









NEC Family Summit

Executive Summary

September 1-4, 2026 • Sacramento, CA

NECsociety.org

NEC SOCIETY®
Building a world without NEC

The world's first Family Summit dedicated to necrotizing enterocolitis.

The NEC Society welcomed families impacted by NEC alongside clinicians and industry partners to the world's first NEC Family Summit – a space to connect, learn, and accelerate the NEC Society's mission, together.

Over four days, we came together to transform the pain and trauma of NEC into power and actionable strategies to fuel our shared vision of a world without necrotizing enterocolitis (NEC).

The Summit focused on using our stories and unique perspectives to advance NEC research, education, and advocacy.



The NEC Society's mission is to advance research, education, and advocacy so every baby is protected from the devastation of NEC.



Committed to an inclusive, collaborative experience.

The NEC Society provided travel stipends and used an application process to ensure the Summit represented families across geographic regions, lived experiences, and backgrounds.

The Summit – and all of the NEC Society's work – is about *and* for every baby and family affected by and at risk of this cruel disease.

9 Workshops. 30+ Perspectives. One Mission. 20+ Deliverables.

Throughout the Summit, participants developed actionable plans for new initiatives and strategized pathways to elevate the NEC Society's current work – all while forming new connections and collaborations.

Together, the Summit generated **more than 20 concrete deliverables and next steps** that the NEC Society and participants will complete and share with the NEC community.

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Workshop #1

Using our stories to fuel our mission

Sharing lived experiences is a powerful way to better understand necrotizing enterocolitis, raise awareness, and communicate *why* we need a world without NEC – essential to advancing the NEC Society's mission.

In this workshop, participants learned how to share their story to inspire change. With feedback from their small groups, they helped each other learn how to articulate the pain and trauma of their lived experiences into actionable takeaways.

Sharing our stories raises awareness, informs research, improves education, inspires advocacy, and ensures that the voices of those most affected by NEC guide efforts to improve outcomes for babies and families.







Goals

- Confidence in sharing their authentic story in a way that connects with others and inspires action
- Understand the stories, perspectives, and needs of other stakeholders in the NEC community
- Gain the tools needed to share their story to fuel our shared vision of a world without NEC

Action Items & Deliverables

Participants will identify and contact media outlets and journalists in their community to share how NEC has shaped their own story, using the NEC Society Media Kit.

Workshop #2

Using your story for advocacy

From introducing state and congressional NEC Awareness Resolutions, to advocating for legislation that helps to eliminate barriers to equitable access to donor milk, to implementing protective care strategies in the NICU – amplifying the voices of those impacted by NEC can drive *powerful policy* change that fuels a world without NEC.





Summit participants split into two breakout groups to:

- Learn how to meet with elected officials, propel NEC Awareness efforts, and brainstorm new policy initiatives that advance NEC research, education, and advocacy.
- Discuss how clinicians and families can advocate within their hospitals to increase access to donor milk and other safe, protective practices that help babies thrive.



Goals

- Understand why advocacy is instrumental to building a world without NEC
- Confidence in using their story for advocacy
- Prepared to reach out and collaborate with hospital leaders and elected officials
- Contact and schedule meetings with local elected officials

Action Items & Deliverables

Participants will work with their elected officials to advance NEC Awareness Resolutions or with their local NICU to advance policies that support NEC prevention, research, and family-centered care.

Workshop #3

Navigating the trauma of NEC years after the diagnosis

The trauma of NEC does not end after the NICU. This session provided space for both survivor and bereaved families to share the ongoing, practical, and emotional challenges they face years after the original NEC diagnosis.



Participants identified opportunities to expand and strengthen the NEC Society's resources for families navigating life after NEC, including a resource box for families with children ages 1-12 navigating long-term NEC outcomes, and ways the NEC Society can honor children tragically lost to NEC.



Lived experiences informed the development of meaningful tools and support materials that will continue to help other families affected by NEC.



Goals

- Expand resources available for families affected by NEC years after the diagnosis
- Ensure every family feels seen in the NEC Society's work and understands how to engage if/when they are ready

Action Items & Deliverables

- Participants drafted materials for a Family Resource Box designed for families navigating the long-term complications of NEC.
- Participants clearly defined ways for bereaved families to honor their children at the NEC Society and ensure their child is honored throughout the NEC Society's work.

Workshop #4

Building the NEC Society's engagement plan

The NEC Society is a global organization serving thousands of families, clinicians, and scientists. Given the organization's extensive work on research, education, and advocacy, the NEC Society's small staff must ensure new and current community members know how to get involved and help fuel the mission.

This workshop identified barriers to engagement in the organization while brainstorming improved strategies to reach, involve, and retain families, clinicians, and scientists.







Goals

- Develop a step-by-step Family Engagement Plan including new ways to involve families, reach families, and keep families engaged.
- Develop a step-by-step Clinician-Scientist Engagement Plan including new ways to involve multidisciplinary clinicians, including dietitians, social workers, and other disciplines that provide guidance and support for NICU families.

Action Items & Deliverables

Finalize a formal engagement plan for families and clinician-scientists for the NEC Society to use in its day-to-day operations.

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Workshop #5

10 Things We Need You to Know

This powerful session centered on one shared goal: strengthening the NEC community through greater understanding and collaboration.



