

ANNUAL REPORT

2021



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The Zaky by Nurtured by Design



NICU PARENT NETWORK



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Great leaders are almost always
great simplifiers who can cut
through argument, debate, and
doubt to offer a solution
everybody can understand.

- COLIN POWELL



nicuparentnetwork.org

my this
+ your that
our magic

- BAILY HANCOCK



"Leadership is not about titles or the
corner office. It's about the
willingness to step up, put yourself out
there, and lean into courage. The world
is desperate for braver leaders. It's
time for all of us to step up."

- BRENE BROWN



The courage of leadership is
giving others a chance to
succeed even though you bear the
responsibility for getting things
done.

- SIMON SINEK



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Welcome

A message from our Founder
& Executive Director

"After the storm comes a calm."

- Matthew Henry (1662 - 1714)

*"Even the darkest night will end and the sun
will rise again."*

- Victor Hugo (1802 - 1885)

In the Old Testament around 750 BC, the prophet Isaiah wrote about "beauty for ashes." There is a reason these quotes and phrases stand the test of time remaining in our vernacular for hundreds, even thousands of years. The words are as true in our life experience as they are in nature. There is peace to be found after a storm, there is hope to be experienced after a dark period, and there is a transformation that can come after an experience so crushing you feel there is nothing left.

The same is true for our network of NICU Parent Leaders and the families they serve as we enter the third year of the COVID-19 pandemic. When you are within the storm in survival mode it is often challenging to step outside and view things through an objective lens.



This is why times of reflection are so critical. Taking a few moments to acknowledge your hard work and the accomplishments of your team may give you (and your co-workers) the energy renewal needed to move on to the next phase of a project.

2021 was very difficult for me personally and professionally. As I shared during NPN Live! 2.0, my Board leadership gave me permission I would not give myself to take an eight-week leave to tend to my mental health and that of my family. It was exactly what I needed to regain my footing as a wife, mother, advocate, and leader. Before that moment, I was entering a state of burnout, distress, and being overwhelmed.

Having a team in place to carry our work forward and to be able to look back over the entirety of 2021 and celebrate all that we accomplished collectively has been the greatest gift.

I want to thank my Board for their unwavering support and hard work. Few will ever truly understand the number of hours and the depth of heart each of our Board members puts into their role. It is an honor to work with them and I am forever grateful for their commitment to innovation and cultivating an organizational culture of inclusion, acceptance, and authenticity.

Thank you to our members for your continued loyalty to the NICU Parent Network and for your steadfast commitment to serving others. You put the full measure of your souls into your work every day to build, sustain, and grow a NICU support organization. We understand what that takes and we celebrate you today and every day.

To our supporters, donors, and partners, thank you for never giving up on us. Thank you for continuing to share your expertise and your resources so that we can continue to skill up and build up this profession of NICU Parent Leadership. The very lives of fragile babies and their families depend on the long-term success of our members and our members depend on us. Without your generosity, we could not continue.

I hope you enjoy reviewing and celebrating all that our network has accomplished over the last 12 months. We look forward to continued engagement throughout the upcoming year.

Warmly,

A handwritten signature in black ink, reading "Kevin Soule". The signature is fluid and cursive, with a large, sweeping loop for the letter 'S'.

“

NPN has chosen to move forward, develop leaders, break barriers, influence change, shape policy, create pathways (and professions) where there were none, and make a real & meaningful difference for NICU families across the USA. Our multi-year strategic plan is helping us make these choices and in equal parts is ambitious, aspirational, inspirational, realistic, and, dare I say, exciting.

- GIGI KHONYONGWA-FERNANDEZ, NPN PRESIDENT

Our Vision

We envision a world where all NICU families are an essential and integral member of their baby's care team.

Our Mission

To be the premier professional organization for NICU Parent Leaders who collectively support and represent the needs and best interests of NICU families.

Our Goals

INCLUSION
&
DIVERSITY



COMMUNITY
ENGAGEMENT



ADVOCACY
&
POLICY



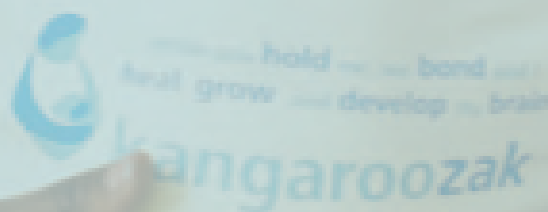
FINANCIAL
PERFORMANCE




PROFESSIONAL
DEVELOPMENT



- ◆ Foster an inclusive, diverse, and equitable organizational culture for all members.
- ◆ To understand and serve the needs of NICU parent leaders through meaningful community experiences.
- ◆ To be the trusted NICU parent and family voice for maternal-infant issues nationally.
- ◆ Create and maintain a diversified development plan for growth and sustainability.
- ◆ To provide high quality professional development opportunities that enhance the knowledge, expertise, and impact of all NPN members.





