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### **Newsletter**



#### **WHAT IS ARDS?**

Acute Respiratory Distress Syndrome (ARDS) is a condition which affects the lungs, causing the alveoli (the small air sacs in the lungs) to become filled with fluid. This makes it extremely difficult for the lungs to carry out their normal function (to put oxygen into the blood and remove carbon dioxide). When this cannot happen, the lungs may fail (respiratory failure) and the disease can become life threatening.

#### **ARDS DIAGNOSIS**

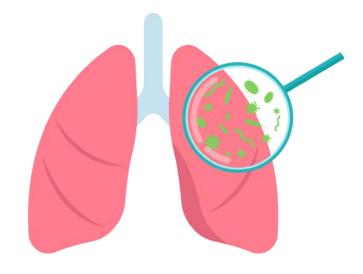
You may have been told that you or your loved one has ARDS; however, there are other terms for the condition. This includes but is not limited to: 'wet lung,' 'ECMO lung' (as ECMO may be used as a supportive measure in patients with ARDS), 'shock lung,' or 'white lung' (as the lungs can appear completely white on a chest X-Ray). There are many different causes of ARDS, such as lung infection (which may be caused by viruses, bacteria, or fungi), the body's overwhelming response to infections elsewhere (sepsis and septic shock), trauma, drowning, or inhaling injuries (such as vomit, toxins, or smoke). Approximately 10% of patients in an ICU may have ARDS.

#### **TREATING ARDS**

Treatment involves giving the lungs time to heal and treating the cause of ARDS. ARDS can range in severity, and sufferers will be given appropriate support to breathe. Non-invasive methods of ventilation include high flow oxygen delivery devices (such as BiPAP) and are typically delivered while the patient is awake.

When these are not enough, patients may be placed on a ventilator (with a breathing tube), which takes over the work of breathing. To improve the lung function, patients may also be 'proned' (i.e. put onto their front). This helps the lungs to inflate and work more effectively.

Should the above methods be insufficient for the severity of ARDS, a machine known as ECMO (extracorporeal membrane oxygenation) may be used. This can completely take over the function of the lungs. It may be deemed that the lungs have little to no chance of recovery. When this is the case, a lung transplant may be necessary.



#### In this newsletter you can expect:

What is ARDS?

Ventilator Research

PICS Impact Stories

Survivors and Caretakers

Newsletter Highlights

#### LONG TERM RECOVERY

ARDS recovery is not just limited to what occurs in the hospital. There may be changes in functioning which make it difficult to reintegrate with day-to-day life. Everyone's ARDS recovery journey is unique; however, there are common issues people may experience once discharged. These can be broken down to the physical, mental, and emotional aspects of recovery. It is understandable that as the body has endured trauma, a physical recovery must be made - to gain strength, function and adapt to life outside of the hospital. It is important not to invalidate or understate the mental and emotional recovery: the trauma can take its toll. This can affect both the patient and the loved ones around them. It is not unusual for patients to develop PTSD, struggle with nightmares, flashbacks, low mood, anxiety and to struggle cognitively.



# Provider Spotlight Paula Blonski

"My life, and the life of my entire family changed forever on August 8, 1998. That is the day we lost my sister, Marybeth to ARDS."

### Finding Strength in Recovery: Insights from an Advocate for ARDS Patients and Families

Acute Respiratory Distress Syndrome (ARDS) is a life-altering diagnosis—one that impacts not just the lungs but the entire trajectory of a person's life. For those affected, navigating the medical maze and emotional fallout can be overwhelming. In the midst of that storm, support from someone who understands both the science and the human experience of ARDS can be transformative. Here, an experienced ARDS advocate shares her journey, insights, and hopes for the future.

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

My journey into working with ARDS patients and families was deeply personal. I had a loved one who developed ARDS after minor surgery, and watching her fight for her life in the ICU was both terrifying and illuminating. I saw firsthand how isolating the experience can be—not just for the patient but for the family, who often feel helpless and confused. That experience sparked a passion in me to become a bridge—between clinical care and human connection—so that no one facing ARDS would have to do it alone.

