

# Testimony of Ciaran Staunton

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Rory Staunton Foundation

United States Senate Committee on Health, Education, Labor and Pensions

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## **Rory Staunton Foundation Testimony**

Chairman Harkin, Ranking Member Alexander and Members of the Senate Health, Education, Labor and Pensions Committee, and your wonderful staff -- thank you for inviting me here to testify at this important Hearing, "U.S. Efforts to Reduce Healthcare-Associated Infections". My name is Ciaran Staunton. I am Rory's Staunton's dad. I am here today with my wife, Orlaith and Rory's sister, Kathleen.

My son Rory died from sepsis. However, before I give you our personal testimony, I would like to acknowledge all of the families and loved ones who are here today including Carl Flatley, Erin Flatley's dad. Erin died from sepsis aged 23years in 2002. This is a long awaited day for sepsis advocates, those who have lost loved ones, sepsis survivors, and for those in the medical profession globally, who have worked tirelessly to raise awareness of sepsis. I thank you.

- Sepsis kills more Americans than AIDS.
- Sepsis kills more American children than pediatric cancer.
- Sepsis is the most expensive condition billed to Medicare. (Weir, HCUP Statistical Brief #107, 2011)
- Sepsis costs the American economy over \$17 billion a year. It is the most expensive reason for hospitalization. (Hall, NCHS Data Brief, No.62, 2011)

Our son Rory died tragically on April 01, 2012 and that was the day our lives changed forever. It was the day that no parent ever wants to go through. It was the day our beautiful young man died from sepsis, something we had never heard of before. Following his death we read the statistic that 70% of Americans had never heard of sepsis and we also discovered that sepsis is one the largest killers not only in the United States but in the world. Yet, sepsis has not received the attention it deserves from governments

throughout the world or indeed up until today in these United States. The Staunton family, through The Rory Staunton Foundation, is determined to change this situation.

The story of our beloved Rory's tragic death from sepsis begins on Wednesday when he fell and scraped his elbow playing in his school gym. The gym teacher proceeded to cover the wound without washing it and did not send him to the school nurse who was in her office. This was the first of many institutional failures.

When Rory came from school he hung out, did his homework, ate some pizza and went to bed. A little after midnight, in the early hours of Thursday morning, we awoke to hear Rory throwing up in the bathroom, not a lot of sickness but he was screaming "my leg, my leg". My wife, Orlaith brought him back to bed and he fell asleep as she rubbed his leg. The following morning he had a fever and continued to complain of the pain in his leg.

We began calling his pediatrician immediately as his temperature was over 104 (he had never had a temperature that high) but more worrying was that the over-the-counter medication commonly used, wasn't bringing the temperature down. After many calls to the pediatrician's office, she called us back and we insisted that she see him. She agreed to see him at 6pm that evening. On Thursday evening, supported by his mom as he was unable to make the journey on his own, Rory made his way to her office where she, the pediatrician noted that he was shivering, had a fever of 102 auxiliary and had an extremely red throat.

- his pulse she noted as 140,
- his blood pressure 100/60,
- his respirations were 36 per minute,

We pointed out his skin, which the pediatrician noted as being mottled and blanched.

She noted that he had upper abdominal pain and had a cut on his left elbow.

We told her it was the pain in his leg that he was screaming about. He vomited large amounts of yellowish fluid while in her office. Rory said “It’s the pain in my leg that’s bothering me”. The pediatrician said it was from the fall, he said no.

Nonetheless she referred him to the Emergency Room for re-hydration with a diagnosis of gastric flu. This represents the second incidence of an institutional failure.

At the emergency room they concurred with the diagnosis of gastric flu, ignoring any other symptoms present. They gave him IV fluids. We didn’t know then, but in fact blood tests were ordered stat., however as far as we know they were never read.

What we do know is that he was discharged and these blood results, when returned to the ER, showed among other alarming signs that his blood was producing white blood cells at rates that were very abnormal and would suggest a serious bacterial infection.

12 minutes before Rory left the hospital his vital signs were taken, his condition had deteriorated. It appears that no one took the time to review all available information. They discharged him noting “patient improved,” despite that fact that his vital signs were totally irregular and had deteriorated since his arrival there. The Hospital staff concluded he had a sick stomach was suffering from dehydration.