After two years of intense introspection, reflection, dreaming, and coordinating, we are pleased to present our three-year strategic plan. This is a living document that we, as an organization and as a board, are committed to implementing. We are proud of this work and feel that this plan is positioning NPN for overall growth in professionalism and intent to ensure what we say we want and need to do will be meaningful and impactful for NICU families. This plan represents the start of transformation and a new reality for NPN, which will require a combination of a hard reset, an intentional shift in culture and communication, and an even more meaningful engagement and support of you, our members.

ACKNOWLEDGEMENTS: This plan would not have come to fruition without the impeccable leadership of Executive Committee Members, Gigi Khonyongwa-Fernandez & Audrey Cohen, who acted as our Strategic Plan Advisors and stewards. The full board, committee co-chairs, several members, and operations team poured countless hours into the development and brought incredible perspective and insight to ensure the plan is reflective of where our membership wants NPN to go and how they want us to grow. I would like to thank each of these devoted NPN members and representatives for their work:

Kelli Kelley

Lisa Grubbs

Bonnie Berglund

Pam Frasco

Jennifer Driscoll

Cristal Grogan

Jennifer Degl

Audrey Cohen

Tracy Pella

Heather Tanner

Nancy Micca

Courtney Lancaster

Kristy Love

Gigi Khonyongwa-Fernandez

Erin Whaley

Bob Selby

Stephanie Vaughan

Yamile Jackson

STRATEGIC PLAN

OUR GOALS

»»» *Inclusion & Diversity*

OUR OBJECTIVES

1

Increase awareness of unconscious bias within NICU Parent Leader community - internally (BOD, operations team) & externally (NPN members)

2

Improve inclusion scores on DE&I survey

3

Increase the number of NICU Parent Leaders representing underrepresented groups

»»» *Community Engagement*

1

Increase visibility of NPN membership in the broader maternal & infant health community

2

Increase frequency of structured communication among NPN members

3

Increase engagement of Parent Leaders through participation on committees

4

Maintain 85% rate of membership retention

5

Increase new member growth by 25% each year

6

Grow attendance by 35% at all NPN events

»»» *Advocacy & Policy*

1

Increase awareness of NPN position on issues of importance to NICU families

2

Increase our presence at a national level as a thought leader for issues of importance to NICU families

3

Increase recognition in hospitals of the professional role of NICU Parent Leaders/peer support

»»» *Financial Performance*

1

Increase diversified funding streams to support staff and program expansion

2

Increase grant awards year over year to match incremental budget increases

3

Maintain a minimum of 6 months of revenue in reserve (based on monthly run rate)

»»» *Professional Development*

1

Increase creation/dissemination of professional development content

2

Design/develop NICU Parent Leader certification program and method for assessing baseline knowledge level

OUR CSFs/BARRIERS*

CSFs	LT should reflect communities we serve Great trainer with engaging DE&I topics Higher awareness of NPN by other leaders in the Maternal-Infant Community
BARRIERS	Lack of trust by underrepresented NICU parents Lack of training program Lack of awareness Low representation Lack of value proposition

CSFs	Greater awareness about NPN Greater awareness among our members ABOUT our members
BARRIERS	Existing platform is not user-friendly Value of our offerings is not clearly communicated to members Low levels of collaboration

CSFs	Visibility as experts in the field to key leaders (legislators, medical community, & advocacy groups)
BARRIERS	Lack of expertise in advocacy and policy Perceived as "just a mommies group"

CSFs	Experienced Director of Development Experienced Grant Writer
BARRIERS	Lack of budget to hire additional staff Time limitations of current board and staff

CSFs	To have a professional designation for NICU Parent Leaders that is nationally recognized Having engaging, thought-provoking speakers deliver relevant content
BARRIERS	No existing professional designation of nationally accepted training programs for NICU Parent Leaders Lack of clear compensation for NICU Parent Leaders Lack of recognition of the importance of professional peer support in the NICU