### What do you feel is the biggest misconception about ARDS?

One of the biggest misconceptions is that recovery ends when a patient is discharged from the ICU or hospital. In reality, that's just the beginning. ARDS survivors often face a long road of physical, emotional, and cognitive recovery. There's also a general lack of awareness about what ARDS actually is—many people think it's a rare or always fatal condition, but with early detection and proper treatment, survival is possible and quality of life can be regained.

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

First and foremost, take it one day at a time. ARDS is complex, and the path to recovery isn't linear. Ask questions. Advocate for yourself or your loved one. And if you're the patient, give yourself grace—it's okay to not be okay sometimes. Connect with others who've walked this path; their stories can offer hope, perspective, and practical advice. You're not alone and you are stronger than you know.

### What is the importance of support or peer connections for ARDS survivors?

Peer support is vital. ARDS can leave survivors feeling isolated and misunderstood, especially when their experiences don't align with what others expect from a "normal" recovery. Talking to someone who truly understands—who has felt the panic of not being able to breathe or the frustration of fatigue months after discharge—can be life-changing.

These connections validate the survivor's experience and provide a safe space to share fears, celebrate wins, and ask honest questions.

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

There are so many stories, both stories of hope, and just as many heartbreaks. I would like to talk about Alec. His story is a breakthrough, and a story of incredible hope. He was 21 years old, living in the UK doing normal activities. However, one Thursday morning, he woke up and could not breathe.

He had always had asthma as a child but took his medication regularly and it did not usually bother him.

One day, at 4am, he woke up and experienced the worst asthma attack of his life – his inhalers were not working. He struggled until 7am at home and at that point he finally called 999 (hoping that I would just need some nebulizers). The paramedics took him to the local A&E department and before walking to the ambulance, he remembered turning to his mum, hugging her, and saying "well, this is

inconvenient." Little did he know what was about to happen.

He struggled throughout the day in the resuscitation room and at 6pm, the decision was made to put him to sleep and intubate him. He would not wake up for another five weeks. Over that Thursday evening, his lungs failed, his kidneys failed, and early in the hours of Friday, he suffered a cardiac arrest. A referral was made to the regional ECMO service, and he was promptly placed on ECMO and transferred to Wythenshawe Hospital in the UK.

He spent 25 days on ECMO and a ventilator, followed by a further 10 days just on the ventilator. The recovery was both mentally and physically draining. He had severe muscle wastage and had completely lost his independence what felt like overnight. Slowly but surely, with intense physiotherapy in ICU and on a ward, he recovered. He went home on 16th August, 2019. A year later, he was back at medical school and in June 2025, he graduated with his medical degree. Alec is a doctor! He will be the best doctor due to his time with ARDS. He will understand what others are going through. He will be patient and kind. Dr. Alec, an ARDS survivor, will be

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

ready to care for others.

You are not broken. What you're feeling is valid, and your experience is real. Recovery looks different for everyone, and just because others don't see your struggles doesn't mean they aren't there. Keep advocating for yourself. Seek out those who listen without judgment. Healing is not just about the body—it's about your spirit, your identity, and your voice. And most importantly, there is a community that understands you. Reach out—we're here.

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

I hope to see ARDS gain more recognition and dedicated funding for long-term research. We need better tools for early detection, more personalized treatment strategies, and structured post-discharge care that includes mental health, physical therapy, and peer support. I also envision a future where survivor stories are integrated into medical training—where lived experience is valued as much as clinical knowledge. In 5 to 10 years, I want to see survivors thriving, not just surviving.

#### Conclusion

Working with ARDS patients and families is more than a career—it's a calling. Each survivor's story adds another thread to a growing tapestry of resilience, and through continued advocacy, research, and connection, we move closer to a world where ARDS is not only better understood but more compassionately treated. The ARDS Alliance was formed to help all those affected by ARDS. For resources, support, and hope, visit <a href="https://www.ardsalliance.org">www.ardsalliance.org</a>.



