

# FROM SURVIVING TO THRIVING: HELPING FAMILIES IN THE ICU SURVIVORSHIP JOURNEY

"Many people believe medicine is grounded in benevolence, that is, wishing good. It is more than that. The target principle of medicine must be a higher standard: beneficence. Doing good."

– E. Wesley Ely, MD, MPH Author, *Every Deep-Drawn Breath* 

At Vanderbilt University Medical Center, we excel in providing compassionate care to patients, conducting groundbreaking research and training health care leaders. We are grateful for your interest in how philanthropic support can influence the future of critical care medicine and the comprehensive healing journey of our patients and families.

As modern medicine improves and people live through illnesses that previously would have taken their lives, there is a public health crisis unfolding before our eyes. Survivors of critical illness can experience severe cognitive, mental health and physical disabilities that dismantle the life they and their loved ones anticipated living after discharge from the hospital.

To better serve these patients and their families, we seek to grow an endowment to improve survivorship based on the themes covered in the book *Every Deep-Drawn Breath*, a project established by the Critical Illness, Brain Dysfunction and Survivorship (CIBS) Center at Vanderbilt University Medical Center. Proceeds from the book initially established the CIBS Survivorship Endowment; philanthropic additions will deepen its impact and reach over years to come.

## A Program for Improved Survivorship to Elevate the Human Condition

Following a critical illness, patients and their families often lose themselves in the struggle to recover and resume their prior lives. Many aspects of living — jobs, hobbies, independence — become difficult or impossible because of residual effects of underlying illnesses, and often new conditions were brought on by the lifesaving treatments they received in the hospital. For people of any age, this can be devastating to the life they hoped to live for many years to come. Central to our mission is the premise that family members and other loved ones of patients are also significantly impacted by these critical illnesses and should be considered part of the care team within our programs.

Post-intensive care syndrome (PICS) and long COVID are two examples of chronic impairments after acute disease that we are targeting to help patients and families cope. Both syndromes

can cause or exacerbate dementia, depression, post-traumatic stress disorder, and moderate to severe physical and neurological injury. This constellation of problems makes it impossible for many people to work, carry out basic functions and engage meaningfully with the people they love. As a result, many lose their livelihood, struggle financially and experience dysfunction in their relationships and households.

There is a driving, unmet need to improve our care for millions of people and their loved ones experiencing the underrecognized public health problems of PICS and long COVID. Our program also is designed to address the important issues of equity, equality, respect and love that are fundamental to cultural empathy and the role it plays in healing injured patients.

### **Endowing the Program for Long-term Success**

Through the CIBS Survivorship Endowment, we aim to elevate the human condition by extending the life-saving triumphs of medicine into the recovery period — sometimes months and years following critical illness. We want to help those we serve learn to live their "new normal" in the most meaningful manner possible, and to scale our improved survivorship model broadly across the country and world.

Our financial goal is to build the endowment's principal so the income it generates in perpetuity can support our mission to improve survivorship. Our initial goals include the following:

- Create a support network a Survivorship Safety Net with a two-pronged approach:
  - Host support groups for patients and family members to share experiences
  - Develop a sustainable model for post-discharge survivorship clinics that include a physician, psychologist, nurse, pharmacist, physical/occupational therapist and social work navigator to help patients and families cope and find resources
- Fund clinical trial research in PICS and Long COVID designed to improve survival, brain recovery, and quality of life
- Fund professional development for team members in CIBS to maintain top-level skills
- Develop toolkits to help other sites in the U.S. and abroad build similar programs

With sufficient investment in talent and research capacity, our Critical Illness, Brain Dysfunction and Survivorship Center has the potential to become one of the best in the world. Toward this end, we look to grow this endowment to further secure the future of this robust interdisciplinary center for research, patient care and training.

## The Impact of Philanthropy

For CIBS patients and their families, the CIBS Survivorship Endowment will help chart a way forward. Endowed support will ensure this type of life-changing, comprehensive care continues far into the long term, for the benefit of patients and their loved ones at our center and far beyond.

We welcome the opportunity for further discussion. For additional information, please contact:

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#### **Making Health Care Personal**

Managing more than 2.5 million patient visits each year, Vanderbilt University Medical Center is one of the largest academic medical centers in the Southeast and is the principal referral center for adults and children with complex conditions throughout Tennessee and the Mid-South. Vanderbilt is one of the nation's foremost recipients of research awards from the National Institutes of Health and, as a renowned center of learning, trains thousands of physicians, nurses and health care professionals in over 150 medical specialties each year. Philanthropy is making it possible for Vanderbilt to be a transformative leader in treating all diseases impacting humanity through breakthrough discovery science, intensive clinical training and distinctive, personalized care.