OUR STRATEGIES

A1	Design and conduct inclusion survey to assess degree of inclusion experienced by NPN members
A2	Develop recommendations from inclusion survey
A3	Develop a comprehensive I&D strategy
A4	Select or develop an unconscious bias training program suitable across the NPN organization

B1	Understand how our members want to engage with one another and develop the community
B2	Develop a communication strategy plan based on membership feedback on how they want to engage with one another
B3	Implement membership appreciation and retention plan
B4	Review, refine, and update new member recruitment and onboarding plan

C1	Get a read on the relevant policy topics of importance to NICU families (health equity, bereavement care, etc.)
C2	Develop a comprehensive advocacy & policy committee to include medical advisory personnel, lobbyists, health policy analysts, etc.
C3	Educate key leaders about the professional role of a NICU Parent Leader

D1	Develop a strategic fundraising development plan that supports growth objectives
D2	Identify new grant opportunities and corporate sponsors
D3	Identify, launch, and implement new earned income opportunities (trainings, certifications, etc.)
D4	Establish quarterly Finance Committee review of budget to track revenue in reserve

E1	Develop a survey of members to identify the 4 most pressing needs confronting their communities & what their organization needs to meet those needs.
E2	Identify key competencies of NICU Parent Leaders & develop/identify a training program for each competency
E3	Job description and value proposition for NICU Parent Leaders (i.e. the value/impact on families we serve)
E4	Deliver ongoing programming and resources to members
E5	Support professional development of NICU Parent Leaders in alignment with Values & Professional Pillars

*CSFs = Critical Success Factors

GOVERNANCE

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



Jessica Fox

Finance



Cristal Grogan

Graphic Design



Courtney Lancaster

Digital Marketing

BOARD OF DIRECTORS

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



Kristy Love
PRESIDENT

National Perinatal Association



Gigi Khanyongwa-Fernandez
VICE PRESIDENT

Families Blossoming, LLC



Audrey Cohen
Treasurer

Goldman Sachs



Lisa Grubbs
Secretary

NICU Helping Hands



Jennifer Degl

Speaking for Moms & Babies, Inc.



Kelli Kelley

Hand to Hold



Tracy Pella

Connected Forever



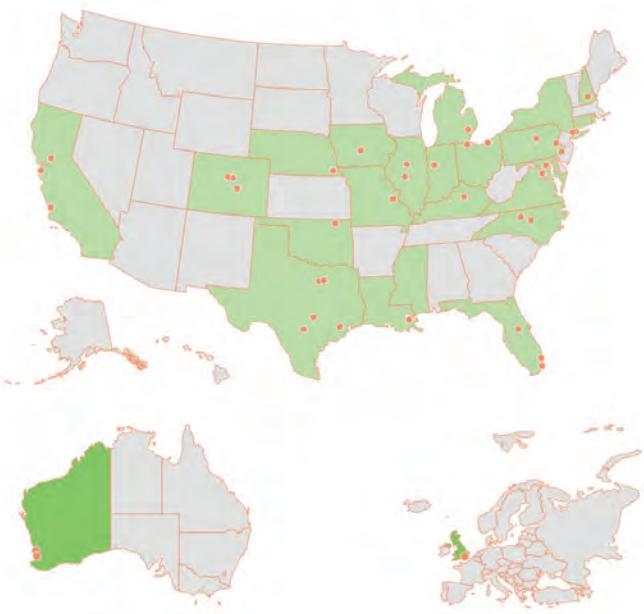
Erin Whaley

Troutman Sanders LLP

MEMBERSHIP



100% Member Retention



Welcome to New Members

Empowering
NICU Parents

TODAY
is a Good Day





Partners in Perinatal &
Pediatric Consulting




A. Carter
A. Fisher
A. Smith
A. Sabo
A. Collins
A. Hickson
A. Spriggs
A. Louden
A. O'Connor
A. Mann
B. Pearman

C. Moss
C. Stensrud
D. Harshfield
D. Kenney
D. Rowan
D. Bradford
E. Nelson
E. Marletta
E. Whaley
F. Moreno
H. Terry

H. Jordan
K. Abra
K. Cundiff
K. Kline
L. Beaumont
L. Dorish
L. Vernon
L. Merritt
L. Rosenfeld
M. Patterson
M. Pavlyuchek

M. Fraust-Wylie
P. Peeples
S. DiGregorio
S. Friedrich
S. Davis
S. Gavin
T. Covington





The most beautiful people we have known are those who have known defeat, known suffering, known struggle, known loss, and have found their way out of the depths. These persons have an appreciation, a sensitivity, and an understanding of life that fills them with compassion, gentleness, and a deep loving concern. Beautiful people do not just happen.

