Pediatric Sepsis Advocacy

Pediatric Sepsis Community of Practice

February 20, 2025

Champions for Children's Health

Welcome

Today's Presenters:

- Peter Silver, Chief Quality Officer | *Northwell Health*
- Melissa Schafer, Director Hospital Medicine | *Upstate Golisano Children's Hospital*
- Deborah Campbell, Vice President | *Kentucky Hospital Association*
- Elizabeth Brown, Vice President Federal Affairs | *Children's Hospital Association*

Advocates for Sepsis: Orlaith and Ciaran Staunton

Peter Silver MD, MBA
Senior Vice President
Associate Chief Medical Officer
Chief Quality Officer
Northwell Health

Northwell Health®

Rory Staunton

- On Thursday, March 29, 2012, 12-year old Rory was brought to his pediatrician's office and then to a university hospital Pediatric ED because of fever, vomiting, and aches in his abdomen and legs.
- One day prior, he fell while playing basketball, opening a cut on his arm.
- At the hospital, vital signs included HR 142, and Temp 102 F.
- Patient's mother (Orlaith) reported his skin to be "blotchy".
- Labs were drawn, hydration given, and Rory discharged home with diagnosis of viral syndrome. Pulse was 131 at the time of discharge.

- 3 hours post-discharge, the CBC resulted with an elevated WBC and marked left shift.

Rory Staunton

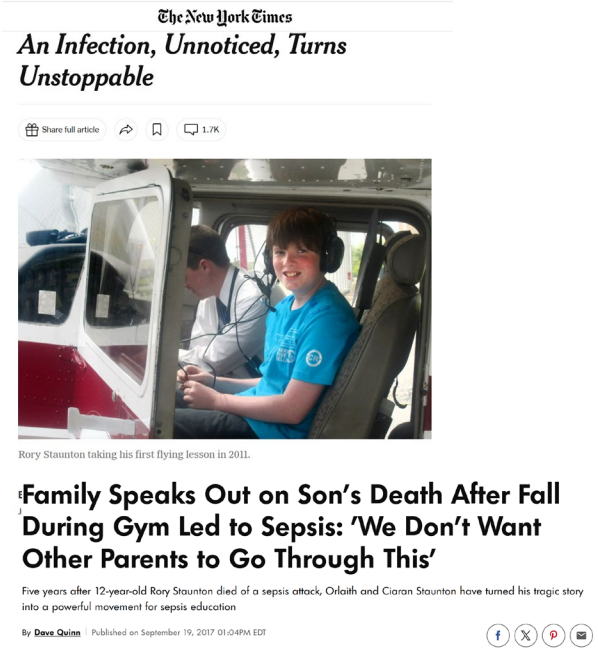
- The next day, Orlaith and Ciaran returned to the ED with Rory because of marked weakness, persistent vomiting, and cyanosis.
- His course progressed to include multisystem organ failure and purpura fulminans.
- Blood culture done on admission was positive for *Streptococcus pyogenes.*
- Rory expired April 1, 2012.

Orlaith and Ciaran Staunton

- Orlaith and Ciaran (civic activist) became advocates for better sepsis detection and treatment, and for patient rights.
- Friends
- Media
- New York State DOH Investigation

- Rory Staunton Foundation
- Endsepsis.org
- New York Public Health Law: “Rory’s Regulations”

“Rory would want no other child to go through what he went through.”



The New York Times

An Infection, Unnoticed, Turns Unstoppable

Share full article 1.7K

Rory Staunton taking his first flying lesson in 2011.

