

ENDSEPSIS

The Legacy of Rory Staunton

ORGANIZATION OVERVIEW



WELCOME.

We founded **END SEPSIS** almost ten years ago, following the tragic and preventable death of our son Rory, determined to channel our grief into action. Over the past decade we have educated millions of Americans about sepsis, empowered families to advocate for their best care, spearheaded invaluable research and brought together leaders from across sectors for the first time to apply their skills and resources to the problem of sepsis.

As nationally recognized patient advocates with firsthand experience of the devastating toll of sepsis, we have consistently exercised our power to hold our leaders accountable. We have taken our campaign from state capitals to the United States Senate and the White House.

Our successes have proven again and again the critical role that patient advocates play in pushing policies forward. Our voices have the power to convince all the necessary stakeholders to take a place at the table, to cut through the noise, the disagreements, the bureaucratic stalling and create policies that result in real, lifesaving change for families across America.

We are at a critical moment in this journey; 2022 will bring an unprecedented opportunity to enact the kind of profound and widespread change that we hardly dared dream of when we embarked on this endeavor. With a firm and respected voice, we will see that the momentum never waivers. We will ensure that the honorable and committed experts engaged in this work never lose sight of the radical impact that their efforts could have—children returned healthy and whole to their parents' embrace, mothers who survive to love and nurture their families, grandparents, sisters, brothers, friends who are alive to make their mark on the world.

After all, this is personal. We know what failure looks like—we have lived it.

Failure is not an option.

- Ciaran and Orlaith Staunton



2022: ACTION, ACTION, ACTION.

In 2022, we are intently focused on realizing the original goal we set for ourselves when we began this journey almost 10 years ago: the enactment of a national sepsis policy that successfully remedies the staggering rates of sepsis mortality and morbidity in the United States. And we're closer to reaching this objective today than at any point over the last decade. We have convened a stellar coalition of health policy leaders and together we are actively working with government partners to facilitate a national approach to sepsis identification and treatment.

We hope you will join us as we take this fight into its next chapter, building on the progress made over the past 10 years. **Sepsis remains the leading cause of hospital deaths and the most expensive condition treated in American hospitals. 275,000 Americans die each year from sepsis and many thousands more are left with life changing disabilities.** The time for bold action to drastically change these numbers is here. We would be pleased to hold a more in-depth discussion of our policy work with all interested parties.





PUBLIC POLICY

SEPSIS PROTOCOLS

In 2013, END SEPSIS led efforts to make New York State the first in the nation to establish a statewide mandate requiring all hospitals to adopt sepsis protocols. Known as Rory's Regulations, the legislation requires every hospital in the state to develop protocols designed to improve rapid identification and treatment of sepsis.

By 2017, reporting showed:

 **20%**
INCREASE
in sepsis identification

40%  
DECREASE
IN PEDIATRIC SEPSIS DEATHS
when protocols were correctly implemented

 **21%**
INCREASE
in survival rate

By 2019, reporting showed:

16,011 LIVES SAVED

Throughout this process, we rallied experts and worked with hospital groups to keep the momentum going and ensured the focus was always on the end goal: saving lives.



PUBLIC POLICY

THE PARENTS' BILL OF RIGHTS

Advocating for the rights of patients is a key priority for our organization. END SEPSIS campaigned for, and secured, a [Parents' Bill of Rights](#) for all hospitals in New York State. It is designed to improve quality and oversight of the care provided to pediatric patients. The bill requires hospitals to improve communication with patients and parents in the emergency room and to implement procedures to ensure that parents and primary care providers receive vital information about children's care. As a result, parents and caregivers are able to make informed decisions that are often critical to the health of their children.

RORY STAUNTON'S LAW

In 2017, New York State passed [Rory Staunton's Law](#) requiring all professionals working in the healthcare field, including physicians, physician assistants, dentists and nurses, to complete coursework or training in sepsis prevention.

This law covers approximately 468,000 professionals across the state, ensuring that the infections that lead to sepsis are prevented from occurring in the first place.



FEDERAL INITIATIVES

Since its inception, our organization has consistently challenged public health officials, legislators and the healthcare establishment to better protect the public against sepsis. In 2013, END SEPSIS was responsible for:

- The first ever Senate Hearing on sepsis
- Increased federal funding for sepsis initiatives
- The creation of a sepsis section on the CDC website
- The formation of the National Family Council on Sepsis to organize and train patient advocates to effectively convey in the most personal terms the real world impact of sepsis and the need for policies that drastically reduce sepsis mortality and morbidity

SEPSIS AWARENESS & EDUCATION

MATERNAL HEALTH

Maternal sepsis is the second leading cause of maternal death in the United States. Those who survive are often left with severe physical, emotional and psychological trauma. In 2020, END SEPSIS was awarded a contract from the US Department of Health and Human Services to develop a comprehensive campaign to raise awareness of maternal sepsis among patients and healthcare providers and reduce its devastating effects on families.

