

JUNE 2-5, ANN ARBOR MI

NEC SYMPOSIUM 2019

BREAKING DOWN THE BARRIERS
OF NEC PREVENTION & TREATMENT



THIS EVENT IS PARTIALLY FUNDED THROUGH A
PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE® (PCORI®)
EUGENE WASHINGTON PCORI ENGAGEMENT AWARD
CONTRACT #EAIN-10633

SUNDAY, JUNE 2



12:00 - 5:00 Registration

1:30 - 4:30 Pre-Conference: Mechanistic Studies into the Prevention and Treatment of NEC
Facilitated by: Steven McElroy, MD; Agostino Pierro, MD; and Akhil Maheshwari, MD
With presentations from: Christopher Gayer, MD, PhD; Catherine Hunter, MD; Camilia Martin, MD; Isabelle De Plaen, MD; Misty Good, MD, MS; Mark Underwood, MD; Matthew Ralls, MD; Doug Burrin, PhD; Venkatesh Sampath, MBBS, MRCPCh

4:30 - 4:45 Podium presentation for select abstract

4:45 - 5:00 Podium presentation for select abstract

5:00 - 5:30 Break / Registration / Exhibits / Refreshments

5:30 **Welcome address by Anne Trontell, MD, MPH**
Associate Director
Clinical Effectiveness and Decision Science
Patient-Centered Outcomes Research Institute (PCORI)

5:45 - 7:00 **Networking**

**Spotlight:
Pre-conference Session**

Sunday afternoon's session will allow an in-depth look at advances in basic science related to NEC.



MONDAY, JUNE 3



7:00 - 7:45 Registration and continental breakfast

7:45 - 8:00 **Welcome remarks**
Jennifer Canvasser, MSW; Samir Gadepalli, MD, MBA

8:00 - 9:00 **NEC: Recent Breakthroughs and Promising Directions**
Facilitator: Mark Underwood, MD

9:00 - 10:00 **Disparities in the Care of Fragile Infants and Opportunities to Overcome Them**
Facilitators: Jochen Profit, MD, MPH; Krista Sigurdson, PhD
Patient-Family Representative: Lelis Vernon

10:00 - 10:30 Break

10:30 - 11:30 **Defining NEC: Using Patient-Family Driven Outcome Measures**
Facilitators: Michael Caplan, MD; Ravi Patel, MD, MSc
Patient-Family Representative: Simone Rosito, MA

11:30 - 12:30 **Diagnosing NEC: Diagnostic Criteria, Proposed Changes, and Emerging Diagnostic Tools**
Facilitators: Jae Kim, MD, PhD; Karl Sylvester, MD
Patient-Family Representative: Cristal Grogan

12:30 - 1:30 Lunch (networking)

1:30 - 2:30 **Risks and Benefits of Probiotic Use in Fragile Infants**
Facilitators: Ravi Patel, MD; Jae Kim, MD, PhD;
with moderating by Mark Underwood, MD
Patient-Family Perspective: Erin Umberger, M. Arch

2:30 - 3:30 **New Directions in NEC with Early Investigators Committed to Bridging the Translation Gap from Bench to Bedside**
Facilitators: Misty Good, MD, MS; Colin Martin, MD; Troy Markel, MD; Hala Chaaban, MD;
Patient-Family Representative: Ryan Raab, PE

3:30 - 3:45 Break

3:45 - 4:45 **Empowering Families and Driving Patient-Centered Outcomes Research**
Facilitators: Heather Denchik, RN, BSN; Noah Canvasser, MD; Linseigh Green;
with moderating by Mark Underwood, MD

4:45 - 5:45 **Evaluating Strategies to Increase the Use of Mothers Own Milk in the NICU**
Facilitators: Aloka Patel, MD; Paula Meier, PhD, RN
Patient-Family Perspective: Jennifer Canvasser, MSW

5:45 - 6:00 Podium presentation for select abstract

7pm **Optional: "Big House" Michigan stadium tour (limited tickets available)**



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TUESDAY, JUNE 4

7:00 - 8:00 **Networking and continental breakfast**

8:00 - 9:00 **Uniting Providers and Patient-Families Towards NEC Prevention and Improved Outcomes**

Facilitator: Roger Soll, MD

9:00 - 10:00 **Promising Novel Therapies for NEC in Preclinical and Clinical Trials**

*Facilitators: Gail Besner, MD; Eamonn Connolly, PhD
Patient-Family Representative: Erin Umberger, MArch*