- ELISABETH KÜBLER-ROSS



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MEMBER HIGHLIGHT



Betsy Pilon

Executive Director

Briefly tell us your personal story and how it led you to start your organization.

My son Max was born in 2012 after a very uneventful and typical pregnancy at 37 weeks, when he stopped moving. I had an emergency c-section at our community hospital and he was transferred to the system's Level IV NICU. We had phenomenal clinical care. We entered a world that was traumatic and unfamiliar, with a diagnosis with very little information and support. In the NICU immediately after transfer, he was placed into whole body therapeutic hypothermia treatment for 72 hours, cooling down his body to 91 degrees for Hypoxic Ischemic Encephalopathy, a type of brain injury. Max was one of the biggest and sickest babies in the NICU, with a diagnosis that was not ever communicated to us directly in the three week NICU stay we had. Once I sleuthed the diagnosis on his discharge notes, I found others in a Facebook group called Hope for HIE, about 200-300 of us at the time, and everyone had a similar story of feeling isolated and "different" from the traditional NICU messaging of prematurity, and the spectrum of outcomes was astonishing -- from very minimally impacted to significant disabilities and loss of life. It was obvious from the very beginning of our journey that there was a significant need to connect families and build out resources for awareness, education and support.

While we had been told HIE was rare, it happens in roughly 2-3 per 1,000 live births, so far more common than what classifies "rare." In 2014, a group of us came together to explore taking the Facebook group into a nonprofit organization, and we've been growing ever since aiming to ensure no family faces HIE alone.

What gap does your organization fill for families? What are the main services your organization provides?

We are the premiere organization globally connecting HIE families and have built a comprehensive peer-to-peer support network with over 100 topic, location and outcomes-based groups, with over 7,000 active families. We have grown our referral programs to provide educational materials and support packages to newly diagnosed families at point of diagnosis in the NICU, and we provide support programming across the continuum of the patient and family journey. We serve as a strong patient advocacy organization, working to ensure equity in messaging and inclusion in the NICU and PICU spaces for our families, advocate for improved care, communication and connection with clinicians, and in particular for awareness of the impact of trauma on our families when they do not have an equitable experience to others. NICU is synonymous with trauma, and we advocate for better mental health supports in the NICU and stronger transitions of care to community mental health services for the entire family. In non-pandemic times, we plan family and parent retreats and meet ups to better connect our community. HIE is a catalyst diagnosis for a myriad of different impacts such as epilepsy, cerebral palsy, vision, hearing and cognitive, behavioral and learning challenges, so the NICU is really the start of a very long journey with the medical system. HIE is a leading cause of neonatal loss as well, and loss can also happen with our HIE children in childhood depending on the impacts, so we provide many supports and recognition of our loss families to ensure the legacies of their children are always cherished by our community. Education is also a significant part of our mission, and we continue to build out resources for our families to best equip them to advocate for their children and figure out how to maximize their child's individual potential. We coordinate our educational offerings through our Medical Advisory Board, ensuring we are bringing the very best information to our families to help them make decisions and understand resources available, especially with any subsequent diagnoses.

Every April, we lead global HIE Awareness Month, where the community has a theme and we share all about HIE, working to connect more families and focus on ways we can work to improve the quality of life for children and families impacted by HIE. Because so many of our children will be diagnosed with a lifelong disability of some kind, even mild, we take part in disability advocacy as well for services, as well as societal changes towards the disability community.

Where does your organization provide services?

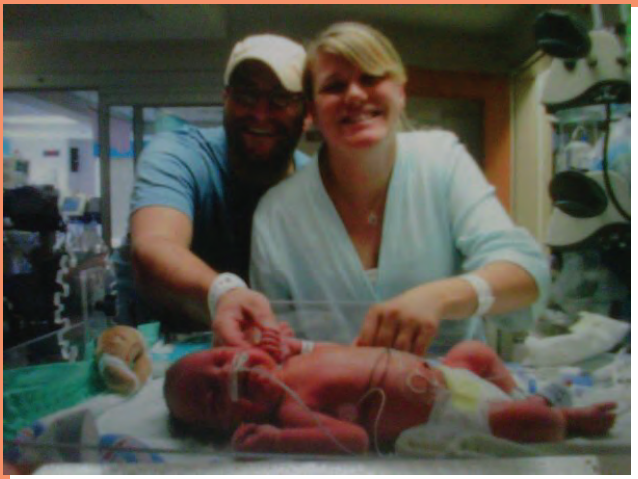
Globally.