Our work included:

- A partnership with the NY Department of Health to analyze all maternal sepsis data in the state and identify those at higher risk so that they could be targeted for education and interventions. These groups included:
 - Very young mothers
 - Women of color
 - Those who underwent C-sections and experienced complicated deliveries.
- The creation of a comprehensive **maternal sepsis public awareness campaign** for expectant mothers
- Education for all women's health providers to improve outcomes for pregnant women and new moms

**No woman should die
from giving birth.**

Maternal sepsis can be deadly for new moms.

Learn how it can
be prevented.

Visit
endsepsis.org/mothers

ENDSEPSIS



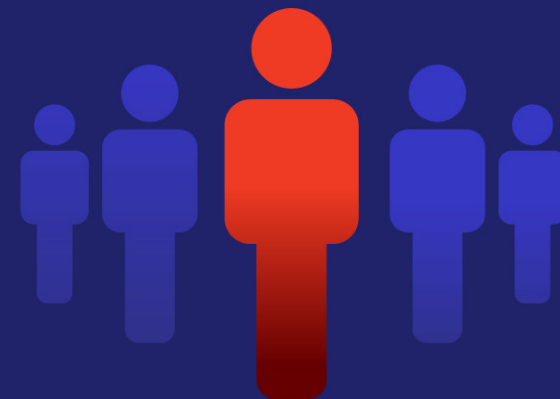
SEPSIS AWARENESS & EDUCATION

FOCUS ON PATIENT ADVOCACY

We strongly believe that all patients and their caregivers should be empowered and equipped to advocate for themselves and their loved ones. In addition to the [Parents' Bill of Rights](#) and [Rory Staunton's Law](#), our awareness campaigns have provided families with the language and encouragement they need to take charge of their care.

We have also elevated the perspective of patient advocates by drafting [editorial commentaries](#) to accompany new research in peer reviewed medical journals.

1 IN 5
DON'T
SURVIVE



Sepsis kills 275,000 Americans each year

KNOW THE SIGNS OF SEPSIS

FEVER/ SHIVERING
OR VERY COLD

RAPID
BREATHING

EXTREME PAIN/
PHYSICAL DISCOMFORT

PALE OR
MOTTLED SKIN

DISORIENTED/ CONFUSED &
SLEEPY/ DIFFICULT TO WAKE

ELEVATED
HEART RATE

endsepsis.org

ENDSEPSIS

ENDSEPSIS

The Legacy of Rory Staunton

&

STELLA

saves lives

PRESENT:

HOW TO ADVOCATE FOR YOUR CHILD'S BEST CARE

IN 4 PARTS



It's our right as parents to speak up, ask questions
and raise concerns about our children's care.

Follow our social media series to learn how.

SEPSIS AWARENESS & EDUCATION

THE SIGNS OF SEPSIS

ENDSEPSIS is continually engaged in educating the public about the signs and symptoms of sepsis. We do this through media appearances in major print and television outlets including People Magazine and the Today Show, public service announcements, social media campaigns, sharing vital materials and patient stories and through speaking engagements across the country. We know that every person who learns to correctly identify the signs of sepsis could mean a life saved.



SEPSIS AWARENESS & EDUCATION

K-12 CURRICULUM

Our education curriculum, developed in partnership with the American Federation of Teachers, is currently being used to educate K-12 students about infection prevention and sepsis across the country. Since the onset of the COVID-19 pandemic, the curriculum has gained even more traction as teachers seek to keep their students safe from infection.

The curriculum meets numerous national education standards and is available for download on the AFT's [Share My Lesson](#) platform, accessed by over a million teachers throughout the country.

In New York State, [Rory Staunton's Law](#) requires that the curriculum be available to all schools in the state free of charge and ensures that a guidance memorandum is issued annually by the education commissioner to remind school districts to encourage its use.



NATIONAL FORUM ON SEPSIS

In 2014, the inaugural National Forum on Sepsis brought together the best and the brightest in healthcare policy, government, critical care, patient advocacy and biotechnology. For the first time, these disparate stakeholders were asked to focus their attention and expertise on the issue of sepsis and to identify and address challenges and opportunities in the sepsis crisis.

Speakers at the annual National Forum on Sepsis have included Senator Charles Schumer, I Centers for Medicare and Medicaid (CMS) and the Centers for Disease Control and Prevention (CDC), prominent patient advocates and leading figures from the medical community and private industry.