#### **Current Research**

Department of Anesthesia, Critical Care and Pain Medicine, Beth Israel Deaconess Medical Center, Harvard Medical School Boston, USA

Dario von Wedel & Maximilian S. Schaefer

### Mechanical Power: A Promising but Imperfect Measure

Among critically ill patients in the Intensive Care Unit (ICU), mechanical ventilation is often a lifesaving intervention. It provides respiratory support to ensure sufficient delivery of oxygen and removal of carbon dioxide. However, this therapy can also cause harm, termed Ventilator-Induced Lung Injury (VILI), which is characterized by damage to the lungs resulting from mechanical ventilation. VILI can manifest as inflammation, accumulation of fluids, as well as structural tissue damage, and ultimately worsens patient outcomes. For decades, clinicians and researchers have been committed to identifying and evaluating strategies to prevent VILI.

A promising concept aiming to identify the potential of VILI for a respective mechanical ventilation strategy is measuring mechanical ventilation intensity, expressed as mechanical power. This measurement combines multiple ventilator settings, such as inspiratory and expiratory pressures, volumes, and respiratory rate. Combined into a single value, mechanical power estimates the energy delivered to the lung over time. In this, excess energy (i.e., energy exceeding a certain threshold) is thought to be a potential cause of VILI. The general idea is that reducing mechanical power through optimization of mechanical ventilation reduces VILI and improves outcomes and safety for all patients. It is, however, unclear whether "safe" thresholds exist that can help guide clinicians and indicate "optimum" mechanical ventilation or the need to adjust.

We explored whether a single, "one-size-fits-all" safety threshold of mechanical power

adequately accounts for the physiological differences between individual patients. Our findings, published in Intensive Care Medicine, highlight current challenges of personalizing mechanical ventilation to each individual and suggest how using proxies for lung size could help improve patient outcomes.

### Understanding the Challenge: Differences in Lung Size

The study analyzed data from nearly 20,000 critically ill patients who required mechanical ventilation. As an example of inter-individual differences in lung size, we focused on a wellestablished physiological difference: on average, females, as compared to males, have smaller lung volumes, even at the same body height. This led to our scientific question: could applying a comparable amount of energy (i.e., mechanical power) to lungs of different sizes lead to different levels of stress and, therefore, different outcomes? As Prof. Gattinoni, who introduced the concept of mechanical power, previously noted, delivering the same amount of energy to the lungs of an elephant versus a mouse would clearly not yield the same physiological effect. However, it remained unclear whether differences between male and female patients would also be clinically relevant in this context.

Our study findings support this line of thinking. While higher mechanical power was linked to higher mortality risk among all patients, the association was more pronounced in patients with smaller functional lung sizes (e.g., females) than those with larger lungs (e.g., males).

The data indicated that for the same increase in mechanical power, female patients had a larger increase in risk of 28-day mortality compared to male patients. Importantly, this does not imply that mechanical ventilation is unsafe, but rather that mechanical power, as a method for measuring its intensity, should be further refined before implementation at the bedside.

#### A Path Toward Personalization: Normalizing Mechanical Power for Lung Size

In subsequent analyses, we demonstrated that the underlying factor explaining differential safety thresholds is not a patient's sex per se, but the patient's functional lung size. Therefore, we tested a solution grounded in physiology: normalization. Instead of using the raw mechanical power value (i.e., the total energy applied to the lung), we normalized mechanical power to the patient's "static respiratory system compliance." Compliance is a measure of how "stretchy" a lung is, and it serves as a good proxy for functional size – the portion of the lung that is open and able to receive air (i.e., participate in gas exchange). Using this "normalized mechanical power," we found that the previously observed difference in mortality risk at a given threshold was substantially reduced. This suggests that normalizing for functional lung size provides a better measure of the actual stress being applied to the lungs, regardless of a patient's stature or sex. This approach offers a promising way to make our assessment of ventilation intensity more accurate.

#### The Nuances of Ventilator Adjustments

We found that clinicians were, on average, already delivering lower absolute mechanical power to female patients, showing an intuitive understanding of the need for adjustment. However, these adjustments may not have fully accounted for the differences in lung compliance, as we observed higher normalized mechanical power among female patients. This underscores the difficulty of tailoring mechanical ventilation and the potential benefit of using more individualized metrics like normalized mechanical power.