What are the greatest needs of families in maternal-infant health you observe through your work?

HIE is very complex and murky. Families need better communication and information, and feel empowered to be parents to their babies, be involved in decision making, and be heard and understood with what their values are when it comes to their children. Trauma impacts everyone, so working on ways to decrease that definitely is a priority.

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?

Collaborating makes so much sense to lift similar missions and not be duplicative, where we can take a collective strength to leverage a larger community that can create greater change and better support for all impacted by a NICU stay. Networking with other member organizations to build a stronger referral network can also improve getting families the dedicated support for their diagnosis. I learn so much from other leaders, whether it is about specific programming implemented, such as best practices in peer support, or even different approaches to a similar issue. Truly, we are better together.



How has the pandemic impacted the community you serve over the last two years?

The pandemic has taken an already isolating event and made many of our newly diagnosed families feel even more isolated, especially when it comes to transitioning home to community-based services that by and large flipped to virtual services. Our community began as a virtual community, so in many ways, we were positioned to do very well to build off of what we had already started and grown, with technology tools catching up. Telehealth, for instance, has decreased many of the barriers that many of our families face after the NICU with access to specialists.

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

Continue on the journey towards equity and connection. Understand that those with specific diagnoses flourish when they are connected to that specific community.

Anything else you want our community to know?

I'm grateful to the NPN leadership for their support of our involvement and advocacy priorities, as well as the offerings to bring the NICU community together.

Fill in the Blank

NICU and bereaved parents
are doing their best.

What is the greatest piece of leadership advice you have ever been given?

With every growth curve, expect change.

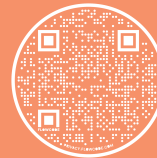
YEAR IN REVIEW



What NICU Parents Need to Know About New Donor Milk Safety Concerns

NICU Parent-Led *Peer-To-Peer Support Services* POSITION PAPER

The NICU Parent Network (NPN) advocates for the establishment and funding of peer-to-peer support services and peer mentoring programs in all NICUs. To provide consistent support and continuity of care, NICU and follow-up care providers should partner with parent-led peer-to-peer support programs in their community or create their own.



PAID LEAVE ADVOCACY *in collaboration with* P L+U S

NPN helped pass national paid leave for everyone in the US. Our sign-on letter from over 30 NICU organizations showed Congress that national paid leave would be life-changing for NICU families and helped make the needs of NICU families visible on Capitol Hill.

PAID LEAVE ADVOCACY *in recognition of*



“

This is one of the first companies we've heard of to provide dedicated leave to support NICU families. Keeping parents and NICU babies together during a hospital stay is critical to ensure the best possible outcomes for these families. This policy will have a powerful impact on the lives of so many, ensuring they thrive well beyond the NICU. We applaud Pinterest's leadership and hope other companies will follow suit to help meet the critical needs of NICU babies and their parents.

- KEIRA SORRELLS

NPN *Pandemic Response* T H I N K T A N K

Thanks to a Medical Education Grant through  **sobi**
rare strength

NPN convened a cohort of 8 Support Organization members to delve into the immediate and longterm needs of NICU Support Organizations in response to the many changes our organizations experienced resulting from the COVID-19 Pandemic. This group of experts in NICU parent support conducted a landscape analysis of what the most pressing needs are for NICU parents in the current global climate, what quickly implemented strategies and programs have worked well, what has not served the community well, and what these organizations need to ensure sustainability of the programs and services offered to families in our new, virtual world. Participating organizations included: *ICU baby, Saul's Light Foundation, The Tiny Miracles Foundation, Speaking for Moms & Babies, NICU Helping Hands, Hand to Hold, Graham's Foundation, & The Colette Louise Tisdahl Foundation*. The full grant report will publish 2022

NPN was pleased to partner with **WaterWipes®** on the launch of the **Pure Foundation Fund**

This new bursary fund in the USA and Canada recognizes the incredible work of all healthcare professionals involved in the pregnancy, birth, and postnatal journey.