Family Speaks Out on Son’s Death After Fall During Gym Led to Sepsis: ‘We Don’t Want Other Parents to Go Through This’

Five years after 12-year-old Rory Staunton died of a sepsis attack, Orlaith and Ciaran Staunton have turned his tragic story into a powerful movement for sepsis education

By Dave Quinn | Published on September 19, 2017 01:04PM EDT

Rory's Regulations

NYS Public Health Law 2803 10NYCRR, Section 405

- All hospitals must have in place (and submitted to NYS) evidence-based protocol for rapid identification and treatment of patients with sepsis
- Minimum requirements
  - Adult: (a) measurement of lactate (b) collection of blood culture © administration of broad-spectrum antibiotics (d) fluid administration e) fluid status assessment (f) vasopressors and remeasurement of lactate for eligible patients.
  - Pediatrics: (a) blood culture collection (b) antibiotic administration © fluid administration and therapeutic endpoints
- Hospitals must report data to NYS DOH
- Hospitals must train providers to recognize and treat sepsis.
- Other:
  - Criteria for Pediatric ICU and requirement for transfer
  - Parent's Bill of Rights: Critical lab values must be communicated to patient/family (including outstanding/pending tests if not resulted)

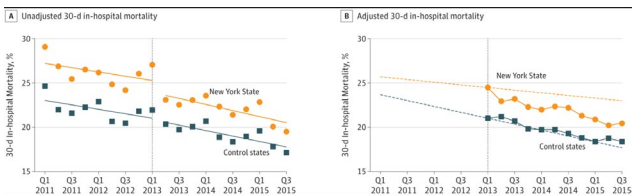
Impact of Rory's Regulations in NYS

JAMA | Original Investigation

Association Between State-Mandated Protocolized Sepsis Care and In-hospital Mortality Among Adults With Sepsis

Jeremy M. Kahn, MD, MS; Billie S. Davis, PhD; Jonathan G. Yabes, PhD; Chung-Chou H. Chang, PhD; David H. Chong, MD; Tina Batra Hershey, JD, MPH; Grant R. Martsolf, PhD, MPH, RN; Derek C. Angus, MD, MPH

- Review of New York vs other state data from 2011-2013 (pre-implementation) and 2013-2015 (post-implementation)
- Findings: NYS mandated sepsis care was associated with a greater decrease in sepsis mortality compared with control states that did not implement sepsis regulations.



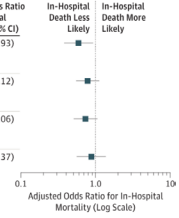
JAMA | Original Investigation

Association Between the New York Sepsis Care Mandate and In-Hospital Mortality for Pediatric Sepsis

Idris V. R. Evans, MD, MSc; Gary S. Phillips, MAS; Elizabeth R. Alpern, MD, MSCE; Derek C. Angus, MD, MPH; Marcus E. Friedrich, MD; Niranjan Kissoon, MD; Stanley Lemeshow, PhD; Mitchell M. Levy, MD; Margaret M. Parker, MD; Kathleen M. Terry, PhD; R. Scott Watson, MD, MPH; Scott L. Weiss, MD, MSCE; Jerry Zimmerman, MD, PhD; Christopher W. Seymour, MD, MSc

- Review of New York cohort of pediatric patients 4/2014 – 3/2016, comparing completion of 1-hour bundle vs not completing bundle.
- Findings: Completion of entire bundle within 1 hour (24.9%) was associated withlower risk-adjusted odds of in-hospital mortality (odds ratio 0.59 [95% CI, 0.38 to 0.93], p=0.020

Model	Total Deaths/Total No. (%)		Risk-Adjusted In-Hospital Mortality, % (95% CI)		Risk Difference From Adjusted Model, % (95% CI)	Adjusted Odds Ratio for In-Hospital Mortality (95% CI)
	Completed Within 1 h	Not Completed Within 1 h	Completed Within 1 h	Not Completed Within 1 h		
Completion of the entire 1 h bundle within 1 h	22/294 (7.5)	17/885 (13.2)	8.7 (5.4-12.0)	12.7 (10.5-14.7)	4.0 (0.9 to 7.0)	0.59 (0.38-0.93)
Antibiotics administered within 1 h	89/798 (11.2)	50/381 (13.1)	11.1 (9.1-13.1)	13.2 (9.7-16.6)	2.1 (-1.1 to 5.2)	0.78 (0.55-1.12)
Blood cultures prior to antibiotics completed within 1 h	71/740 (9.6)	68/439 (15.5)	10.7 (8.3-13.0)	13.3 (10.5-16.0)	2.6 (-0.5 to 5.7)	0.73 (0.51-1.06)
Intravenous fluid bolus completed within 1 h	59/548 (10.8)	80/631 (12.7)	11.2 (8.3-14.1)	12.3 (9.6-15.0)	1.1 (-2.6 to 4.8)	0.88 (0.56-1.37)



