2025
IMPACT REPORT

The NEC Society is the world's leading nonprofit organization dedicated to necrotizing enterocolitis (NEC). We are led by a global community of patient-families, clinicians, and scientists. Together, we are accelerating NEC research, education, and advocacy to transform what is possible for infants and families.

NEC SOCIETY

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One year closer to a world without necrotizing enterocolitis

NEC SOCIETY®
Building a world without NEC

2025 was a year of momentum

Powered by community

I am filled with hope, gratitude, and awe as I reflect on the NEC Society's work and community in 2025.

Our international movement uniting families, clinicians, scientists, and companies generated the most impactful NEC Awareness Month and the world's largest NEC Symposium.

Together, we are advancing the research, tools, and strategies urgently needed to protect every baby from the devastation of necrotizing enterocolitis. Our remarkable progress and impact are fueled by the experiences and needs of families and clinicians caring for our babies.

Thank you for believing in the NEC Society's vision and being part of this incredible community. Thank you for allowing me to share my son, Micah, with you, and for sharing your stories, babies, hearts, and time with me. I feel deeply honored and privileged to be on this journey with you.

Jennifer Canvasser
Founder, Executive Director
NEC Society

1,139	**600+**	**250+**	**10**
Babies enrolled in the NEC Biorepository	Family resource boxes to NICUs across the US	NEC Symposium global participants	States with NEC Awareness Resolutions

Research. Education. Advocacy.

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Building a world without NEC

Leaders for a world without NEC

The NEC Society is guided by a dedicated community of leaders, experts, and advocates who help ensure our work is both scientifically rigorous and grounded in lived experience. Our **Board of Directors** provides governance and strategic direction, our **Scientific Advisory Council** brings internationally recognized expertise to guide our programs and materials, and our **Patient-Family Advisory Council** ensures that patient-family voices are integrated into all our work. Together, this team is advancing our shared vision of a world without NEC.

NEC Society Staff

Jennifer Canvasser
Executive Director

Erin Pryor
Research Director

Justin Bray
Development Director

Sarah Piephoff
Communications Director

Board of Directors

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Shannan Finegan, Mom of Cash
Samir Gadepalli, MD, MBA
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Tyler Vallano, Dad of Cole

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Jina Maloney, Mom of Remy
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Cassey Oliger, Mom of Nora
Tabitha Pasmino, Mom of Gabriela
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Olivia Gorvy Rotem, Mom of Gali
Marie Spruce, Mom of Freddie
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Ravi Patel, MD, MSc
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Michael Caplan, MD

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Advancing science for a world without NEC

We launched the patient-led NEC Registry

The NEC Registry is a platform for patient-families to share their experiences with NEC, from diagnosis to the long-term physical, social, and emotional impacts of the disease. This is **a powerful opportunity for individuals and families affected by NEC to contribute directly to research** that will help us understand this devastating disease.

> **"We urgently need better strategies to prevent and treat NEC. At the NEC Society, patient-families work alongside researchers and clinicians, which inspires our broader community to collaborate."**
>
> *Ravi Patel, MD, MSc, NEC Society Scientific Advisor and neonatologist at Emory University and Children's Hospital of Atlanta*

1,139 Babies enrolled in the NEC Biorepository led by Dr. Misty Good

UNC Chapel Hill NEC Biorepository Team

NEC Research Incubator

What began in 2022 as a small group of clinician-scientists sharing NEC research has **grown into a global collaborative of nearly 200 members across disciplines,** united by their dedication to building a world without NEC.

120+ Global institutions represented in the Research Incubator

Conference Highlight

Pediatric Academic Societies (PAS) NEC Club

The 2025 PAS NEC Club, hosted by the NEC Society, brought together hundreds of clinician-scientists from around the world and explored the exceptional nutritional needs of babies at risk of, and diagnosed with, NEC.

The largest NEC Symposium

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Building a world without NEC

Cincinnati Children's

UNC HEALTH Children's

Uniting the global community for a world without NEC

The NEC Symposium in Chicago was the world's largest meeting dedicated to necrotizing enterocolitis (NEC). Over three days, more than 250 clinicians, researchers, and patient-families came together to advance understanding, prevention, diagnosis, and treatment of NEC.

The meeting provided a transformative learning experience for renowned leaders, clinicians, researchers, and trainees, while centering patient-families in every conversation.