Two nominated healthcare professionals won funds for their department to continue to improve the care of parents & babies. Also, a WaterWipes Pure Foundation plaque.

My NICU Network My Perinatal Network



National Perinatal
Association



NICU Parent
Network



18

online staff education courses
offered for Maternity Care &
NICU Providers



4,113

courses completed since our
launch in 2018



93

fellows have enrolled and 24
have completed the program

- The highest number of completions include the courses on Emotional Support of NICU Parents and Communication.
- A grant from Mednax-Pediatrics enabled us to offer the 2-hour Advanced Provider Program and its accompanying Virtual Simulation Exercise, that includes NICU Parent Network members as advisors, to Neonatal Fellows for free.
- We conducted a study in partnership with Stanford University and proved the program's efficacy in improving Fellow knowledge and efficacy.



INC

INTERNATIONAL NEONATAL
CONSORTIUM

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Journal of Perinatology

ARTICLE OPEN

The culture of research communication in neonatal intensive care units: key stakeholder perspectives

Jennifer Degl¹, Ronald Arlano², Judy Aschner³, Sandra Beaman⁴, Wakako Eklund⁵, Elissa Faro⁶, Hiroko Iwami⁷, Yamilé Jackson⁸, Carole Kenner⁹, Ivone Kim¹⁰, Agnes Klein¹¹, Mary Short¹², Keira Sorrells¹³, Mark A. Turner^{14,15}, Robert Ward¹⁶, Scott Winecki¹⁰, Christina Bucd-Rechtweg¹⁶ and International Neonatal Consortium*

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OBJECTIVE: To assess the perspectives of neonatologists, neonatal nurses, and parents on research-related education and communication practices in the neonatal intensive care unit (NICU).

STUDY DESIGN: Questionnaire circulated through interest groups and administered using the Internet.

RESULTS: 323 respondents responded to the survey, 52 were neonatologists, 186 were neonatal nurses, and 83 were parents of NICU graduates. Analysis was descriptive. Differences were noted between stakeholder groups with respect to whether current medications meet the needs of sick neonates, research as central to the mission of the NICU, availability of appropriate education/training for all members of the research team, and adequacy of information provided to parents before, during, and after a research study is completed.

CONCLUSION: Engagement of nurses and parents at all stages of NICU research is currently suboptimal; relevant good practices, including education, should be shared among neonatal units.

Journal of Perinatology (2021) 41:2826–2833; <https://doi.org/10.1038/s41372-021-01220-5>

INTRODUCTION AND STATEMENT OF THE PROBLEM

Technological and scientific advances have significantly improved neonatal outcomes over the past several decades. While the field has progressed, prematurity remains the leading cause of infant mortality worldwide and results in thousands of annual admissions to neonatal intensive care units (NICUs) along with substantial health care expenditures [1]. Despite legislative efforts to promote drug development in the pediatric population, policies incentivizing research have failed to entice manufacturers to invest in neonatal therapeutics. Further, policies obligating manufacturers to conduct research are tied to adult investigational drugs and biologic products whose mechanisms of action may play no role in addressing neonatal conditions and therefore will not serve the needs of neonates [2]. As a result, preterm neonates are routinely exposed to multiple drugs that have not been researched adequately and have not been approved by regulatory agencies for their intended use [3, 4]. This translates to the use of drugs that have not been sufficiently tested for safety, dosing, or effectiveness in this population [5]. The last class of drugs approved for use in preterm neonates that significantly impacted survival and outcome was pulmonary surfactant for respiratory distress syndrome [6].

Since it is widely recognized that the study of new and existing drugs for use in neonates has lagged behind other populations, there is a critical need to facilitate the conduct of neonatal clinical trials. While there is a critical need to innovate, participation in neonatal clinical trials has been viewed by many as ethically challenging, too risky, burdensome for parents, and as a favor provided by altruistic families to future generations [7, 8]. Practices regarding the design and conduct of neonatal clinical trials, including multi-stakeholder involvement, have been identified that may help to overcome some of these challenges [7].