EndSepsis.org

- Founded by Orlaith and Ciaran Staunton in 2012
- Families and individuals fighting for improved sepsis care
- Pursue implementation of public health policies
- Host public awareness campaigns
- Annual meetings with national leaders in Washington
- Recent lobbying successes (FY23, FY24):
  - CDC funding for sepsis (Senator Schumer)
  - CDC Core Elements for Sepsis
  - Release of updated AHRQ data report
- Current discussion:
  - Sepsis outcomes
  - Federal reporting of pediatric sepsis measures

ENDSEPSIS
The Legacy of Rory Staunton

PRESS RELEASE: END SEPSIS Opens First White House Sepsis Event

From Problem to Statute: Getting a bill across the finish line

Deborah R Campbell, MSN, RN, CPHQ, IP, T-CHEST, CCRN alumna

VP of Clinical Strategy and Transformation

Kentucky Hospital Association

KENTUCKY NURSES ASSOCIATION

What is KHA?
Represents 129 facilities (all of them!)

- The Kentucky Hospital Association was established in 1929 to represent hospitals, related health care organizations, and integrated health care systems dedicated to sustaining and improving the health status of the citizens of Kentucky.

"The Kentucky Hospital Association will be the leading voice for Kentucky health systems in improving the health of our communities."

Acute Care Hospitals

Critical Access Hospitals

Long Term Acute Care Hospitals

Rehabilitation Hospitals

Behavioral Health Hospitals

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KHA Advocacy

- Represent Kentucky's hospitals in Frankfort and Washington, D.C.
  - Testify regularly in Frankfort
  - Submit comments on regulations and rules
- **KHAPAC** – KHA Political Action Committee
- **VoterVOICE** Advocacy Action Center
- **KentuckyHospitalAdvocacy.com**

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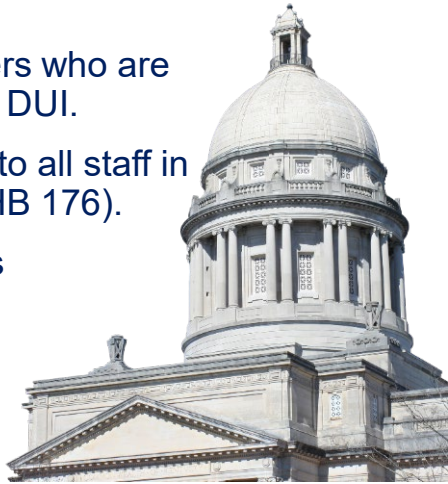
Past Advocacy Wins

- ✓ **House Bill 75** updates the Hospital Rate Improvement Program (HRIP) to include Medicaid outpatient services.
- ✓ **House Bill 200** establishes the framework for a public/private partnership that can be used for scholarships and financial support to health care training programs.
- ✓ **Senate Bill 199** provides liability protection for HC workers who are court ordered to draw blood from a patient suspected of a DUI.
- ✓ **House Bill 194** expands workplace violence protections to all staff in healthcare facilities, not just hospitals (follow up to 2023 HB 176).
- ✓ **House Bill 477** legislates reimbursement for early sepsis treatment not be eliminated

*Supported KNA decriminalization of error bill



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The beginning
Kentucky Statewide Sepsis Consortium

- Started with **one person** - Darrell Raikes (sepsis survivor on a mission)
- Grew to encompass all Kentucky hospitals
- Monthly data collection
- Monthly educational webinars
- Quality improvement activities
- Sepsis metrics included in our state directed payment program (HRIP)
- Improvement!