98%

of participants plan to use what they learned to improve their patients' outcomes

> **"I have dedicated my career to infants at risk of NEC and more than a decade to the NEC Society. The NEC Symposium is a rare opportunity to collaboratively confront and break down barriers to move closer to a world without NEC."**
>
> *Jae Kim, MD, PhD, NEC Society Scientific Advisor; Director of Neonatology at Cincinnati Children's Hospital*

> **"This is the most amazing meeting I have been to in my entire career. The power of having families, clinicians, and researchers together is unmatched in the other meetings we attend as physicians and healthcare providers."**
>
> *Aloka Patel, MD, NEC Society Scientific Advisor; Chief of Neonatology; Research Director for Neonatology, Rush University Children's Hospital*

Learn more about the NEC Symposium and join us in San Diego, September 19-22, 2027.

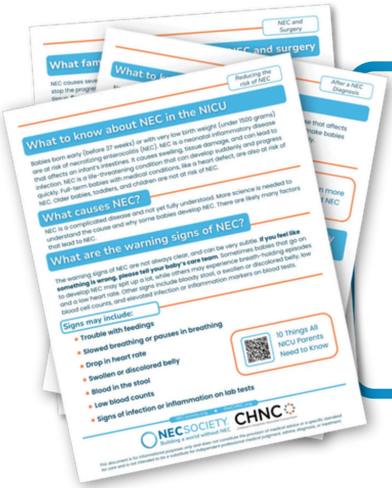
Family-Centered Impact

In 2025, we strengthened partnerships and reached more families than ever before. We also developed new educational resources to empower families to advocate for their child. The NEC Society is an essential resource and trusted leader in the NEC community for families and clinicians alike.

We distributed 600+ family resource boxes to NICUs across the US

Our Family Resource Boxes provide evidence-based information about NEC and resources to empower families. **Thanks to the unwavering support of partners like Medela, our boxes are in more NICUs, reaching more families than ever.**

> "The NEC Society's resource box for bereaved families helped us put words to how we were feeling and how to tell those around us to love and support us. It continually reminds us that we are Gabriela's parents even if she is no longer here."
>
> *Tabitha Pazmino, Mom of Gabriela,*
> *NEC Society Patient-Family Advisor*



Reducing the risk of NEC

What to know about NEC in the NICU

Babies born early (before 37 weeks) or with very low birth weight (under 1500 grams) are at risk of necrotizing enterocolitis (NEC). NEC is a neonatal inflammatory disease that affects an infant's intestines. It causes swelling, tissue damage, and can lead to infection. NEC is a life-threatening condition that can develop suddenly and progress quickly. Full-term babies with medical conditions, like a heart defect, are also at risk of NEC. Older babies, toddlers, and children are not at risk of NEC.

What causes NEC?

NEC is a complicated disease and not yet fully understood. More science is needed to understand the cause and why some babies develop NEC. There are likely many factors that lead to NEC.

What are the warning signs of NEC?

The warning signs of NEC are not always clear, and can be very subtle. **If you feel like something is wrong, please tell your baby's care team.** Sometimes babies that go on to develop NEC may spit up a lot, while others may experience breath-holding episodes and a low heart rate. Other signs include bloody stool, a swollen or discolored belly, low blood cell counts, and elevated infection or inflammation markers on blood tests.

Signs may include:

- **Trouble with feedings**
- **Slowed breathing or pauses in breathing**
- **Drop in heart rate**
- **Swollen or discolored belly**
- **Blood in the stool**
- **Low blood counts**
- **Signs of infection or inflammation on lab tests**

10 Things All NICU Parents Need to Know

NECsociety.org • theCHNC.org

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CHNC Children's Hospitals Neonatal Consortium

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Expanding family education through partnership

In partnership with the Children's Hospitals Neonatal Consortium NEC Focus Group, we developed new resources to guide families at risk of or affected by NEC. **These are the first resources designed to reach families before diagnosis, sharing essential information about risk factors and potential early warning signs to help build a world without NEC.**

Breaking down medical jargon for families

To meet the needs of our community, the NEC Society created a NEC glossary that **simplifies complex medical terminology and empowers families to better understand their baby's care in the NICU.**

Preparing for the world's first in-person Family NEC Summit

In 2026, we will build off the momentum of the NEC Symposium to host the world's first in-person Family NEC Summit — a space for families to connect, learn, and accelerate our mission, together.

"It's so great to have a stage to tell my son's story, and incredible to be around parents who have gone through what I went through—who understand that pain in a totally different way. And to meet parents who have been able to take their children home and watch them grow, to hear about the challenges and the successes of that. To have different perspectives together has been extremely inspiring."