The Critical Path Institute's (C-Path) International Neonatal Consortium (INC) has united stakeholders from around the globe with a shared aim of accelerating the development of safe and effective therapies for neonates [9]. INC includes parents, neonatal advocacy organizations, neonatologists, clinical pharmacologists, neonatal nurses, regulators, and representatives from the pharmaceutical industry. INC's primary focus is on developing practical tools and processes to facilitate the conduct of ethical and efficient neonatal clinical trials. The literature describes communication in general on neonatal units [10–15] and challenges posed to parents and staff by research [16–21]. This literature includes some suggestions about how to improve communication

The Culture of Research Communication in Neonatal Intensive Care Units: Key Stakeholder Perspectives

JOURNAL OF PERINATOLOGY

In this paper published in the American Journal of Perinatology, we are reminded of the differences in perception of various aspects of neonatal research that exist between key stakeholders who are integral to the care of premature and medically fragile babies in the NICU.

The lead author (and NPN Board Member) Jennifer Degl brought the very same survey results and draft of the paper to NPN Executive Director, Keira Levit Sorrells and fellow NPN members Deb Discenza (Premie World) and Yamilé Jackson (The Zaky) for further review and comment. Their unique perspectives as NICU graduate parents allow them to interpret the results in an integral way and to reflect and make recommendations to bring back to the hospitals and families they serve. These reflections were also published in the Journal of Perinatology as an Editorial to the primary paper.

PRIMARY PAPER

PARENT EDITORIAL

*Speaking for Moms and Babies, Inc., Mahopac, NY, USA. ²Stanford University, Palo Alto, CA, USA. ³Stacksack Meridian Health, New York, NY, USA. ⁴ONG Consulting/National Association of Neonatal Nurses, Albuquerque, NM, USA. ⁵Pediatric Medical Group of The National Association of Neonatal Nurses, Nashville, TN, USA. ⁶Cancer College of Medicine, University of Iowa, Iowa City, IA, USA. ⁷Osaka City General Hospital, Osaka, Japan. ⁸Nurture by Design, Sugar Land, TX, USA. ⁹Council of International Neonatal Nurses, Inc., The College of New Jersey, Ewing, NJ, USA. ¹⁰U.S. Food & Drug Administration, Silver Spring, MD, USA. ¹¹Health Canada, Ottawa, ON, Canada. ¹²Uly & Co, Indianapolis, IN, USA. ¹³NICU Parent Network, Madison, MS, USA. ¹⁴University of Liverpool, Liverpool, UK. ¹⁵University of Utah, Salt Lake City, UT, USA. ¹⁶Novartis Pharmaceuticals Corporation, East Hanover, NJ, USA. *A list of authors and their affiliations appears at the end of the paper. *A list of authors and their affiliations is available in Supplementary Information. This article reflects the views of the authors and should not be construed to represent FDA's views or policies. *Email: Mark.Turner@verpoda.co.uk

NPN *Live!* 2021 IN REVIEW

- 1 INDUSTRY 1:1
- 2 MEMBERS ACTION MEETING
- 3 NPN LIVE! 2.0

88 Organizations

TOTAL EDUCATIONAL PROGRAMMING TIME

17 HOURS
46 MINUTES



TOTAL ONE-ON-ONE NETWORKING TIME

8 HOURS
41 MINUTES

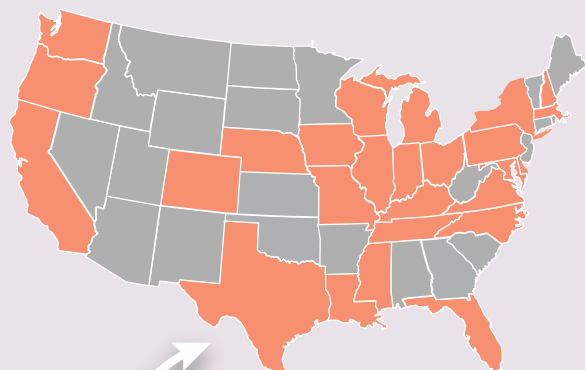


66.6%

ATTENDANCE RATE INCREASE THROUGHOUT EVENTS IN 2021

86.3%

AVERAGE ATTENDANCE RATE



27 States

Over 50% of the US

6

Countries

United Kingdom France
Germany United States
Puerto Rico Japan



2471
comments

NPN *Live!*

NPN Live! is a unique series of virtual events that are personalized for NICU Parent Leaders to connect with peers, advance leadership skills, and improve support for NICU families everywhere.

These are **NOT** webinars.

We give our members what they want and need by creating a space that supports thought-provoking conversations and connections to the best NICU Parent Leaders and Industry Executives in the country.

