# NICU PARENT NETWORK ANNUAL REPORT



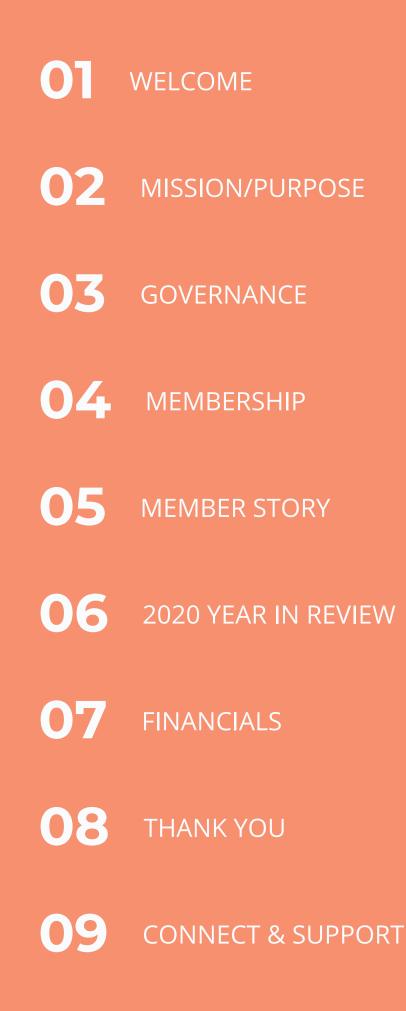


nicuparentnetwork.org

The NICU Parent Network (NPN) is a collaborative of NICU Support Organizations led by NICU Parent Professionals.

NPN provides a platform for these leaders to come together as a collective voice representing the needs & best interests of NICU families in all facets of healthcare policy, care guidelines, advocacy, education, and family support.







# KEIRA SORRELLS

Great things are brought about and **burdens are** lightened through the efforts of many hands anxiously engaged in a good cause.

- M. Russell Ballard

## WELCOME

I could not tell you how many times I sat in front of my computer staring at the blank screen and blinking cursor. My hope for this letter is for it to be inspiring. I would like it to be one of those messages you read that gives you just the encouragement you were craving. The problem is that I am not sure the appropriate words even exist to fully express the myriad of emotions swirling around in my mind. Like everyone, my entire way of day-to-day working and living was upended (as evidenced by the photo at the bottom of the page - that would be my setup co-hosting a webinar from the changing table in my daughter's nursery!).

The COVID-19 pandemic coupled with the tensions around social and racial injustice wrapped inside an incredibly divisive election year has left many feeling exhausted, overwhelmed, and ready to crawl under a rock for a while. Though the date now says 2021, all that came to a head in 2020 is far from resolved and there is much work yet to be done.

But, you are NICU Parent Leaders, and no matter how much you may wish to escape reality and run to the farthest corner of the world... you don't. You run toward the people most in need. I have watched in awe over the last 12 months at how you brilliantly adapted and pressed on as you faced new barriers in reaching and supporting families. I wholeheartedly believe it is your experience as a NICU and/or bereaved parent that has prepared you to face the all-encompassing uncertainty with grit and determination.

Quite simply, I want to say "thank you."

Thank you to our members for the tireless work you do. No matter the circumstances and conditions you must work in, you never cease providing support, resources, and education to NICU and bereaved families everywhere. You are the very definition of resilience, courage, and compassion.

Thank you to our supporters for continuing to give your time and your finances. In a year when it would have been understandable to pull back on giving, you did the opposite and gave MORE than any year before in professional services, individual donations, corporate contributions, and grants. Without your belief in our mission, we could not continue and for that, I am truly thankful.

Thank you to our operations team, committee members, and Board of **Directors** for keeping this engine running. Nothing would have made an ounce of progress without your talent, enthusiasm, and commitment! It is an honor to work with each of you and I am deeply proud of all we were able to accomplish against incredible odds.

I hope that you will all take a look at our 2020 Annual Report and know that every single one of you had something to do with the successes celebrated in the following pages.