These findings demonstrate how thorough analysis of clinical data can lead to new insights that help improve patient care. In the past years, the medical community has been continuously working to move toward more individualized care. Using non-normalized mechanical power may be less precise than a personalized approach. The good news is that tools to improve this may be readily available. Calculating a patient's respiratory system compliance is routinely done in the intensive care unit. By using this value to normalize mechanical power, clinicians may be able to better estimate the intensity of ventilation for their patients. This research helps pave the way for future studies and clinical trials to establish individualized strategies of mechanical ventilation. By embracing such strategies, clinicians can continue to improve the safety of this critical, life-saving intervention for every patient.



### My Story: I had Two Double Lung Transplants

Rick Bressler, Survivor and Advocate

### Aside from you having ARDS, what do you want people to know about you?

I have been married for almost 26 years. We have two daughters, both young adults now. My wife and I have three dogs, all rescue animals. I enjoy bicycling and have a passion for music.

#### Tell me what sent you to the ICU.

I was exposed to and contracted COVID-19, which led to multiple health concerns; COVID induced ARDS, bi-lateral COVID pneumonia, aspergillus, pneumothoraxes, and more. My O² saturation was dropping drastically to the point where I could not breathe. I understand all too well what it feels like to suffocate, as well as drowning due to the fluid buildup in my lungs and chest cavities. I was placed on a ventilator and ECMO (extra corporeal membrane oxygenation) shortly after. Despite all efforts, my lungs could not recover, which led to me having my first life-saving double-lung transplant on May 28, 2021.

#### What brought you to the ARDS Support group?

I felt a great need to connect with people that understood what I went through. I needed to not feel judged, especially when I spoke about my mental health issues after experiencing severe ICU delirium. It affected every aspect of my life and my family's lives. We may not all have the same aftermath from ARDS, but we have what changed our lives in common.

#### How has being a member been for you?

I've met so many people and have made some of the best friends I've ever had since joining the ARDS support group. It's a humble experience listening to others discuss their connection to ARDS and how it's changed their lives.

### What made you want to be involved with advocacy work with the ARDS Alliance?

When I realized there was a lack of awareness of ARDS, it made me want to speak openly and share my experiences in hopes that others could learn and support the need for research and education regarding ARDS, with the ultimate goal of eradicating it.

### What would you want others to know about ARDS?

There is no living with ARDS. You either survive it or die from it. There are more than 80 different ways to contract ARDS, with sepsis being the number one cause. ARDS does not discriminate; it can affect anybody regardless of background.



### Aside from having PICS, what do you want people to know about you?

I am a psychologist who retired early due to multiple disabilities. I live in northern Arizona. I love being able to see the red rocks and appreciate the beauty of this area. One of my favorite things is watching the wildlife frequently pass through our yard. We get to see bobcats, coyotes, javelinas, foxes, deer, lizards, and many birds. I live with Sally, my best friend and caregiver, and our cat Harley. My mother lives with us part time and part time with my sister (who lives two doors down). I am a coffee geek and look forward to drinking my coffee each morning. Sometimes I go to bed thinking of how wonderful that first sip of coffee will be.

#### Tell me what sent you to the ICU?

In 2018, 3 months after moving to AZ, I contracted H1N1 influenza. I was very ill with a temperature of 104.7, a terrible cough, and difficulty breathing. Our local stand-alone ER sent me home two times. Finally, on the third visit, they transported me via ambulance to the small community hospital in a nearby town and I was admitted to the ICU with sepsis, ARDS, double pneumonia, and organizing pneumonia. I was on a ventilator for three weeks and had a 10% chance of living.

#### What brought you to the ICU support group?

The first year after discharge the focus was primarily on physical therapy and learning to walk again and regain my strength and stamina. I had great support for this from my physical therapist.