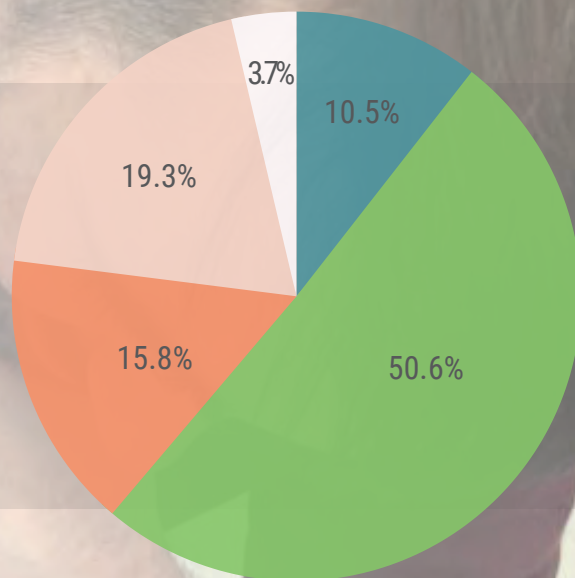
#NPNLIVE

NICU PARENT NETWORK
YEAR END EVENT ANALYSIS

FINANCIALS

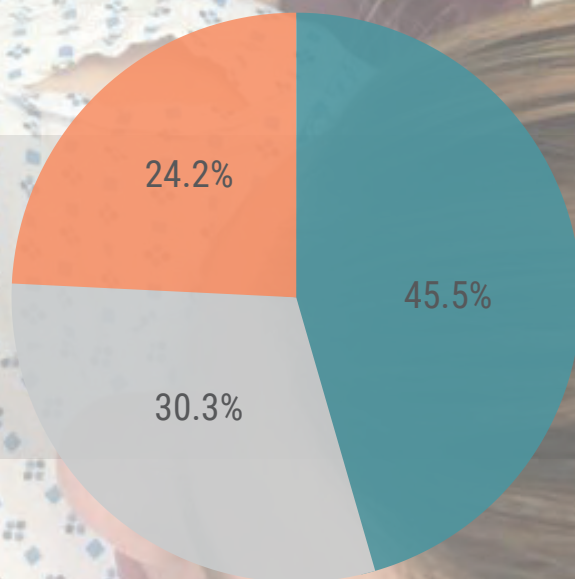
2021 REVENUE SUMMARY

Membership	\$20,975.00
Events	\$17,170.00
Grants	\$55,000.00
Donations	\$11,457.03
Professional Services	\$4,000.00
<hr/>	
	\$108,602.03



2021 EXPENSE SUMMARY

Operations	\$68,404.56
Programs	\$45,460.72
Grant Projects	\$36,400.00
<hr/>	
	\$150,265.28



\$3,800+ in dues relief provided to NPN Members

The appearance of a loss is due to the accrued amount not credited in the calendar year & an expense increase as an investment in the operations team.

Thank You

INDIVIDUAL DONORS

R. Carbonier

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J. Degl

E. Whaley

M. Hynan, PhD

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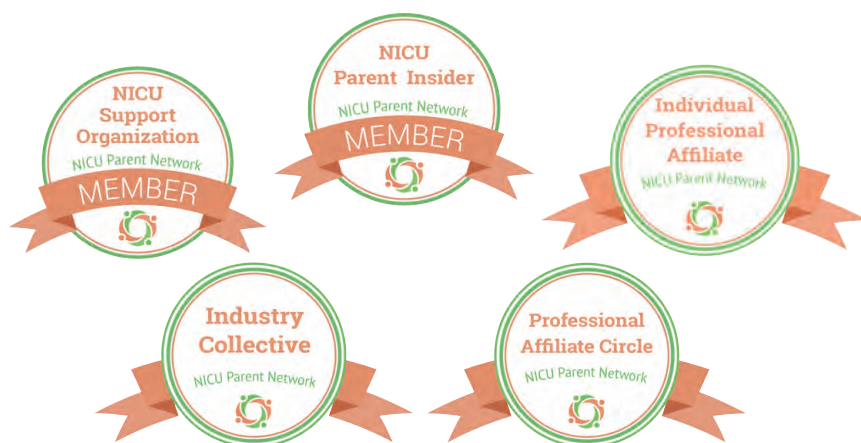


Photo Credit: The Zaky

CONNECT & SUPPORT

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 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.

Show Your Support!



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