With deep gratitude,

eire Couell

Keira Sorrells, Executive Director **NICU Parent Network** 



# Who are the members of NPN

As the ONLY professional association for NICU Parent Leaders in the US, the NPN provides a platform for NICU Parent Leaders to come together as a collective voice representing the needs and best interests of NICU families in all facets of healthcare policy, care guidelines, advocacy, education, and family support. Our members are NICU Parent Leaders working in highly influential positions in local, regional, national, and international capacities. Their work focuses on improving access to and the quality of education, resources, and support for families along the continuum of care from high-risk pregnancy to life after the NICU. They all have one crucial characteristic in common; they have all been personally impacted by a NICU stay or infant loss.

# REPRESENT

### Best Interests of Families

The NPN represents the needs and best interests of NICU families in all facets of healthcare policy, care guidelines, advocacy, education, and family support.

# EDUCATE

SION

### Emerging and Established NICU Parent Leaders

Educate emerging and established parent leaders about the urgent needs, concerns, and policies affecting parents with a critically ill baby in the Neonatal Intensive Care Unit.

# ELEVATE

Our Collective Voice

The NPN provides a platform to bring the collective voice of NICU families to the forefront.



# **Executive Director Keira Sorrells**



The Executive Director is responsible for overseeing the administration, programs, and strategic plan of NPN and ensuring the core values of NPN are maintained and promoted.

# **Operations** Team

The Operations Team handles daily administrative, communications, marketing, and financial duties.







Bonnie Berglund **Administrative** Support

Cristal Grogan Graphic Design

Cortney Lancaster Digital Marketing

"No one can whistle a symphony. It takes a whole orchestra to play it." - H.E. Juccock

# **Board of Directors**

Supports the work of NPN and provides mission-based leadership and strategic governance.



**Kristy Love** 

President



Giqi

Khonyongwa

**Fernandez** Vice President





**Audrey Cohen** 

Lisa Grubbs

Secretary







Jennifer Deal

Kelli Kellev

**Tracey Pella** 

**Bob Selby** 



**Erin Whaley** 

# 2020 Committee Chairs

Committee Chairs ensure the purpose and initiatives for each committee are carried out.

### Member Engagement

Co-Chair: Bob Selby Co-Chair: Ashley Mann

### **Event Program Planning**

Co-Chair: Cristal Grogan Co-Chair: Keira Sorrells

Standards & Review Co-Chair: Jennifer Degl Co-Chair: Stephanie Vaughan

Finance & Strategy

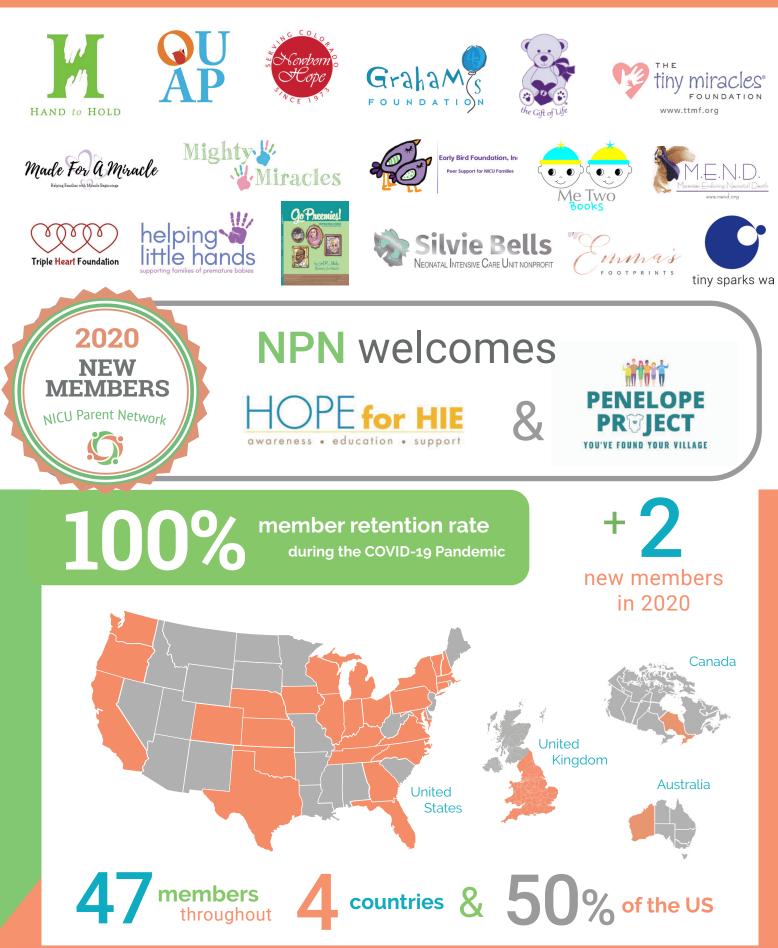
Co-Chair: Audrey Cohen Co-Chair: Kristy Love