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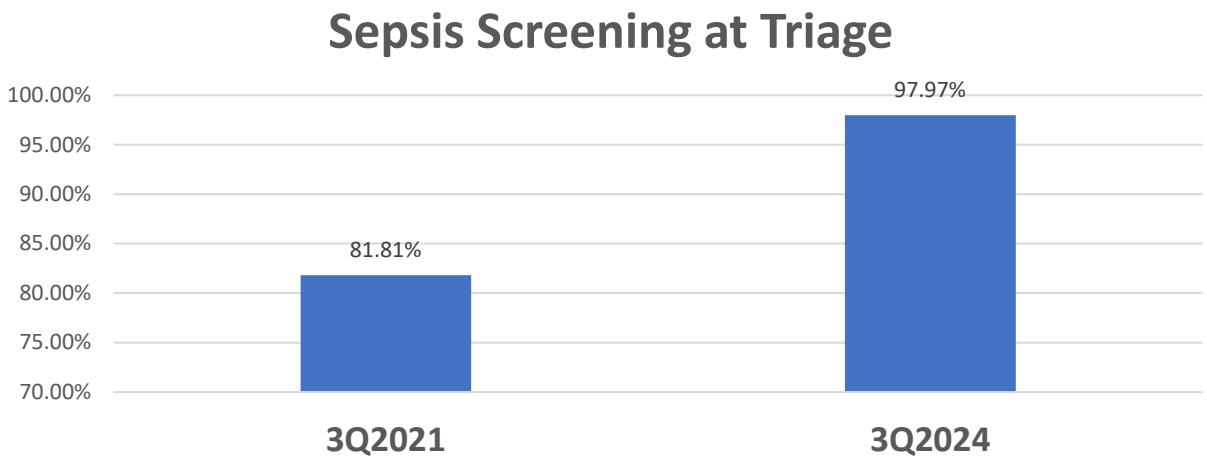
First metric- Screening at Time of Triage in the ED



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Defining the Problem- sepsis claim issues

- Hospitals were reporting denials and down-coding of claims if the SEP-3 definition was not met.
- SEP-3 requires signs of organ failure so early recognition, care and treatment were not being reimbursed.
  - Facts v. Anecdotes
    - All hospital representatives invited to share via a listening session
    - Requested data on actual numbers
  - Scope
    - One hospital? 129 hospitals? **Universal problem**
    - Type of entity
      - Critical Access Hospital(s) v. Large Urban Hospitals
  - Harm- who is being hurt? Is the harm significant?
    - Patients? Would hospitals change the care they are providing?
    - Hospitals- financial impact certain and demonstrable

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To Engage or Not to Engage: That is the Question!

- Assessing Alignment with Organizational Mission/Strategic Goals
  - Gaining Agreement from the Bosses- the Board
    - Are all hospitals aligned? A majority? How large a majority?
    - Opposed? Understand their perspective. Seek consensus if possible.
  - Bandwidth/Resources
    - Bill/regulation writer
    - Research
    - Lobby efforts
    - Partner development
      - Built in/long standing partners
        - KNA (KMA, KONL, KDPH, KBN)
      - Opposition research and mitigation- initially DMS

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Assessing for Opposition

- Shoot out the OK Corral beats a sniper attack
- Remove?
  - Convince (Data, stories, trade support)
  - “Other states have already changed to use of SEP-3” **FALSE**
- Mitigate?
  - Will they oppose or just agree to remain silent on the issue?
- What clout does your opposition have?

