



CHILDREN'S
HOSPITAL
ASSOCIATION

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



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

f x p e

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 resultated)

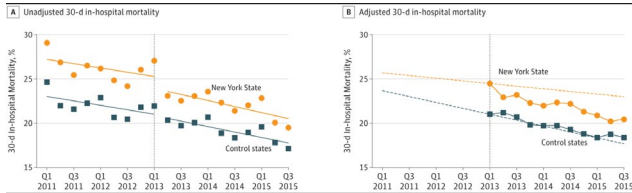
Impact of Rory's Regulations in NYS

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; Nirangan Kissonoo, MD; Stanley Lemesnow, PhD; Mitchell M. Levy, MD; Margaret M. Parkes, 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 with lower 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) | In-Hospital Death Less Likely | In-Hospital Death More Likely |
|--|----------------------------|--------------------------|---|--------------------------|---|--|-------------------------------|-------------------------------|
| | 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) | ■ | |


Adjusted Odds Ratio for In-Hospital Mortality (Log Scale)

- 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



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

| KHA Strategic Plan: 2023-2024 | | | | | Kentucky Hospital Association |
|---|--|--|---|--|--|
| Mission: The Kentucky Hospital Association will be the leading voice for Kentucky health systems in improving the health of our communities. | | | | | |
| Vision: To transform the health landscape to make high quality care more affordable and accessible for the people of Kentucky. | | | | | |
| Strategic Pillars | Thought Leadership | Patient Access and Service | Membership VALUE | Patient Safety and Quality | Business Operations |
| Goals: | <ul style="list-style-type: none"> • Represent our members as their leading advocacy voice in Kentucky and Washington, D.C. • Produce industry leading research, data and policy | <ul style="list-style-type: none"> • Convene and connect key stakeholders and resources to create an adequate workforce for the future • Expand pathways; remove barriers to education and retain workforce | <ul style="list-style-type: none"> • Direct a consistent high level of member engagement and satisfaction • Support our members in achievement of economic stability and success | <ul style="list-style-type: none"> • Aid our members in improving health outcomes • Assist our members in reducing preventable health care associated harm | <ul style="list-style-type: none"> • Lead a fiscally responsible, efficient and effective organization • Drive a workplace culture of excellence and accountability |
| Objectives: | <ul style="list-style-type: none"> • Successful State & Federal Advocacy, including: <ul style="list-style-type: none"> • Fund Medicaid • Protect & maintain CDR • Workforce development • Appropriate adjustment • Address white billing and EHR reform • Preserve SDOH program • Address site neutral payment • Develop a communication strategy to highlight hospital success | <ul style="list-style-type: none"> • Support worker safety initiatives through expansion of legislation and technology • Convene and connect with stakeholders to build an adequate supply of health care workers • Provide resources to support members and stakeholder addressing workforce development | <ul style="list-style-type: none"> • Continue to ensure member engagement and satisfaction • Continue the successful implementations of HRSA and LPE programs • Develop and coordinate solutions with health plans • Provide economic and financial policy expertise, initiatives and reporting • Enhance member educational programs & events • Increase PAC contributions & provide political opportunities | <ul style="list-style-type: none"> • Continue support for HRSA Quality grants • Provide clinical expertise • Provide education, training and certifications • Improve and expand access to behavioral services • Continue expansion of our successful clinical leadership program • Facilitate Peer to Peer Learning • Expand ED Bridge Programs across Kentucky • Increase engagement in the SANE ready program • Connect community providers to assist with social determinants of health | <ul style="list-style-type: none"> • Strengthen staff engagement, including strategic plan development • Manage performance to strategic plan and track deliverables • Standardize and enhance business processes • Develop more robust fundraising process and leadership team engagement • Elevate website, social media and CRM capabilities and utilization • Grow non-due revenue, including cross-selling alliance |

