ISSUE # 2 MARCH 2025

# **Newsletter**





## **International Walk 4 PICS 2025**

#### Save the date!

## Saturday, September 27, 2025!!!

Mark your calendars and lace up your shoes! Join us Saturday, September 27 for Walk 4 PICS, a community event dedicated to raising awareness of Post-Intensive Care Syndrome (PICS) and supporting ICU survivors and their families.

Whether you're an ICU survivor, a family member, a healthcare professional, or an advocate, this walk is an opportunity to come together, share stories, and show support for those impacted by critical illness.

#### **Event Highlights:**

- A community walk to raise awareness of PICS
- Resources and information
- Opportunities to connect with fellow survivors, families, and advocates

Every step we take brings more awareness and support to those affected by PICS. Let's walk together to make a difference!

Register today at Walk4PICS.com and help us spread the word!

# In this newsletter you can expect:

Newsletter insights

PICS 101 class & PICS 201 support group

Provider spotlight

Hopeful words

Survivor impact story

Walk for PACS Team

## **Newsletter Insights**



**Cheryl Thompson** 

ICU Survivor to Advocate: Finding Strength and Community After PICS

I am a wife and mom of 2 teenagers. I live in Orlando, Florida. I am a teacher. I love Disney World. I am also an ICU survivor. In May of 2022, I had outpatient surgery to remove a cyst, which ended up getting infected and leading to septic shock. After being in the hospital five days, I suffered cardiac arrest. I spent the next nine days in a coma, on a ventilator, fighting for my life. I had double pneumonia, two collapsed lungs, septic shock, and cardiac arrest. No one knew if I would make it. When I woke up 10 days after coding and learned about what had happened, I thought I had made it through the worst. My struggles were just beginning. I suffered from ICU delirium and trauma from the ICU.

When I finally got home, I was suffering with severe anxiety, PTSD, hospital acquired weakness, cognitive deficits, and trouble sleeping. I felt alone in my struggles and had no idea that other ICU survivors had similar difficulties. I have since learned that I had PICS. A few months after discharge, I went through exposure therapy at UCF Restores through a research study with Dr. Brian Peach. This helped me tremendously.

I learned about the PICS 101 group from Jenna and decided to join. I wanted to learn more about PICS, how I could help myself get better, and how I could help prevent others from going through what I did. What I didn't expect is to become part of a community of people who get it! I met so many other ICU survivors who have PICS. Although our stories are all so different, our traumas are so similar. I found many others who I could relate to. I enjoyed the education about what I was going through and why, as well as ways to improve. I would 100% recommend the PICS 101 group for all ICU survivors! You will learn more about PICS, even getting to understand the why behind it. You will meet people who you connect with and who empathize with you because they have been through it too. You will have wonderful leaders who work hard to educate and help you advocate. After PICS 101, the transition to PICS 201 was very helpful. It is a larger community of ICU survivors who have completed the PICS 101 class. They are amazing people who are there for you. In PICS 201, we have weekly meetings to discuss PICS, ask questions, vent, praise, support, and lift each other up. I am so glad that I chose to join PICS 101 and then 201. It has made such a difference in my post-ICU journey and has helped in my continuing recovery.



Steve Edmonson

PICS 201 Peer Leader

After I left the ICU way back in 2010, it was immediately apparent that I was struggling with many different issues in the areas of cognition, mental health and physical disability. I didn't know enough at the time to understand where my difficulties were coming from, but I later learned I had PICS with its accompanying symptoms. I had profound cognitive deficit issues, as well as PTSD and some severe physical damage related to fighting against my restraints while in the ICU.

It was eight years later when I found Dr. Ely, Dr. Jackson, and the Vanderbilt support group. For many years my doctors had assured me that it wasn't possible that anything in the ICU could have resulted in any changes in me.

Since then, I have been committed to doing whatever I can to help others from going through what I have. This includes being a peer supporter, which I have found to be immensely rewarding!



### WHY JOIN A POST-ICU CLASS?

This class helps members recognize they are not alone in their experience and educates members on common challenges that ICU survivors face.

# GAIN SUPPORT FOR YOUR ICU RECOVERY JOURNEY, WHICH MAY INCLUDE:

- Cognitive impairment/brain fog
- Mental health impacts including sleep disturbances, depression, anxiety, and PTSD
- Physical challenges such as extreme fatigue, chronic pain, and new diagnoses

### **ABOUT THE CLASS:**

- The class meets over Zoom for 12 weeks, Mondays at 1pm Central
- Class members learn about Post-Intensive Care Syndrome, with weekly topics presented by group leaders, followed by open discussion
- The unique combination of education and peer support allows members to ask questions and utilize resources presented to the class
- The goal is to empower members throughout their lifetime & develop lasting support
- This class is open to individuals who are struggling to adjust to life after the ICU.