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Establishing Trust

- Building Relationships with Legislators
  - Finding a Partner
    - Party affiliation matters
    - Constituents can be powerful
    - Similar background, profession- **2 RNs**
    - Knowledge of personal experience he/she may have had
      - Senator
      - Representative

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The Bill

- Writing the Bill
  - Scope of ask- Medicaid Managed Care Organizations
  - Experience with legalese but keep it as simple as possible
  - Are there similar bills from other states/federal
  - Seek input before, during and before finalizing the draft
  - Be prepared to revise multiple times

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Building a Coalition

- Relationship first!
- Strange Bedfellows at times
- Previous liaisons
- Quid pro quo
- Seeking active support v. signature on

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Lobbying

- When to start
  - Funding needed?
  - Budget year- Don’t wait!
- Who to start with
  - Party affiliation
  - Committee membership (Chair?)
- Use your members
  - ‘Voter voice’, calls, letters
- Clear concise communication- verbal and written (One Pagers)

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Preparing to Testify

- Anticipating questions
- Move to vote??
- Recording of testimony (at mark 12:06) 12 minutes
- https://ket.org/legislature/archives/2024/regular/house-health-services-committee-9kz49o
- https://www.weku.org/the-commonwealth/2024-02-23/kentucky-legislature-eyes-bill-seeking-to-ensure-medicaid-coverage-for-early-sepsis-diagnosis

1:31 minutes

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Questions/Comments

Thank you!

Deb Campbell, MSN, RN, CPHQ, IP, T-CHEST, CCRN alumna

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Educate Before you Advocate: How CHA Works with You in DC

February 20, 2025

Elizabeth Brown, VP, Federal Affairs

Champions for Children's Health

Stronger Together

CHA is the only pediatric-focused hospital association, bringing together more than 200 children's hospitals and health systems to advance child health and the delivery of care.

This year it will be important to continue to work together to protect and strengthen pediatric health care.

CHILDREN'S HOSPITAL ASSOCIATION

Who are your advocates in DC?

- Your friendly CHA lobbyists
- Your Government Relations Professionals

Advocacy and Policy Foundation

The basics…

- Insert **children** into policy conversations so that their unique needs are addressed and not forgotten.

- Highlight the critical role that **children's hospitals** play for children and the need for additional support to meet their vital missions.

Meeting Policymakers Where They Are

- Preserving access to care
- Sen. Schumer's sepsis work
- Children's Cancer Caucus
- SG mental health work
- Connecting members with hospitals

Top Policy Priorities

A **national force** to protect and improve children's health care.

- Protect and strengthen Medicaid and access to pediatric care.
- Stop proposals that negatively impact children's access to care.
- Bolster support for the pediatric workforce.
- Address the children's mental health crisis.

childrenshospitals.org/advocacy

Photo: Joseph M. Cascio, John R. Oishei Children's Hospital

Medicaid is Critical to Children and Children's Hospitals

Asks:

- Swiftly pass Accelerating Kids Access to Care.
- Act immediately to stop pending DSH cuts.
- Consult us as you look at Medicaid policies and seriously consider any impact on children the providers who care for them.
- We share your desire to ensure our nation’s children are healthy and able to thrive into adulthood.