Nicola Juri, Mom of Ronan, who tragically passed away from NEC, speaking about the NEC Symposium; NEC Society Board Member

Addressing families' need to transform their pain into power

Families impacted by NEC collaborate with clinicians and scientists at the NEC Symposium because it is essential to integrate the lived expertise of families so we can better understand, prevent, diagnose, and treat NEC.

We launched the first NEC Symposium in 2017, and it is now the world's largest, most impactful scientific meeting on NEC. **With your support, we can build an equally powerful experience for families with the Family NEC Summit.**

Families at the NEC Symposium in Chicago

"I had never met another family affected by NEC until I became part of the NEC Society. The NEC Symposium was so moving and powerful—to be not only with families who have also lost their children to NEC, but also with clinicians and scientists dedicating their careers to babies like mine. It would be incredible to build an equally transformative learning experience for patient-families, where we can connect and collaborate with other families to advance the research, education, and advocacy this community urgently needs."

Stephanie Ruidiaz, Mom of Luna, who tragically passed away from NEC; NEC Society Board Member

Advocating for babies and families

The NEC Society is actively engaged in advocacy efforts to protect the health of NICU babies and families, improve equitable access to healthcare and pasteurized donor human milk, and advance science and research funding.

Protecting preemies with March of Dimes

At the March of Dimes Advocacy Summit, we met with elected officials to advocate for the **PREEMIE Act**, which represents the federal government's commitment to preventing prematurity, and called for the urgently needed protection of Medicaid.

On The Hill with NICU Parent Network

We teamed up with NICU advocates from across the US, and met with congressional offices to advocate for H.R. 236, the **NICU Babies' Bill of Rights**, which raises awareness for patient-family integration and shared decision making in the NICU.

Actively engaging with the FDA

The NEC Society continues to work with the FDA to help advocate for the neonatal community, from families to clinicians and scientists, to optimize the strategies and tools available to best support the health of infants and protect them from the devastation of NEC. **It is essential for families and clinicians to work together to navigate the risks and protective factors associated with NEC in the NICU.**

Community Highlight

Running to advocate for a world without NEC

As a charity partner with the California International Marathon (CIM), our team of 18 runners woke up before sunrise, put on their NEC Society jersey, and ran 26.2 miles for a world without NEC!

"I'm running for the NEC Society because I want to be part of the solution that is fighting for better early detection and more research."
Ethan Kissock, NEC Society CIM Charity Runner

The most impactful NEC Awareness Month *ever*

22 Community events raising NEC awareness

350+ New donors inspired by our community

$135K Raised for babies & families impacted by NEC

10 States with NEC Awareness Resolutions

Katie and Aslan worked with elected officials to pass **New Jersey's NEC Awareness Resolution** in honor of their son, John, who tragically passed away from NEC.

Sara and Joe worked with elected officials to pass **South Carolina's NEC Awareness Resolution** in honor of their son, Zack, who was diagnosed with NEC and now has long-term complications.

[Learn how to recognize NEC Awareness Month in your community!]

The NEC Society relies on an international network of individuals to support and advance our mission of building a world without NEC. Here are just a few powerful highlights from 2025!

A Toast to Tiny Tummies

Tyler and Janelle hosted their first annual event, to honor their son, Cole, who developed NEC while he was in the NICU. They invited their friends out for a night of food, drinks, and games, all to raise funds and awareness to advance our mission.

YOLO 2K, 5K, 10K

We partnered with UC Davis Children's Hospital to host our first annual YOLO Run for a world without NEC.

On May 17, NEC Awareness Day, **300 runners gathered in Davis, CA, and virtually,** to run in honor of babies and families.

[Register for the 2026 YOLO Run here!]

FY25 Financials

Financial Health

I am thrilled to be the newest member of the NEC Society team and encouraged by the organization's strong financial position as we close out FY25. Thoughtful planning and the transformational support of the Chan Zuckerberg Initiative have allowed us to invest strategically in our operations while drawing on unrestricted investment assets that provide stability and long-term runway, all while maintaining a clear focus on sustainability as we work toward a world without NEC.