Partnerships & Collaborations

Co-Chair: Erin Whaley Co-Chair: Tracy Pella

Webinar Planning Co-Chair: Ali Dunn Co-Chair: Tracy Pella

# **NICU Support Organization Members**



# **NICU Support Organization Members**



Integrated Care for NICU parents and their infants.



# Member Highlight

# SAUL'S LIGHT

### Briefly tell us your personal story and how it led you to start your organization? What are the main services your organization provides?

In 2014 my son, Saul, died 20 days following his premature birth. As I moved through the NICU and grief journeys, I realized that there was a void of resources in our community that addressed these specific birth traumas. Not only that, the access to mental health services were not equitable. I realized that in order to process these experiences and ultimately heal was a privilege and it should not be.

# Where are you located and what are the greatest needs in maternal-infant health in this area?

We're located in New Orleans, LA. The greatest needs in maternal infant health in this area is maternal mortality, premature birth, and infant mortality.

### What led you to join the NICU Parent Network? And how has the network empowered, equipped, and/or enabled you to grow as a NICU Parent Leader?

I joined the NPN in an effort to network. I know that nonprofit organizations led by women of color are notoriously under funded and resourced. I thought it might be helpful to meet other leaders across the country, learn new industry information, and develop new partnerships to be able to provide the best support to our local families.

# How has COVID impacted the community you serve?

The pandemic has severely impact our community. In early 2020, our community was one of the hardest hit. New Orleans is also a city with a lot of citizens being economically disadvantaged. Those factors combined with the daily stressors of having a NICU baby, enduring loss, and experiencing an active hurricane system have made this time extremely difficult.

# What/how did your organization have to change/enhance/adapt the services you provide due to COVID?

As a result of COVID, Saul's Light has had to increase the amount of support given to individual families, increase the number of families supported, and extend services to include new outreach services including assisting families who experienced housing and food insecurity as a result of the pandemic.

### How has being a member of NICU Parent Network supported or assisted your ability to meet these additional needs?

NPN has supported the mission of Saul's Light through the mini grant program and served as a hub of information.

# "My greatest wish is for all NICU families across the country to not only not feel alone, but also feel supported.

# What is your greatest wish in terms of the positive impact the NICU Parent Leader community can make in maternal-infant health?

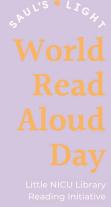
My greatest wish is for all NICU families across the country to not only not feel alone, but also feel supported.



To learn more about Saul's Light or to connect with Kimberly, please visit

saulslight.org social media handle @sauls\_light



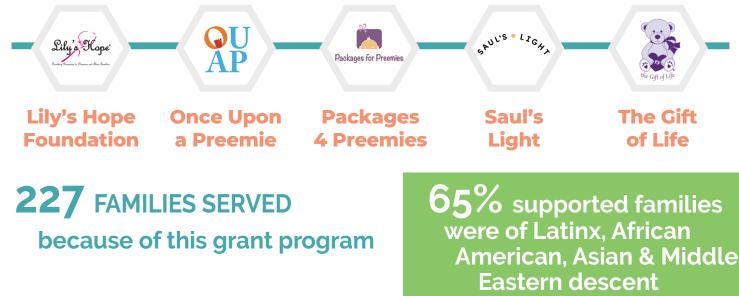


Sponsored by Star Bright Books



Launched NPN Mini Grants Program

The COVID-19 pandemic has touched every aspect of humanity. Our member organizations are no exception at a time when NICU families need their support more than ever. By supporting our members through the development of the NPN COVID-19 Mini Grants Program, generously supported by the Prolacta Bioscience Foundation, we are ensuring parents in the NICU will be able to access and receive the support and resources they need.