This flu they said, might take up to a week to clear. They said he will have diarrhea but will feel better in a few days. This was the third and final failure of an institution causing Rory’s death.

On the following morning, Friday, Rory’s temperature continued to be high, he was very tired, his leg hurt a lot and he had complained of dizziness. We were not convinced of the stomach virus diagnosis, and we began calling his pediatrician.

The pediatrician told us not worry about the temperature. We were told to focus on getting food into him. Despite our attempts to convince her that that was impossible, we nonetheless bought him Gatorade, sprite, ginger ale, coke-anything we thought he would drink. Late that afternoon we made a trip to get chicken soup. He took one sip and returned to sleep. He had diarrhea and we were elated as the pediatrician told us to expect this – a common sign of intestinal flu. We thought for sure this was definitely the stomach virus they told us about.

His mom stripped him down and checked to see if they had missed a bug bite. She also checked him for signs of meningitis.

Finally that evening, seeing his skin turn blue/black and his face begin to turn yellow, we returned with him to the ER where all hell broke loose. Despite the best efforts of the wonderful staff in the ICU our son Rory died at 6:29 pm on that Sunday evening, April 1<sup>st</sup>, 2012. He was in severe septic shock with multiple organ failure.

Our beloved son Rory was the light of our lives. He should never have died.

Rory was a child no one ever forgot. Although, only 12 years old, he was already 5'9" tall and weighed over 160 pounds!

Rory was deeply interested in life and had many questions on international politics, science, technology and the ways of the world. In fact, CNN was his favorite station!

He was captain of his school debate team where he had won many awards for speaking, he was on the Lego Robotics team, and he was elected by his peers to serve on the school's Student Council.

An advocate for special needs children and working in conjunction with the Special Olympics, Rory had already set up a campaign to curtail the use of the "R" word at his school. The "R" word being the word retard, a put-down term used by some children. Rory was deeply upset by the use of this word and had the children at his school sign a pledge to stop using it.

He was a natural leader, eyeing a career in politics or aviation. He dreamed of being the next Sully Sullenberger. He read and reread Sully's memoir. He had already flown his first airplane, a 12<sup>th</sup> birthday gift from us. Although he was only 6 when Rosa Parks died, he had already read everything about her. Her bravery deeply affected him. We believe, as those around him do, that the world has lost an incredible human being who was also a fantastic big brother to his sister Kathleen.

After Rory died we found a letter that he had written to the Swedish ambassador to North Korea asking how a country like North Korea could afford such an enormous army and experience such famine at the same time. Rory had such an incredible moral compass.

Rory was named President of "Kidadelphia", a country formed by his neighborhood friends whose motto was, "In God and Fun we Trust."

Here is how other in the world saw Rory:

- "He was the most profound twelve year old I have met," Kevin Burgoyne/Debate Coach and Sixth Grade Humanities teacher.
- "It was possible to look at a child and, as an adult said, I could be more like him," Roger Hitts, President Sunnyside Gardens Park.
- "Even after one meeting, I knew I would never forget him and I would say the same about his sister Kathleen. Two powerful young people," said, Pulitzer Prize winner and New York Times writer, Jim Dwyer.

After he died, we discovered that Rory had died from sepsis. In our deep state of despair we were shocked to find out that sepsis kills more Americans than the combination of breast cancer, lung cancer and stroke combined. It kills more Americans than AIDS. It is the largest killer of children in the world – 6 million.

We as a family felt compelled to ensure that no other child or adult died because of this killer. We contacted our New York State Governor Andrew Cuomo. He shared our anger and he immediately put us in touch with the New York Health Commissioner Nirav Shah. Commissioner Shah felt an urgent need to address sepsis and vowed to change New York State policy.