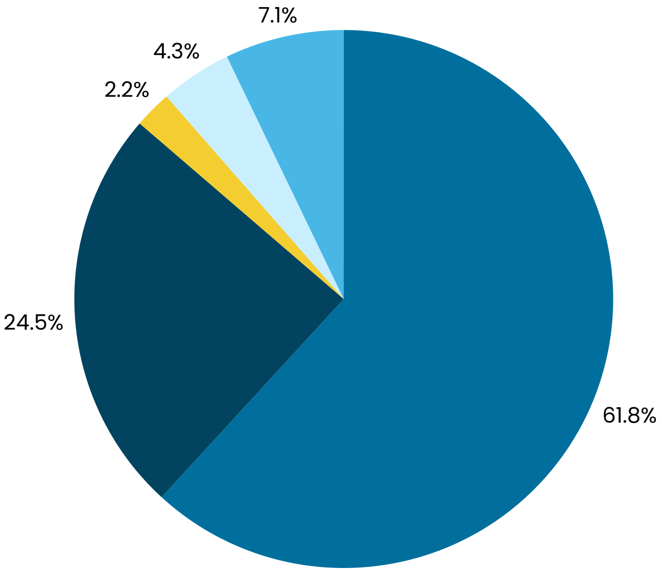
As we look ahead, I am excited to steward these and future resources through a multi-year development strategy that builds on this foundation. In 2026 and beyond, our focus will be on growing our Champions Program, expanding our global community of recurring donors, and securing foundation and grant support to advance the NEC Society's mission and impact for babies and families.

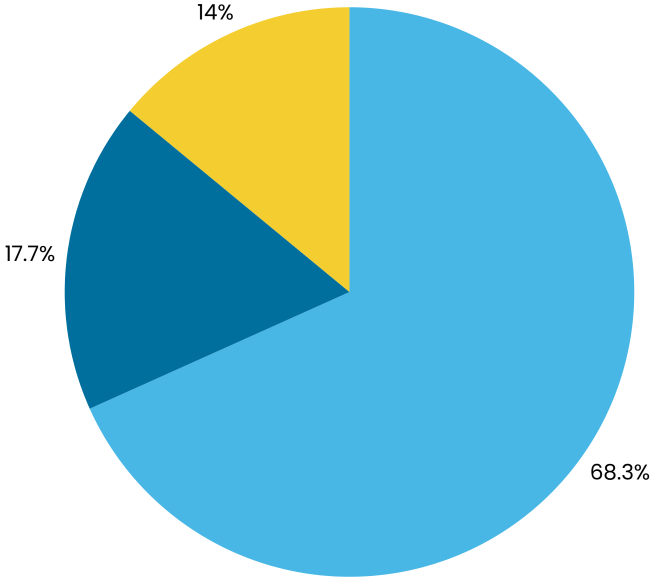
Justin Bray, Development Director

Revenues

$275,000	● Individual Contributions
$109,000	● Corporate & Foundation Grants
$10,000	● Hospital Grants
$19,100	● Earned Income
$31,760	● Investment Income

Total Income - $444,860





Expenses

$340,208	● Programming
$88,169	● General & Administrative
$69,868	● Fundraising & Development

Total Expenses - $498,245

Donor Spotlight

$5,000+

- Alfred D. Vallano Jr.
- Ceres Chill
- David Canvasser
- Donna Gregerson
- Infinant Health
- Jenn & Noah Canvasser
- Jeong-Jeong Chu
- Kathleen Thomas
- Keriton
- Kovler Foundation
- Leslie Napolitano
- Medela
- Martin Blakely
- Milkify
- Misty Good
- Noveome
- Plakous Therapeutics
- Thurman Allen Merritt
- Shannan Finegan

$1,000+

- Abigail Martin
- Adam Gilbert
- Amy Hair
- Ashley Kreyskop
- Baird Foundation
- Brent Cunningham
- Cassandra Oliger
- Christian & Beth Barry
- Dana Gemma
- David Bok
- Deron Donalson
- Diana Hallas
- Enterprise Mobility
- Jae Kim
- Jennifer Smith
- Jill Tillotson
- Joanne Kapetansky
- Joe Pewdo
- Jonathan Kaufman
- Jordan Lovett
- Kimco, LLC
- Kurt Carlson
- Lily Lou
- Lindsay Pollak
- Mark Underwood
- Martin Ryan
- McKinsey
- Rebekah Beach
- Ronald K. Revell
- Ryan Oliver
- Samir Gadepalli
- Shaina Starks
- Sharon Lundgren
- Stavroula & Nikolas Doris
- Stephanie Ruidiaz
- Steve Abrams
- Gerber Foundation
- Tyler & Janelle Vallano
- UPMC Health Plan