10:00 - 10:30 **Break**

10:30 - 11:30 **How Human Milk Protects Against NEC: Breaking Down the Science**

*Facilitators: Tarah Colaizy, MD, MPH;
Christina Valentine, MD
Patient-Family Representative: Simone Rosito, MA*

11:30 - 12:30 **Opportunities for the Federal Government to Help Advance NEC Research**

*Facilitators: Gerri Baer, MD; Tonse Raju, MD, DCH
Patient-Family Representative: Jennifer Canvasser, MSW*

12:30 - 1:30 **Lunch (networking)**

1:30 - 3:00 **Workgroups Round 1** (six workgroups, each repeat once)

Participants will choose to attend two different workgroup sessions, the first at 1:30 and the second at 3:15.

1. NEC Biorepository: A New Tool to Improve Our Understanding of the Disease

*Facilitators: Misty Good, MD, MS; Sunyoung Kim, PhD;
Troy Markel, MD; and Matthew Ralls, MD;
Patient-Family Representative: Erin Umberger, MArch*

2. Innovative Quality Improvement Projects in the NICU

*Facilitators: Minesh Khashu, MD, FRCPC; Robert E. Schumacher, MD; and Rebecca Vartanian, MD
Patient-Family Representative: Ryan Raab, PE*

3. NEC Advocacy and the Prioritization of Resources

*Facilitators: Samir Gadepalli, MD, MBA; Alexander Penn, PhD
Patient-Family Representatives: Heather Tanner, MSA;
Heather Denchik, RN, BSN*

4. Advancing the Needs of Patient-Families through the NEC Research Collaborative

*Facilitators: Jae Kim, MD, PhD; Ravi Patel, MD, and Anne Trontell, MD, MPH
Patient-Family Representative: Jennifer Canvasser, MSW*

5. Medically Fragile Term Infants with NEC

*Facilitators: Amy Hair, MD; Steven McElroy, MD
Patient-Family Representative: Simone Rosito, MA*

6. Tools to Support Families with NEC Survivors

*Facilitators: Sheila Gephart, RN, PhD, Wakako Eklund, DNP
Patient-Family Representatives: Cristal Grogan, Lelis Bauzá Vernon, Linseigh Green*

WORKGROUPS

3:15 - 4:45 **Workgroups Round 2**

4:45 - 5:00 **Podium presentation for select abstract**

5:00 - 6:00 **Workgroup reports and proposed next steps**

6:00 - 7:30 **Poster Session**

Spotlight: Workgroups

Workgroups will be interactive, with participants actively engaging with the faculty facilitators to develop PCOR/CER.

Each workgroup should culminate in a patient-family-centered project for the NEC Society Research Collaborative to investigate.



"I met colleagues at this meeting that will stimulate collaborative projects related to NEC research. I was especially pleased and informed by having a multidisciplinary perspective on this disease, it increased my awareness of the obstacles and challenges we face in preventing this disease."

- 2017 NEC Symposium Attendee

WEDNESDAY, JUNE 5

7:00 - 8:00 **Networking and continental breakfast**

8:00 - 9:00 **International Opportunities to Improve NEC Practices and the Patient-Family Experience**

Facilitators: Wakako Eklund, DNP; Minesh Khashu, MD, FRCPC; Agostino Pierro, MD; Simone Rosito, MA; with moderating by Steven McElroy, MD

9:00 - 9:15 **Podium presentation (for select abstract)**

9:15 - 10:15 **Adding Fortifier to Human Milk: How to Optimize Safety**

Facilitators: Amy Hair, MD; Sarah Taylor, MD, MSCR; with moderating by Jae Kim, MD, PhD Patient-Family Representative: Cristal Grogan

10:15 - 10:45 **Break**

10:45 - 11:30 **NEC Risk: Early Identification and Risk Stratification**

Facilitators: Sheila Gephart, RN, PhD; Karl Sylvester, MD Patient-Family Representative: Lelis Bauzá Vernon

11:30 - 12:45 **Priorities for Driving PCOR and NEC Prevention**

Facilitators: Jennifer Canvasser, MSW; Jae Kim, MD, PhD; Anne Trontell, MD, MPH; Erin Umberger, M.Arch; Mark Underwood, MD; with moderating by Samir Gadepalli, MD, MBA