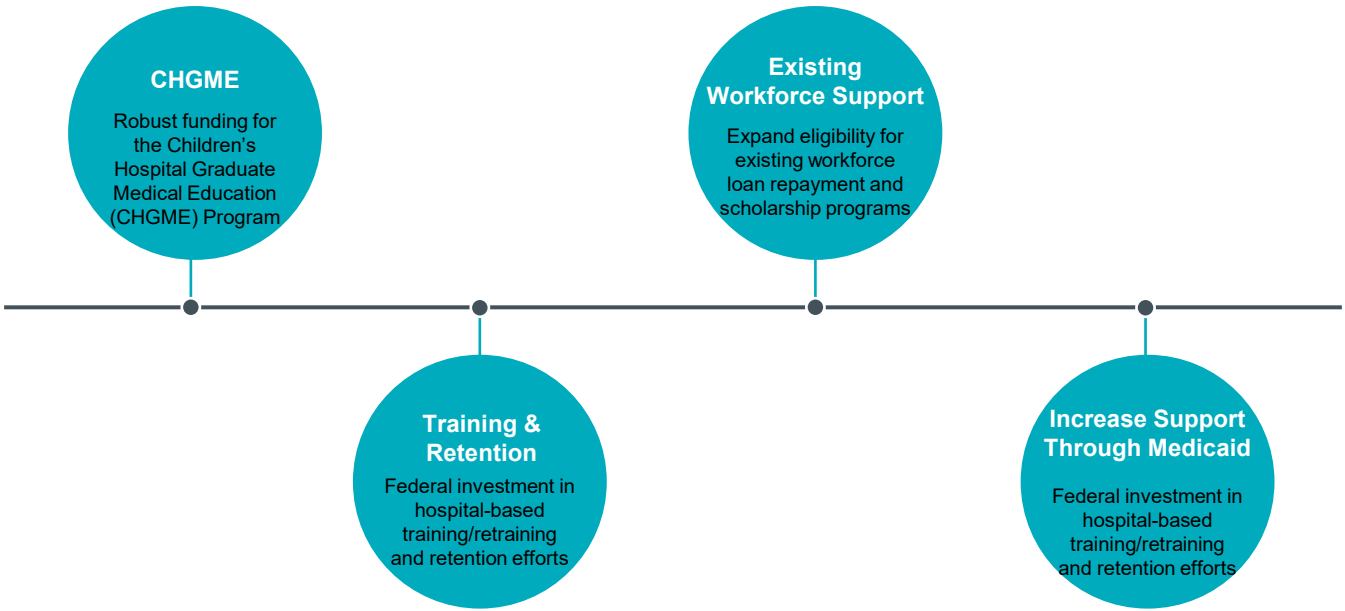
CHA sent letter to Congress on Medicaid last week

Policies are being considered that jeopardize children's access to care.

We want to share the unique and harmful specific impact these policies can have on children's access to care at your hospital and in your state and communities.

- Site neutral and facility fees.
- Explain the importance of facility fees to supporting care for children with complex needs closer to their homes.
- Changes to 340B.

Pediatric Workforce Priorities



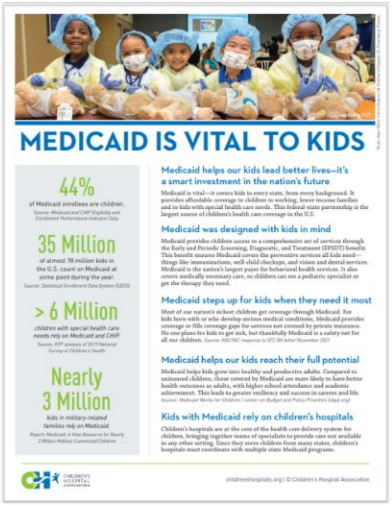
Pediatric Mental Health

The kids' mental health crisis continues to present challenges for children's hospitals. The increase in boarding is particularly difficult with, **84% of hospitals boarding more youth patients, and 75% reporting longer boarding stays**, compared to before the pandemic**.**

- Strengthen mental health investment in Medicaid.
- Bolster community-based systems of care.
- Invest in pediatric mental health workforce and infrastructure.
- Extend and enhance telehealth flexibilities.
- Improve implementation of the mental health parity law.
- Ensure support for mental health crisis services and suicide prevention designed to address the unique needs of children and teens.

Advocacy Resources

State of Children's Health Dashboard



Find additional resources here!


Anyone can be an advocate!!!

Family Advocacy Day

20th Anniversary in Washington, D.C.

June 11 - 13, 2025

Contact Us!

Elizabeth Brown, VP, Federal Affairs:
Elizabeth.Brown@childrenshospitals.org
615-512-9991

Sepsis CoP Updates

Webinar: Phoenix Criteria	• Thursday, March 20 • 12pm ET |11a CT| 10a MT | 9a PT
Sepsis CoP Survey	• Due date extended! • Purpose: Evaluate effectiveness of CoP & build on the model!
Sepsis CoP Metrics Submission	• Sent to designated contacts ***only at former IPSO sites NOT in Sepsis Data Tracking***. • Due ***Sunday, February 23*** • Purpose: Evaluate sustainability of key IPSO process measures.

Questions? Email quality.programs@childrenshospitals.org

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