$500+

- Aloka Patel
- Angela Lang
- Annie and Gus Engel Charitable Fund
- Brandon Hook
- Carolyn Libman
- Courtney Montgomery
- Cynthia Smith
- David Foster
- Davis Food Co-Op
- Fit House
- Jason Gutman
- Jenise Phelps
- Joe Pagluica
- John Featherston
- Jordan Saunders
- Joshua Gonzalez
- Joyce Johnson
- Kaitlan Cobb
- Kelly Thomsen
- Kimberly Fleming
- Lyddia Revell
- Mark Canvasser
- Michael Katz
- Mike Johnson
- Monica Broughton
- Nadia and Chuck Scott
- Pittsburgh Fluid Systems
- Ravi Patel
- Ryan & Michelle Helbling
- Shawn Summers
- Stanley Lo
- Steven Manicki
- Steven McElroy
- Susan Hintz
- Susie Fleck
- Victor McKillop
- Wells Fargo
- Yolo Federal Credit Union

Join the NEC Society in 2026

The NEC Society's progress is only possible because of our community, and **there is still so much work to do.** Babies and families are being devastated by this cruel disease every day.

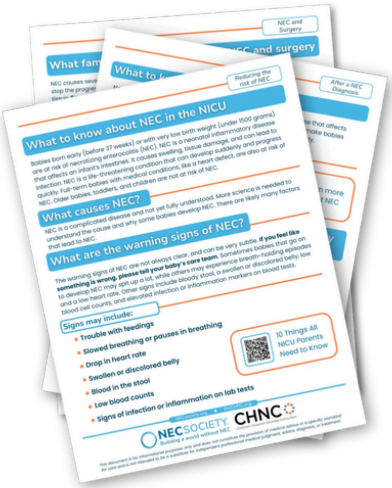
We need you to join us in 2026 to advance research, education, and advocacy for a world without necrotizing enterocolitis.

Organize an event or host a fundraiser in your local community

Engaging your local community is a powerful way to share your story, raise awareness, and help fuel the NEC Society's work to protect babies and families.

Questions on how to get started? Contact our Development Director, Justin@NECsociety.org

Lyddia and Glenn host an annual Rexercise event in honor of their son, Rex, who tragically passed away from NEC.



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- Drop in heart rate
- Swollen or discolored belly
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10 Things All NICU Parents Need to Know

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Share our resources with your local NICU

Help us reach families at risk of or currently being devastated by NEC. Parents are their baby's voice in the NICU and need to be empowered with information to advocate for their child.

Questions on how to get resources in your local NICU? Contact our Research Director, Erin.Pryor@NECsociety.org

Recognize NEC Awareness Month in your community or hospital

Join us in **May for NEC Awareness Month** and **May 17 for NEC Awareness Day**! Every gift, event, photo, and social media post advances our mission to build a world without NEC.

Does your state have a NEC Awareness Resolution? Find out here!

Learn all the ways you can get involved in the NEC Society's mission here.

Thank you to our Champions for a world without NEC!

INDUSTRY CHAMPIONS

CERES CHILL

Infinant™ HEALTH

medela
THE SCIENCE OF CARE™

milkify

noveome
BIOTHERAPEUTICS

PLAKOUS
THERAPEUTICS

KERITON

NONPROFIT CHAMPIONS

EFCNI
european foundation for the care of newborn infants

HUMAN MILK BANKING
ASSOCIATION OF NORTH AMERICA

MARCH OF DIMES®

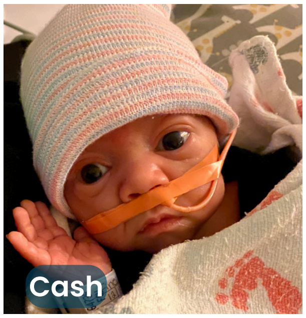
National Association of Neonatal Nurses

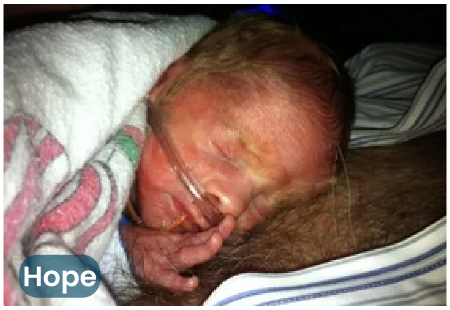
National Perinatal Association
Convene. Educate. Advocate. Integrate.

NPN
NICU PARENT NETWORK

UC San Diego
Human Milk Institute

Building a world without NEC for all babies





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