**JOIN US** 

For more information, contact:

Jenna MacDonald, LMSW
Jennifer.Macdonald@vumc.org





# Provider Spotlight James "Jim" Jackson, PsyD

Dr. Jim Jackson is an internationally renowned expert on the cognitive and mental health impacts of PICS. He is a licensed psychologist specializing in neuropsychology and cognitive rehabilitation and a leading authority on Long COVID and its affect on cognition and mental health. He is a research professor of Medicine and Psychiatry at Vanderbilt, where he is co-founder and Director of Behavioral Health at the award-winning ICU Recovery Center.



#### What made you choose the path of working with PICS patients and families?

I came to Vanderbilt in 2000, and Wes Ely was just starting a research program focused on ICU survivors. He needed a psychologist on his team, and I was happy to oblige - little did I know that I would have the privilege of spending my professional life supporting PICS patients and their families - what a blessing this has been.

#### What do you think is the biggest misconception about PICS?

I think many people don't understand that PICS is often what we call an "invisible" illness - that is, a significant portion of people with PICS look perfectly fine, so friends, family, employers, etc., often assume they are fine. Far too often, they are far from fine, and they need support instead of judgment.

#### What advice would you give to someone who is newly diagnosed with PICS?

Take a deep breath - maybe not literally - but take a deep breath, reflect on the fact that you are fortunate to be alive, and do two things - 1) find a support system - friends, other ICU survivors, healthcare providers, etc. to be there for you when things get difficult and 2) find a purpose that will help propel you and empower you to do to the hard things you need to do to begin to recover.

#### Can you share a memorable success story or breakthrough moment from your work with PICS patients?

I've been fortunate to see so many beautiful stories. One stands out. A delightful young patient - a surfer, so lively and dynamic, who lost part of her foot while in the ICU. A year or two after her discharge, she sent me a video of her riding a wave on a surfboard. She had accepted her limitations, yes, but in spite of these, she had found a way to do the things she loved and live the life she wanted. Her problems didn't go away - there was no magic wand - it wasn't easy, but it was beautiful. There will be limitations, but growing, thriving, and pushing against the boundaries of your limitations is possible, and when it happens, it is quite a sight to see, as it was in her case.

# What message would you like to share with survivors who feel alone or misunderstood in their recovery journey?

I would point out that recovery isn't easy and, honestly, you can't do it alone. There is a popular phrase that many people use today - "choose your hard." Asking for help and being vulnerable with others is hard, and suffering alone in silence is also hard - so choose your hard. Engage with people and let them know your needs - usually, there will be a few, at least, who will be glad to support you. It is messy - yes - but we need each other. Don't do this alone.

#### What are your hopes for the future of PICS research and survivor care in the next 5 to 10 years?

I think we're entering an exciting time in PICS research, and I see a few developments on the horizon:

- 1) I think we're only going to get better at identifying the people who are at the highest risk for developing PICS, and eventually, we'll be able to target them with specialized care to reduce the risk of PICS;
- 2) I think we're beginning to recognize how crucial rehabilitation especially cognitive rehabilitation is, and I'm hopeful that in the next decade, it will be the standard of care as opposed to the rare exception that it is now.



You are a priceless human being, and no amount of disease or disability from your illness has or will diminish your value. Always remember please that you are enough, and that I and your team of clinicians and researchers care about your recovery and well-being.

Dr. Wes Ely



We think you'll love these books!

**Every Deep Drawn Breath** 

Dr. Wes Ely

<u>Clearing the Fog</u> James C. Jackson. PsyD

Speechless

Vanessa Abraham M.S. CCC-SLP



## Mike's Corner

In the midst of suffering, when pain seems unending and hope feels distant, remember the story of the phoenix. The mythical bird, consumed by fire, rises anew from the ashes, stronger and more radiant than before. Like the phoenix you too possess the inner strength to overcome your trials.

Each challenge you face is not a dead end, but a force, refining you and fortifying you will. Embrace each day as an opportunity to rise, to heal, and to grow.

The path to recovery may be steep, but with each step, you are crafting a story of resilience, courage, and renewal. Believe in your power to transform and soar above the flames of adversity.

## Mike

Mike is a survivor of critical illness and fierce PICS advocate.



# **PICS Impact Story:**

## Finding Her Voice Again: A Speech Pathologist's Journey Through PICS and Advocacy

This month, we would like to spotlight PICS Survivor Vanessa Abraham. She is a Speech Language Pathologist with over fifteen years of experience and has recently written a book on her journey of surviving a critical illness called "SPEECHLESS: How a Speech Therapist Lost Her Ability to Speak and Her Silent Struggle to Reclaim Her Voice and Life."