Clinicians, industry, and families worked in groups to create 10 things they want the NEC community to know, offering unique perspectives shaped by their experiences, expertise, and goals for the future.



While each perspective is unique, we share a common goal: to drive meaningful progress toward a world without NEC.

By learning from one another, we can identify opportunities for collaboration, build greater empathy and understanding, and ensure that research, care, innovation, and advocacy are informed by all who are affected by NEC.



The 10 Things are focused, authentic, and meant to bridge the gaps between stakeholder groups.

Goals

- Understand the 10 most impactful, significant things families, clinicians, and industry want others in the NEC Community to know.

Action Items & Deliverables

Finalize and publish *10 Things Families Need You to Know, 10 Things Clinicians Need You to Know,* and *10 Things Industry Needs You to Know,* and disseminate across the NEC community.

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Workshop #6

Communication Standards in the NICU

Parents are the most important members of their baby's care team. Too often, families first learn about NEC when their baby is being diagnosed or rushed into surgery. Families at risk of NEC want to be better informed about this devastating disease and the potential early warning signs.

During this workshop, participants discussed when, how, and by whom NEC is introduced to families with an at-risk baby, as well as the power of human milk and how the NEC Society can help more NICUs use its resources.

While acknowledging barriers like variation in practice, inequitable access to the most protective care, and the field's limited understanding of the disease, families, clinicians, and industry discussed strategies to improve how NEC is communicated in the NICU.







Goals

- Draft 10 steps for effective communication about NEC
- Draft 10 steps to help protect babies against NEC for clinicians to use when communicating with families, hospital leadership, and multidisciplinary teams

Action Items & Deliverables

The NEC Society will finalize the 10-step handouts and work to disseminate them to NICUs across the US.

Workshop #7

Developing Partnerships in Research

The NEC Society is dedicated to advancing the NEC Research Priorities and integrating family leaders in the research process.



This workshop explored ways to improve research communication, informed consent, participation, and engagement.

We discussed ideas to expand the NEC Registry and add content-specific surveys on topics like feeding, surgical experience, and ongoing follow-up care.



Family participants completed the PCORI research fundamentals training to help support the NEC Society's research projects and collaborations.



Goals

- Family participants will gain a better understanding of the research process, the importance of confidence in study participation, and the role of families in advancing NEC research.
- Develop family-informed recommendations to enhance research communication, consent processes, educational materials, and participant recruitment and retention.
- Identify priority topics and outcomes that should be incorporated into future NEC Registry surveys and data collection efforts.
- Create strategies for introducing and promoting the NEC Registry to families across the continuum of care.

Action Items & Deliverables

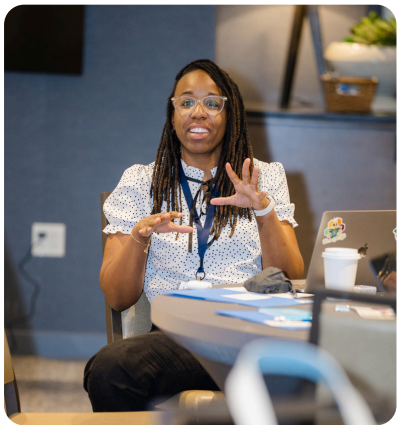
- Include information about the NEC Registry in all Family Resource Boxes.
- Develop a script for NICUs to use when recruiting families to participate in research.
- Expand outreach plans for NICUs and follow-up clinics to share information about the NEC Registry.

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Workshop #8

Collaborating to Optimize Human Milk



Human milk is our most powerful tool for protecting infants from the devastation of NEC, even though it does not eliminate the risks.

This session explored opportunities to improve awareness, education, support, and advocacy related to mother's own milk and pasteurized donor human milk for NEC prevention. Families and clinicians shared their experiences, identified gaps in current resources, and developed ideas for educational tools that will inform the development of a digital Human Milk Toolkit.





Goals

- Share lived and professional experiences with human milk in the NICU (and before the NICU)
- Identify gaps in education and support
- Develop recommendations for NEC Society educational resources and a digital Human Milk Toolkit
- Explore strategies to increase milk donation and donor milk access/utilization
- Identify advocacy priorities to improve equitable access to donor milk

Action Items & Deliverables

- Develop a digital Human Milk Toolkit for families and clinicians, highlighting the life-saving role of human milk in the NICU, including printable resources for clinicians to use when talking with families.
- Expand collaborations with the UC Health Milk Bank, HMBANA, the California Breastfeeding Coalition and other oganizations with aligned goals.

Workshop #9

Communicating the Complexity of NEC

A clear, consistently used definition of necrotizing enterocolitis is essential to advancing research, improving diagnostic timing, ensuring families receive accurate information, and helping babies thrive.

Developing a common, evidence-based definition of NEC—one that reflects clinical expertise *and* the lived experiences of families—can strengthen research, improve study design, support more consistent diagnosis, and improve communication with families at diagnosis and across the NEC community.

A shared understanding of NEC is essential for better care, better science, and better support for the NEC community.







Goals

- Determine how to share and articulate the need for a clear definition of NEC for use in:
  - Research
  - Diagnosis at the bedside
  - Family communication

Action Items & Deliverables

The NEC Society will use lessons from this session to draft and publish a position paper on the urgent need to improve the definition of necrotizing enterocolitis.



Building a world without NEC for all babies



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