I had an absolute lack of support for the other aspects of post-ICU syndrome - cognitive deficits and mental illnesses. Thankfully as a psychologist, I was able to identify that my difficulties were mostly executive function deficits - attention, focus, organizing, planning, multitasking, switching gears, low frustration tolerance. I was devastated by my difficulty reading as I had been an avid reader my whole life. However, I couldn't get help despite multiple efforts at trying.

Despite being a psychologist, I was slow to recognize the PTSD that I was experiencing. I kept thinking that that most of my symptoms were cognitive until I was supposed to take a trip to visit with a family member's new baby. I had a panic

attack. I was confused and trying to figure out why something that saved my life, the ICU, would cause PTSD.

However, I figured there must be others out there like me. I found my discharge paperwork and saw the term ARDS so I searched for that on the internet and came across the term PICS. Luckily, I found the CIBS Center support group. I emailed them and was extended an offer to join. I must admit it took me many months before I found the courage to join.

### What made you want to be involved in advocacy work and Walk 4 PICS?

The alarming and harmful lack of awareness within the medical and mental health profession gave me a desire to do something to help others who suffer with PICS. I wanted to find a way to raise awareness and if I could help reduce even one person's suffering, then I would feel I accomplished something important.

When the PICS Advocacy Network formed, I immediately joined. It gives me a sense of meaning and purpose to help raise awareness and work to change the system. There are millions suffering with PICS each year and they are falling through the cracks of the healthcare system.



I Am A
Survivor!!
Kirsten Harrell, PsyD

I know how awful it is to experience the symptoms of PICS - to know you are not the same person you were before ICU, to experience cognitive deficits, severe PTSD, and to feel alone as others don't understand what you are going through, and you can't find help within the medical or mental health systems. Even my loving family didn't understand or know how to help. I had times that I felt such despair, I experienced suicidal ideation.

These experiences have given me a calling to help make changes in the system so that others can get diagnosed and connected with services sooner to reduce suffering.

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

First, I want the term PICS to become as well known as diagnoses like MS or Parkinsons. I want people to understand that surviving the ICU is just the beginning for us. While our family/friends celebrate our survival, we are now faced with the beginning of a very long and arduous battle and need support through this. Unfortunately, way too many suffer alone and without support and that is a massive disservice to people who faced death and survived. It is imperative that we educate healthcare providers and do better at supporting both ICU survivors and families who suffer their own trauma.

I want people to understand that a great many of us experience ICU delirium and hallucination/delusions that were terrifying and still impact us even many years later. While we come to understand that these experiences were not real, they are super "sticky" in our brains. We feel confused that something that wasn't "real" can still cause PTSD and that we can experience flashbacks and intrusive memories and nightmares of these hallucinations. That, in and of itself, is disturbing and frightening.

Mental health providers need to understand this and treat these ICU delirium experiences with as much finesse and care as any traumatic experience. I want medical providers to understand that medical trauma and PTSD is real and makes it difficult for many of us to seek healthcare. Medical trauma/PTSD is different in a couple of ways. The threat came from inside us versus an external threat and it is often an ongoing threat. Many of us are left with new or worsened health conditions that could lead to future ICU stays. So it is difficult to work through the trauma and find healing and regain resilience.

### What would you like people to know about you beyond your involvement in ARDS?

I think that something people should know about me beyond ECMO and ARDS- is I am a sister of three! My sisters mean the world to me and have helped me through so much of my struggles in life. They never left my side when I was sick, in the hospital, or struggling with mental health outside of the hospital. I love them more than anything. I am also an avid music lover! I love classic rock and play the guitar!

### Could you provide an account of the circumstances that led you to the ICU?

On November 21, 2022, I was rushed to the hospital unable to breathe. I had Flu A, which in turn was a perfect storm combined with my asthma, and it quickly took a turn for the worse. I developed pneumonia, ARDS, and mucous plugs, as well as a collapsed lung. I was intubated and then placed on Veno-Venous ECMO as a last resort.

# How did you become involved in the ICU Support Group? In what ways has membership in the ARDS support group been beneficial to you?