Working with us Commissioner Shah and Governor Cuomo announced the introduction of “Rory’s Regulations.” These regulations, named for Rory now require all hospitals in New York State to adopt protocols to identify and treat sepsis. The protocols will be evidence-based and will in addition; deal with fluid resuscitation timeframes for infants and children. It includes the demand for sepsis training of all staff including laboratory and pharmacy. The sepsis regulations were adopted on May 1, 2013 with the support of all New York hospitals. Rory’s Regulations will help New York set a “gold-standard” for patient care. Governor Cuomo believes that 5,000 to 8,000 lives a year in the State of New York will be saved as a result of Rory’s Regulations.

Sepsis is a medical emergency. It is the body’s often deadly response to infection. It requires early detection and treatment for survival. Every minute counts. Administration of antibiotics and fluids saves lives. For example, Intermountain Health Care in Utah reported savings of \$38 million per year as a result of a sepsis program. When the Intermountain team launched a protocol-based approach to improving sepsis care, the health system’s 25% sepsis mortality rate was already below the national average. Four years later Intermountain had a 9% mortality rate; as a result, Intermountain saves 85 more lives each year and saves \$38 million in annual costs. (*See Needles in a Haystack: Seeking Knowledge with Clinical Informatics*, PwC Health Research Institute, 2012)

Experts agree that key to fighting sepsis is ensuring quick diagnosis and treatment within the “golden hour,” when it can be most effective.

The New England Journal of Medicine states, “... During septic shock, there is an absolute decrease of 7.6 percentage points in the survival rate for each hour.” ((10.1056/NEJMe1203412) was published on

May 22, 2012, at NEJM.org) Global Sepsis Alliance concurs, that we must “recognize sepsis as a medical emergency requiring administration of fluids, antibiotics and other appropriate treatments of infection within one hour of suspicion of sepsis”.

Pilot initiatives in some hospital systems have shown great strides in decreasing sepsis mortality through effective implementation of what is basically a “check list” – a standardized protocol to facilitate quick and accurate diagnosis and fast and effective treatment as soon as any sign of sepsis arises. A recent multi-hospital report showed that mortality rates dropped in half with these basic steps. (Miller, Am J Resp Crit Care Med 2013).

If this strategy was applied to all Americans, it could save more than 150,000 lives a year-more than 400 people a day,

But only one state has required these simple protocols be implemented in all hospitals. New York State’s adoption of Rory’s Regulations represents the first government in the United States mandating evidence-based protocols for the early diagnosis and treatment of sepsis.

Sepsis is a medical emergency. Sepsis needs to be suspected; once it is suspected and treated we can save lives and save the US economy billions.

We are calling on Congress to institute a federal nationwide program of education on early detection of sepsis with similar standards in all fifty states. We are also calling on Congress to create a comprehensive educational resource so that doctors, nurses and, yes, parents and patients can include sepsis as a possible diagnosis when a patient shows up in an emergency room with similar symptoms to Rory. Sepsis is not a deadly disease when caught in time. Antibiotics are remarkably effective and many die from ignorance of how to recognize the condition as Rory did.

Mr. Chairman we have heard from at least five sets of parents since Rory died who are certain that Rory and the publicity surrounding his case saved their children’s lives when their kids began to suffer from



similar symptoms and they demanded that doctors test for it. We want to ensure that it becomes common practice in every state in the union that such tests and consideration of a sepsis diagnosis be the norm in medical practice. There can be no more Rorys. Our hearts are broken and we want to ensure that no other parent lives through this nightmare. Know that the care that Rory received is not unusual for sepsis patients in America, is this the care you would choose for your children?

In Britain, the government there recently outlined a complete overhaul of sepsis procedures after an examination that revealed 37,000 people had died many of them needlessly. (<http://www.theguardian.com/society/2013/sep/12/nhs-patients-dying-sepsis-care-failings>) We in America can hardly fail to match that.

Rory's story of sepsis was a wake -up call to many. We believe that knowledge is power. If we had known about sepsis, Rory would be alive today. If Rory's doctors had suspected sepsis he would be alive today. Unfortunately, there are many, many Rory's in the United States.

There is hope. Sepsis is treatable in a manner that reduces costs.

The Rory Staunton Foundation seeks to reduce the number of sepsis-caused deaths through education and outreach. Our son Rory should not have died. The Rory Staunton Foundation will work tirelessly to advocate for changes and press ahead with awareness and education regarding sepsis.

Thank you for your attention today.