intensive care who can't yet voice their experiences. I realized advocacy is not just about improving care; it's about honoring the struggles of families and caregivers, who bear unimaginable burdens alongside us.

Through this work, I've met survivors, families, and clinicians who share my vision of a world where every patient and caregiver feels seen and supported. Advocacy has become my way of giving purpose to pain—both mine and theirs. It's a chance to help others navigate the suffering my family and I experienced, so no one has to endure it alone or in silence.



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