In January, I realized that I wanted to become an advocate for survivors of ECMO and reached out to Jenna at Vanderbilt to see about creating a survivor group. Upon finding there was already a group, I was so excited to become involved. The PICS team, the incredible people in the groups, and Jenna have made such a difference in my work and my outlook.

### What motivated you to become an advocate for Walk 4 PICS?

Upon waking up from my ECMO stay, I had no idea where to turn. I was experiencing severe mental and physical health issues and did not know what had happened to me. I felt so alone even though I had people surrounding me with support. I realized I did not want others to go through this, and upon connecting with other survivors, I realized I was not crazy. The hallucinations, fears, and depression I felt were valid and common among survivors. I am honored every day to be making a difference and spreading awareness to survivors, loved ones, and healthcare providers about PICS.



# My Story: Surviving ECMO and ARDS

By Kira Rhyne
Advocate for ECMO and ARDS

### What information would you like others to gain about ARDS and ECMO?

If there is one thing I could tell others about ARDS and ECMO, I would tell them that they are not alone. No matter how hard and terrifying each individual journey is, we are united in small ways that make big differences. I encourage you to reach out, research, and find community (we ARE out there!!), as it makes the biggest and most important difference.



When making this website, my goal was to put everything all into one. When I woke up, all I received education-wise was a pamphlet along with my discharge papers. I did not understand the medical terms, and the doctors did not have time to really sit down and explain what ECMO is to me, so I took it upon myself to research the how's, why's, and what's of ECMO. This website is something that I will continue to add to as I pursue my education and career in healthcare, so there will be updates added as I learn of new research studies and connect with more survivors. The goal was also to include a pamphlet of questions for loved ones to ask in the ICU so that it is ensured that their family member is being adequately advocated for, and so that it can be documented. Often times, when someone wakes up from ECMO, their version of events versus the actual timeline of what happened is mixed up and fuzzy. I was so inspired reading David Richards' story, which showed the importance of "ICU diaries" and keeping things documented when someone is on ECMO. In short, on the website you will find a compilation of research, studies, and patient stories in terms you can understand, relate to, and learn from. My hope is that this will reach those who have been on ECMO, and help them both understand what it is, as well as knowing there is community in survivors, family members, and even healthcare workers. It is a one stop shop for all things ECMO. Please visit my website at survivingecmo.com

Thank you,

Kira



# **Caretaker for an ARDS Survivor**

Sally Clements, RN Caretaker and Advocate

### Walk me through a day caring for a family member.

As a nurse and a loving friend this is an exceedingly tough time to remember. When Kirsten left the ICU after surviving ARDS and was discharged home, I had little to no information on how to care for her. Caring for Kirsten was challenging on many levels. She had confusion and delusions daily. I had to try to get information on what she was thinking every minute of the day. She was living in another world that went between reality and some place I did not understand filled with fear and confusion. She was at times living in another universe with stories of evil people and places. I listened and reminded her she was home and safe with me, but she still had fears that I did not understand. She would talk about living in another place when she was in the hospital that was scary and evil. I was there every day with her in the hospital, and as a nurse, knew they were taking excellent care of her. She was weak and worked extremely hard to regain strength. She had periods where she was just silent in deep thoughts and memories. It was difficult for me because I was happy she survived with only a 10% chance of survival but constantly had to see her struggle. I felt very confused at times when I was celebrating her survival, and she questioned it and did not seem to be happy about surviving at times.

### What challenges verses rewards has this situation brought you?

The challenge to me is always worth the reward because my dearest friend survived ARDS. She is alive today even though our lives are quite different. We are still together as close friends. Caring for someone with ARDS is difficult but mostly for her. She has constant struggles, and I have always been there for her needs.

### Has this affected your relationship with your family members?

Yes, I also have needs. I am lonely at times because our lives are quite different. We no longer feel like we can do the things we enjoy together such as hiking, traveling to see family and friends. This is incredibly sad for both of us. This kind of evolved into question. I feel isolated at times, and our family feels like if they visit, they may bring infection with them. They do not want to bring anything into our home that may potentially cause an infection and rehospitalization due to her immune deficiency.