KHA Advocacy

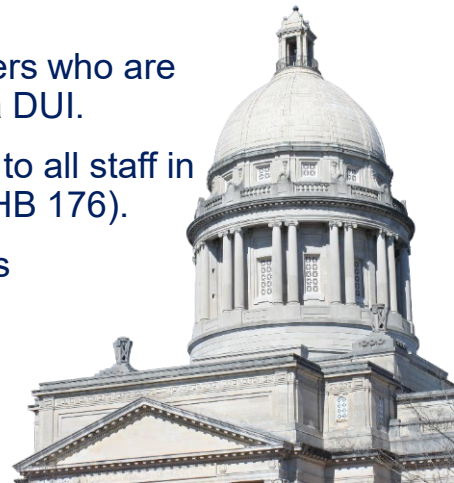
- Represent Kentucky's hospitals in Frankfort and Washington, D.C.
 - Testify regularly in Frankfort
 - Submit comments on regulations and rules
- **KHAPAC** – KHA Political Action Committee
- **VoterVOICE** Advocacy Action Center
- **KentuckyHospitalAdvocacy.com**



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**



The beginning Kentucky Statewide Sepsis Consortium

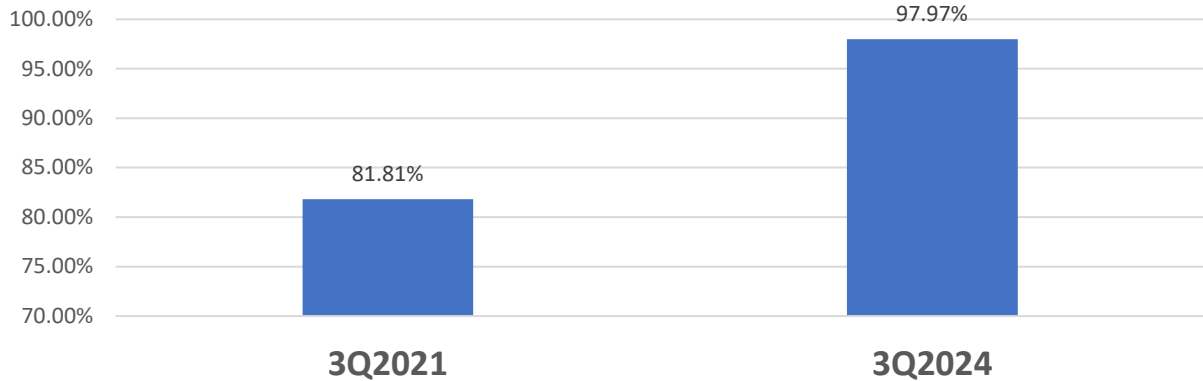


- Started with one person - Darrell Raikes (sepsis survivor on a mission)
- Grew to encompass all Kentucky hospitals
- Monthly data collection
- Monthly educational webinars
- Quality improvement activities
- Sepsis metrics included in our state directed payment program (HRIP)
- Improvement!

First metric- Screening at Time of Triage in the ED



Sepsis Screening at Triage





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

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**

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?

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

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

Building a Coalition

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



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)

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



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

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.



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

CHGME

Robust funding for the Children's Hospital Graduate Medical Education (CHGME) Program

Existing Workforce Support

Expand eligibility for existing workforce loan repayment and scholarship programs

Training & Retention

Federal investment in hospital-based training/retraining and retention efforts

Increase Support Through Medicaid

Federal investment in hospital-based training/retraining and retention efforts



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



MEDICAID IS VITAL TO KIDS

44%
of Medicaid enrollees are children.
Source: Medicaid and CHIP Enrollment and Expenditure Performance Report, July 2022

35 Million
of almost 78 million kids in the U.S. count on Medicaid at some point during the year.
Source: Medicaid Enrollment Data System (MEDSD)

> 6 Million
children with special health care needs rely on Medicaid and CHIP.
Source: ASP analysis of 2019 Medicaid Survey of Children's Health

Nearly 3 Million
kids in military-related families rely on Medicaid.
Source: Medicaid & CHIP Resources for the Family, Children's Military Community Coalition

Medicaid helps our kids lead better lives—it's a smart investment in the nation's future.
Medicaid is vital—it covers kids in every state, from every background. It provides affordable coverage for children, ensuring they can get the care and services they need to thrive. This federal-state partnership is the largest source of children's health care coverage in the U.S.

Medicaid was designed with kids in mind.
Medicaid provides children access to a comprehensive set of services through the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit. This benefit ensures Medicaid covers the preventive services all kids need—things like immunizations, well-child checkups, and vision and dental services. Medicaid is the nation's largest payer for behavioral health services. It also covers medically necessary care so children can see a pediatric specialist or get the therapy they need.