# Locations served:

Pennsylvania • Florida • Louisiana • South Carolina • Virginia • Washington DC New Jersey • North Carolina • California • Maryland

# Ways families were served:

Peer-to-Peer Support • Book donations to encourage parent/infant bonding • Equipment for safe transport of babies from NICU to home • Direct financial support • Purchase of breast pumps • Purchase of diapers & other basic infant care necessities • Coolers for safe transport of breast milk from home to NICU • Purchase of infant hearing aids

"The Prolacta Bioscience Foundation was proud to support these grassroot organizations serving their local NICU communities as parents navigated one of the most challenging life experiences, especially during the pandemic. Their work inspires us all."

- Vanessa Scott, Administrative Manager, Prolacta Bioscience

KALEB Photo credit: The Moore Family

Great opportunities to help others seldom come, but small ones surround us every day. - Sally Koch

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Bill of Rights
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# **REVISED** & UPDATED NICU Baby's Bill of Rights. Scan for more information

# YEAR

# Launched NPN Live

The premier virtual event for NICU Parent Leaders Scan for more information.



### LAUNCHED MONTHLY MEMBER VIDEO CHATS

In response to members' needs to connect and discuss the impacts of COVID-19 on their organizations and the innovative solutions they created to meet the needs of NICU families during the pandemic.

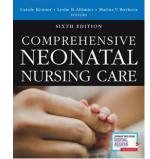


# **PUBLICATIONS**

## **Noteworthy Professional News**

"Caring for Babies and Their Families: Providing Psychosocial Support in the NICU": An innovative online educational tool to empower Neonatal Nurses to support NICU families.





# Comprehensive Neonatal Nursing Care, Sixth Edition

NPN members provided real-world perspectives of NICU parents to be used throughout the new edition's content. Dr. Kenner stated, "Parents and families are an integral part of the healthcare team and we wanted to bring their experiences, in their own words, to this work." The preeminent provider of compelling perinatal education on psychosocial support created through interprofessional collaboration

# **5** Collaboration Highlight: My NICU Network - My Perinatal Network

myperinatalnetwork.org

### LAUNCHED TWO NEW PROGRAMS:



"Coping with COVID-19: Trauma-informed Care for Frontline Maternity and Pediatric/NICU Providers During the COVID-19 Pandemic"





"Caring for Pregnant Patients and Their Families: Providing Psychosocial Support During Pregnancy, Labor & Delivery"

### **GRANTS AND RESEARCH:**

Awarded a grant from the **Health Resources and Services Administration (HRSA)** to produce an online course on trauma-informed care to support maternity patients during the COVID-19 pandemic; engaged in a national study on the efficacy of our Advanced Provider course for Neonatal Fellows with colleagues from **Stanford University**.

### My NICU Network My Perinatal Network



Association



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COURSE COMPLETIONS TO DATE

# 

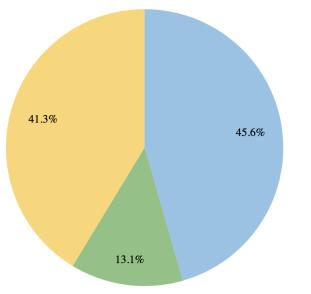
Arrytine Photo credit: Naomi Levit Photography

Avery Photo credit: The Sorrells Family

# 9,7%

2020 REVENUE

### 2020 EXPENSES



# **2020 REVENUE SUMMARY**

Membership	\$72,900.00
Events	\$38,050.00
Grants	\$12,500.00
Donations	\$4,347.00
Professional Services	\$1,500.00

\$129,297.00

# **2020 EXPENSE SUMMARY**

Operations
Member Gr
Programs

erations \$38,231.00 mber Grants & Donations \$11,000.00 grams \$34,679.00

\$83,910.00



# **INDIVIDUAL DONORS**

- R. Carbonier
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- R. Orr T. Pella B. Selby M. Swanson E. Whaley



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# **IN-KIND DONATIONS**

Gigi Khonyongwa-Fernandez

Lovevery





# YOUR GENEROSITY MATTERS

# We Appreciate Your Willingness to Help. Your generous support will help foster the continued growth and success of NICU family support programs, collaborative parent/provider

**SUPPORT US** 

relationships, and initiatives across the country.



The NICU Parent Network offers a variety of ways for support organizations, graduate NICU parents, industry stakeholders, and providers to be a part of our mission.





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