### Is there anything you wish you had known sooner?

I wish I had known from the ICU staff about the potential effects of Post-ICU Syndrome (PICS). The potential of PICS was not discussed; we were not given any information or places to seek help. I wish home care was more responsive to her needs. She was only given a few PT visits for teaching a home exercise problem. It was a joke to be honest. Yes, I was a nurse and knew a lot about home care, but the average person would not know how to deal with this.

### Is there anything you would recommend to others in your situation that has been helpful?

Most of all I would recommend that before she went home that I was instructed on ICU delirium and PICS and when to seek help. I also would have loved to know any support groups in the area to help with what she was feeling and how I was feeling. It was a very scary and lonely time.





#### Turning Suffering into Meaning: Reflections From the American Delirium Society Conference

Spencer Freeman, ESQ Survivor and advocate for Walk 4 PICS

This month we had the privilege of attending the American Delirium Society Conference in Nashville. We were deeply inspired by clinicians from across the world who gathered with one goal: to better understand and treat delirium. The passion in that room was undeniable—and personal. This conference allowed us to do something we've longed hoped for: turn suffering into meaning.

We were especially moved by the determination of Dr. Mikita Fuchita, who used to attend ICU survivor support groups as a young physician, eager to understand "what it's really like." Now, he's transforming care in his own ICU—mobilizing patients early, implementing delirium-prevention strategies, and making culture change real.

What struck us most was the way survivor voices were placed right alongside providers. That kind of inclusion is rare—and invaluable. It doesn't just validate those of us who've lived through delirium and Post-Intensive Care Syndrome (PICS); it equips providers with empathy and insight that only lived experience can offer.

Dr. Wes Ely spoke—not about triumphs, but about failures. He showed how, if we are honest and thorough from the start, our mistakes can become our greatest teachers.



### Mike's Corner

Mike is a PICS Survivor and Advocate

#### YOU HAVE SURVIVED!

You've been through more than most people will ever understand — surviving the ICU, facing fear, pain, and the shadows of PTSD.

You are still here, and that means something. It means there is more ahead for you... more healing, more light, and more peace.

Recovery is not a straight line. Some days will feel heavy, but each breath you take is a quiet act of courage. Do not rush your healing. Your spirit is doing sacred work; even when progress feels slow.

You are not alone. Grace walks with you in silence, in the small victories, and in the strength it takes to try again.

This is not the end of your story. It's a new BEGINNING — and every step forward, no matter how small, is proof that hope is still alive in you.

Remember, you are held, you are healing, and you are deeply and endlessly loved.

### **Newsletter Insights**



#### **Get involved in Walk 4 PICS!**

Join us in September at one of our walk sites around the world or in your community. We walk to challenge our bodies while raising awareness of Post-Intensive Care Syndrome (PICS). We want ICU survivors living with PICS to know that they are not alone and there is hope and support for their journey. If you haven't registered, please <u>click here</u> to join an existing walk or to walk in your community! We have set a goal to have 10,000 registered walkers worldwide; please sign up to walk and help us reach our goal.

#### U.S. Walks

Baltimore, MD Charlotte, NC Houston, TX Indianapolis, IN Lynchburg, VA Nashville, TN Orlando, FL Philadelphia, PA Pittsburgh, PA Rome, GA The Triangle, NC

#### **International Walks**

Brisbane, AUS Chester, England Perth, AUS The Hague, Netherlands

Interested in being featured in a future Walk 4 PICS newsletter? We would love to hear from survivors, caregivers, family members, healthcare providers, researchers - anyone who is passionate about their PICS story! Email Walk4PICS@gmail.com with a brief introduction. Survivors' stories are essential in raising awareness and moving the mission of Walk 4 PICS forward.

"It's important that we share our experiences with other people. Your story will heal you and your story will heal somebody else. When you tell your story, you free yourself and give other people permission to acknowledge their own story." Iyanla Vanzant

"Sharing our stories can also be a means of healing. Grief and loss may isolate us, and anger may alienate us. Shared with others, these emotions can be powerfully uniting, as we see that we are not alone, and realize that others weep with us." Susan Wittig Albert

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