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

My name is Vanessa Abraham. I am a wife, mother, speech pathologist, author and critical illness survivor. I recently published a book about my medical journey called SPEECHLESS: How a Speech Therapist Lost Her Ability to Speak and Her Silent Struggle to Reclaim Her Voice and Life, where I chronicle my journey from active mother to critical illness patient in the fight to recover from a neurological illness called Guillain Barre Syndrome that left me paralyzed and unable to communicate in the ICU for nearly a month. Through my book, I hope to raise awareness about the often-overlooked challenges faced by critical illness survivors, such as Post-Intensive Care Syndrome (PICS), and provide hope for others navigating their own recovery journeys.

#### What sent you to the ICU?

My medical journey began unexpectedly in 2019. My initial symptoms were loss of voice, nausea, and severe neck pain, which I assumed was simply a bad case of the flu. At the time, I thought the neck pain was a result of whiplash from the repetitive coughing and vomiting I was experiencing. But little did I know, a virus was attacking my brain stem and spinal cord, causing me to lose my voice, my ability to swallow food safely, and movement in my upper body.

As a speech pathologist, this was terribly scary, as I suddenly found myself on the other side of the equation—being a patient in the bed and on the receiving end of speech therapy services. It was a humbling and overwhelming experience to go from providing care to needing it, and it gave me a new perspective on the challenges patients face in their recovery.

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

I was referred to the ICU support group for PICS by my doctor at the University of California San Diego (UCSD) after she interviewed me and recognized the severity of my depression, anxiety, and suicidal thoughts. This was a pivotal moment in my recovery, as it forced me to confront just how much my mental state had deteriorated. The doctor's quick action and understanding gave me a sense of relief, knowing that I wasn't alone in my struggle and that there was help available for what I was going through.

At that time, I couldn't shake the overwhelming feeling that I would have been better off dying in the ICU than facing the life I had ahead of me. I missed my old life, grieving the person I once was, and struggling to accept my current state. I was terrified of the thoughts I was having and knew I needed help. My mental health was spiraling, and I realized I had to seek support, as no one in my family truly understood the depths of what I was experiencing.

I have been attending support groups for nearly five years now, and they have been an essential part of my healing journey. These groups have provided me with a sense of community and understanding, allowing me to connect with others who have faced similar struggles and helping me navigate the complexities of my recovery.

#### How has being a member of the ICU Survivor's Support group benefited you?

Many times I feel that being a member of the ICU support group saved my life. The group and community of survivors provided me with a group of people that understood me, supported me, and made the journey less isolating. Not only did it give me purpose, but it also gave my child her mom back. Whenever I felt alone or scared, I knew there was someone always readily available for me to talk to, lean on or to encourage me to keep fighting when I felt alone and abandoned by others.

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

PICS can extend to family members as well. This is known as PICS-Family. This refers to the emotional and psychological toll that a loved one's critical illness can take on family members. Just like the patients themselves, families may experience stress, anxiety, depression, and even symptoms of PTSD as they cope with the trauma of seeing a loved one suffer in the ICU and navigating the uncertainty of recovery. This strain can be compounded by the emotional exhaustion of caregiving, and the changes in family dynamics as the patient works to regain their health. Support for family members is crucial, as they too need help in processing the emotional impact and adjusting to the long-term challenges that may arise as the patient recovers.

One thing I personally learned during my recovery is that as a family member or friend, your natural instinct may be to give the patient space to process their trauma, heal, and have privacy, but from my experience, this can actually be harmful. While giving the patient space may seem like a compassionate approach, in reality, isolation can exacerbate feelings of loneliness, anxiety, and depression, making recovery even more challenging. It's crucial for family members to provide emotional support, be present, and engage in open conversations, as this connection can significantly aid in the healing process, helping both the patient and the family navigate the complexities of recovery together.

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

Participating in advocacy work is part of my healing journey. For me, it has been about my community and building a community of people that understand me, understand the trials that I have experienced, and continue to live with motivates me to continue to advocate for ICU survivors and spread the word about post intensive care syndrome. Another reason I choose to become involved with advocacy work is to discuss the topic of PICS as I have found as a speech pathologist not many are aware of this topic or even realize it is a thing we deal with.

To connect with Vanessa or have her speak to your organization, please contact her directly.

Vanessa Abraham, M.S., CCC-SLP vabraham14@gmail.com

WALK 4PICS	Walk4PICS@gmail.com
This newsletter is written and designed by survivors living with PICS.	2525 West End Avenue, Suite 450 Nashville, TN 37203