12:45 - 1:15 **Closing remarks**

Samir Gadepalli, MD, MBA; Jennifer Canvasser, MSW

1:15 **Adjourn, take-away lunch**

3:00 **Tour of C.S. Mott Children's Hospital (optional)**

FACULTY

COURSE CHAIRS

Jennifer Canvasser, MSW

Founder, Director
NEC Society

Samir K. Gadepalli, MD, MBA

Pediatric Surgery and Surgical Critical Care
C.S. Mott Children's Hospital
University of Michigan, Ann Arbor, MI

Erin Umberger, M.Arch

Director
NEC Society

PLANNING COMMITTEE

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Chief Scientific Officer
NorthShore University HealthSystem
Clinical Professor of Pediatrics
University of Chicago, Pritzker School of Medicine

Sheila M. Gephart, RN, PhD

Associate Professor
Robert Wood Johnson Foundation
Nurse Faculty Scholar
University of Arizona College of Nursing
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Amy Hair, MD

Assistant Professor
Program Director of Neonatal Nutrition
Program Director of NICU Intestinal Rehab Team
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Department of Pediatrics
Baylor College of Medicine
Texas Children's Hospital

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Hepatology and Nutrition
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Director of Neonatal-Perinatal Medicine Fellowship
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Immunologist
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Abdul-Karim Yassine

Project Manager
Pediatric Surgery
C.S. Mott Children's Hospital



The NEC Symposium is certified as a Patients Included meeting.

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FACULTY (CONTINUED)

Gerri R. Baer, MD, F.A.A.P.

Medical Officer, Neonatology Team Leader
Office of Pediatric Therapeutics
Office of Medical Products and Tobacco/
Office of the Commissioner
U.S. Food and Drug Administration

Doug Burrin, Ph,D

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Noah Canvasser, MD

Bereaved father

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Eamonn Connolly, PhD

Chief Scientific Officer
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Heather Denchik, RN, BSN, OCN

Mother of NEC survivor
Project Coordinator
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Linseigh Green

Adult survivor of NEC

Cristal Grogan

Mother of NEC survivor
NICU Helping Hands

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Founder, SIGNEC
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Professor of Pediatrics
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Past President, International Society for Research in Human
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Bereaved father

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Heather Tanner, MSA, BSBA

Mother of NEC survivor
Project Coordinator
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Medical Director, North America, RB Health

Rebecca Vartanian, MD

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Department of Pediatrics and Communicable Diseases
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Medical Director of Respiratory Care
C.S. Mott Children's and Von Voigtländer Women's
Hospitals

Lehis Bauzá Vernon

Mother of NEC survivors

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The NEC Symposium is made possible through a partnership between the NEC Society and Section of Pediatric Surgery at the University of Michigan, with support from a Patient-Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Award (Contract #EAIN-10633), and our generous community of supporters.

HIGHLIGHTS

- NEC: Recent Breakthroughs and Promising Directions
- Disparities in the Care of Fragile Infants and Opportunities to Overcome Them
- International Opportunities to Improve NEC Practices and the Patient-Family Experience
- Risks and Benefits of Probiotic Use in Fragile Infants
- Evaluating Strategies to Increase the Use of Mothers Own Milk in the NICU
- Promising Novel Therapies for NEC in Preclinical and Clinical Trials
- Opportunities for the Federal Government to Help Advance NEC Research
- NEC Biorepository

TARGET AUDIENCE

This activity is designed for physicians, scientists, nurse practitioners, physician assistants, nurses, pharmacists, dietitians, lactation consultants, health policy makers, nonprofit leaders, industry, and other diverse stakeholders committed to driving patient-centered outcomes research, comparative effectiveness research, and improving the prevention and treatment of outcomes for infants at risk of necrotizing enterocolitis in fragile infants.

WHY YOU SHOULD ATTEND

The NEC Symposium will convene multidisciplinary stakeholders to fundamentally improve the understanding, prevention, and treatment of NEC. It will support the development of quality improvement projects, novel research, and refined clinical guidelines.

The Symposium will provide opportunities for education, collaboration, and networking for junior and senior providers and investigators. Attendees will be actively engaged throughout the meeting and encouraged to share their diverse expertise and perspectives to help cultivate specific recommendations and standards. Content from the NEC Symposium will be published in *Pediatric Research*.

CALL FOR ABSTRACTS

Attendees are encouraged to submit abstracts for the Symposium's poster presentations. Categories are basic science, clinical, and translational. The call for abstracts will open soon. All submissions must be received by March 4th.