Medicaid steps up for kids when they need it most.
Most of our nation's at-risk children get coverage through Medicaid. For kids born with or who develop serious medical conditions, Medicaid provides coverage for the extra costs they face. Medicaid also covers private insurance for some plans for kids to get work, but thankfully Medicaid is a safety net for all our children. Source: Medicaid resources | 1/17/24 | 10/18/2023

Medicaid helps our kids reach their full potential.
Medicaid helps kids grow into healthy and productive adults. Compared to uninsured children, those covered by Medicaid are more likely to have better health outcomes as adults, with higher school attendance and academic achievement. This leads to greater resilience and success in careers and life. Source: Medicaid & CHIP Resources for the Family | 10/18/2023

Kids with Medicaid rely on children's hospitals.
Children's hospitals are at the core of the health care delivery system for children. Bringing together the best of medical care, prevention and care available in any other setting, these hospitals serve children from every state, children's hospitals most consistently seek multiple state Medicaid programs.



childrenshospitals.org | © Children's Hospital Association



FOCUSING ON CHILDREN'S MENTAL HEALTH

Childhood Development Matters

While mental and behavioral health conditions can and do occur at any age, symptoms, and conditions often begin in childhood. By investing in prevention and treatment, children will grow up healthier and develop the skills they need to go on to successful and fulfilling lives.

Youth Mental Health Crisis

America is experiencing a crisis in the mental health of children and adolescents, which begins long before the pandemic, and worsened as a result of the tremendous stress and uncertainty experienced by families. Children's hospitals are among the largest on youth every day, through a steep rise in the number of emergency department (ED) and inpatient visits for suicidal thoughts or self-harm, with rates more than doubling since 2016.

42%
of high school students feel so sad or hopeless at least some of the time for at least one month in a year that they stopped doing their usual activities.*

1 in 10
high school students attempted suicide one or more times during the past year.*

59%
of youth with major depression do not receive any mental health treatment.*

1.2 million
youth who are covered under private insurance do not have coverage for mental health care.*

1 in 5
children and adolescents experience a mental health condition in a given year*.

50%
of mental illnesses begin by age 14*.

14%
of suicides are youth and young adults between the ages of 15 and 24, making it the second leading cause of death*.

1 in 5
teens have contemplated suicide*.



childrenshospitals.org | © Children's Hospital Association

The Children's Hospitals Graduate Medical Education Program (CHGME)



Children's hospitals are Congress to provide **\$778 MILLION** for CHGME in FY 2024.

Who does CHGME train?
15,860
residents and fellows were trained with support from CHGME funds in academic year 2022-2023.

More than half of both pediatricians and pediatric specialists are trained at CHGME hospitals.*

The future of children's health in our nation is directly tied to the strength of our pediatric workforce. Congress created the Children's Hospitals Graduate Medical Education (CHGME) program in 1999 because it recognized that a dedicated source of funding for training pediatricians and specialists in children's hospitals was critical to ensuring a robust pediatric workforce. CHGME has enabled children's hospitals to dramatically increase pediatric physician training and significantly increase the number of pediatricians and specialists who care for the nation's children. However, there continues to be a significant shortage in pediatric specialists due to disparities between funding for physician training at adult hospitals compared to training at children's hospitals.

Which hospitals receive CHGME funding?
Though CHGME-funded hospitals make up just 1% of all hospitals nationwide, these children's hospitals provide close to one-third of the inpatient hospital care received by children covered by Medicaid. At the least funding hospitals may offer pediatric training but are not eligible for CHGME since the majority of their patients are not children under the age of 18.

59
children's hospitals, which provide care to children under the age of 18 and have an inpatient pediatric training program, receive CHGME funds.

60%
of CHGME-funded physicians who complete their training program choose to practice in the state where they completed their residency*.



childrenshospitals.org | © Children's Hospital Association

Find additional resources [here!](#)

A young girl with blonde hair, wearing glasses and a cochlear implant, is looking upwards with a smile. She is wearing a pink shirt. The background is a vibrant field of colorful flowers. There are several circular graphic elements: a large white circle on the left containing text, a yellow circle in the top right, a grey circle in the bottom left, and a blue circle at the very bottom left.

**Anyone
can be an
advocate!!
!**

Family Advocacy Day

20th Anniversary in Washington, D.C.



June 11 - 13, 2025





Contact Us!

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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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