For more information and to submit an abstract, visit:

<http://bit.ly/NECabstracts2019>

EDUCATIONAL PURPOSE

Despite significant advances in neonatal care, NEC remains a leading cause of death for neonates, with survivors frequently facing lifelong health challenges. This conference will provide a rare opportunity to have a multidisciplinary conversation about improving NEC outcomes and driving patient-centered outcomes research. It will convene some of the most committed NEC professionals and patient-families from around the world. The Symposium will foster collaboration, develop new strategic lines of research, empower families, and refine protocols to help diagnose, prevent, and treat NEC.

EDUCATIONAL OBJECTIVES

- Summarize recent breakthroughs in NEC basic science research
- Understand current disparities in the care of fragile infants and opportunities to overcome them
- Summarize potential new treatments for NEC
- Understand the need for a refined definition of NEC
- Articulate emerging tools for NEC diagnosis
- Explain the risks and benefits of probiotic use in fragile infants
- Summarize strategies to increase the use of mothers own milk in the NICU
- Describe international practice differences related to NEC
- Identify methods to partner with and empower families in reducing the risks of NEC

The NEC Society supports breastfeeding mothers. Mothers are welcome to breastfeed their child anywhere throughout the conference. A lactation room will be available for mothers who need to pump or prefer privacy.

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"One of the best conferences I've been to. The ability to convene scientific researchers, families and health care providers is astounding and much appreciated"

- 2017 NEC Symposium Attendee

LOCATION

The NEC Symposium will be held at the Michigan League on the University of Michigan campus. The Michigan League is located in the heart of Ann Arbor, where you can walk to incredible restaurants, unique galleries and independent bookstores.

TRANSPORTATION

Ann Arbor is a 24-mile drive from Detroit Metropolitan Wayne County International Airport (DTW), which has direct flights from around the United States, Canada, Europe, South America and Asia. There are multiple ground transportation options between DTW and Ann Arbor, including private cars, taxis, and shuttles.

LODGING

Rooms have been blocked at the Bell Tower, The Inn at the Michigan League, and Graduate Hotels. Additional lodging information can be found at VisitAnnArbor.org. NEC Symposium participants are encouraged to stay in or near downtown Ann Arbor.



SYLLABUS

The electronic syllabus will be available to pre-registered attendees prior to the conference for downloading and printing. A flash drive containing the syllabus will be distributed at the conference.

ACCREDITATION

This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint providership of the University of Michigan and the NEC Society. The University of Michigan is accredited by the ACCME to provide continuing medical education for physicians.

CREDIT DESIGNATION

PHYSICIAN CREDIT: The University of Michigan designates this live activity for a maximum of *20.5 AMA PRA Category 1 Credits*.™ Physicians should claim only the credit commensurate with the extent of their participation in the activity.

AMA PRA Category 1 Credits™ acceptable for other health care providers:

NURSE: For the purpose of recertification, the American Nurses Credentialing Center accepts *AMA PRA Category 1 Credits*™ issued by organizations accredited by the ACCME. Report a maximum of 20.5 hours of credit and fill in “CME Category 1” for the provider number.

PHARMACIST: You may petition the Michigan State Board of Pharmacy for CE credit for this symposium.

PHYSICIAN ASSISTANT: The National Commission on Certification of Physician Assistants (NCCPA) states that *AMA PRA Category 1 Credits*™ are acceptable for continuing medical education requirements for recertification.

CONFERENCE REGISTRATION

Please register early - space is limited.

Tuition is **\$375** for physicians and **\$275** for all others. Fees will increase after April 1st.

Tuition includes welcome reception, continental breakfasts, refreshment breaks, lunches, electronic syllabus, and an online certificate of attendance for those earning CMEs.

Cancellation and Refund Policy: Registration is non-refundable.

For further information contact: Jennifer Canvasser, NEC Society
Jennifer@NECsociety.org

To register for the NEC Symposium, visit
<https://NECsymposium.eventbrite.com>

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"The environment of the 2017 NEC meeting was unlike anything I had ever experienced. For the first time in my life, I witnessed hundreds of individuals setting aside the need for personal recognition, titles, and any form of hierarchy to collectively come together in a desperate effort to find the cause of and cure for this tragic disease. It was breathtaking to watch how fervently they worked, how ideas, examples, experiences, and research was freely shared, and how insight from every angle was valued."

- 2017 NEC Symposium Attendee

