

# The Role of Parent Advocates in the NICU Community: Mike Hynan, Ph.D. and Kristy Love were honored at the 2022 Gravens Conference

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The National Perinatal Association (NPA) is an interdisciplinary organization that strives to be a leading voice for perinatal care in the United States. Our diverse membership is comprised of healthcare providers, parents & caregivers, educators, and service providers, all driven by their desire to give voice to and support babies and families at risk across the country.

Members of the NPA write a regular peer-reviewed column in Neonatology Today.



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Stan and Mavis Graven Award recipients, Kristy Love (2021) and Mike Hynan, PhD (2022)

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The recipients of the Stan and Mavis Graven Award for Leadership in Enhancing Physical and Developmental Environments for High-Risk Infants and their Families were Kristy Love and Michael Hynan, Ph.D. Both of whom are NICU parents and have long histories of leadership and advocacy with the National Perinatal Association.

### Parents as Leaders

Love and Hynan spoke of the transformational experience of having a baby in the NICU and how those experiences propelled them to advocate for change. Each has a long list of accomplishments.

After her NICU experiences, Kristy Love became a parent advocate within her unit. What was at first a volunteer role evolved into a paid position as it became apparent what her contributions meant for the well-being of both the families and staff? She went on to become more involved in the community-at-large - joining quality

improvement initiatives, developing programs that could be implemented in other units, helping to found the NICU Parent Network (a collaborative of NICU support organizations led by NICU parent professionals [www.nicuparentnetwork.org](http://www.nicuparentnetwork.org)), and ultimately becoming the Executive Director of the National Perinatal Association [www.nationalperinatal.org](http://www.nationalperinatal.org). Love's family-centered focus was informed by the work of Stan Graven, who founded NPA. When she joined NPA, she found a community that shared her passion. At NPA, she met and was mentored by other parent leaders like Becky Hatfield, who founded the first NICU parent support program while at the University of Utah, and Mike Hynan, whose writing and research serves as the foundation on which the movement for mental health services for NICU families and staff has been built.

In his acceptance speech, Mike Hynan further explained the connection between Stan and Mavis Graven, NICU family advocacy, and the development of parent leaders. After his NICU stay and with the



## Principles of Family-Centered Care

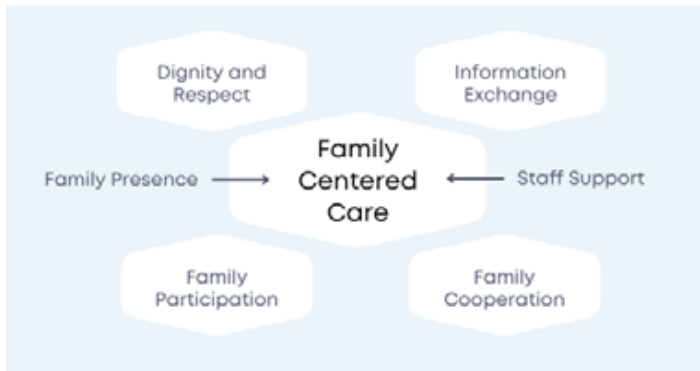


Figure 1

encouragement of his son's neonatologist, Mike got involved with the Wisconsin Association for Perinatal Care (WAPC), another organization founded by Stan Graven. The trajectory of Hynan's professional career as a clinical psychologist and professor at the University of Wisconsin – Milwaukee was set when he met people like Sheri Nance, the president of Parent Care, who spoke powerfully about how the focus of neonatology must change from "getting the baby home in the best possible shape" to "getting the family home in the best possible shape." Dr. Hynan's work demonstrates that shift in focus, whether it is the publication on NPA's Interdisciplinary Recommendations for the Psychosocial Support of NICU Parents [www.nature.com/collections/vrqhjdywxv](http://www.nature.com/collections/vrqhjdywxv) or the creation of the National Network of NICU Psychologist (NNNP), a professional organization that advocates for the role of mental health professionals in the NICU [www.nationalperinatal.org/psychologists](http://www.nationalperinatal.org/psychologists).

### Parents as Partners in Advocacy

We know that babies and families have better outcomes when parents are integral to their babies' caregiving team. Similarly, we propose that our community benefits when we support and embrace parents as leaders.

The principles of family-centered care (figure 1.) - dignity and respect, information exchange, family participation, and cooperation – apply whether we are talking about caregiving or advocacy. While parents are in the NICU, they develop the skills and tools they need to advocate for their babies, for themselves, and for

## Components of Family-Centered Advocacy



Figure 2

their communities. As members of the neonatal community, they are powerful agents of positive change.

We believe the essential components of **family-centered advocacy** are (figure 2):

- **Information sharing** – NICU care improves when we offer observations, share insights, and learn together.
- **Family-informed policymaking** – When policies need to be developed or changed, parent input can lead to fair, thoughtful guidance and promotes the best interests of families and staff.
- **Inclusive and equitable representation** – Our NICU leadership should look like the families we serve. We need the contributions of all parents and providers, especially those that may have been marginalized.
- **Advisory councils** – Patients and families should be represented wherever decisions are being made.
- **Quality improvement initiatives** - Safety initiatives and quality improvement efforts must account for the factors that families have become experts in during their NICU stay and after they have gone home.
- **Participant-led research** – We apply the principle of “nothing about us without us.” Rather than being the subject of studies, families need a say in how research is designed and carried out. The goal should always be to seek parent and patient input, share the research findings with families, and use the results to improve the care parents and babies receive.

The Gravens conference in March and the National Perinatal Association's conference in May are meetings where parents and providers come together and develop innovative programs and initiatives.

Kristy said, “I attended my first Gravens Conference fifteen years ago as a family advocate upon receiving her award. A nurse in my NICU attended the year before and won a free conference registration. However, due to a family conflict, she was unable to attend. So she passed the free registration on to me. I have only missed three over the last fifteen years. This is truly an honor. I explained this award to my family like this, in the perinatal community, this award is like receiving a Grammy.” She continued, “Please advocate for your family advocates to come to all Interdisciplinary conferences. Their voices need to be heard.”

We invite you to hear the parent voice and the voices of other members of our interdisciplinary community at the National Perinatal Association's 2022 conference, “Perinatology at the Intersection of Health Equity and Social Justice.” We will meet in person in Aurora, Colorado, and virtually online. [www.npaconference.org](http://www.npaconference.org) There are special conference rates for parent participants. Parent researchers and scholars are encouraged to present.

### Important Publications:

- Interdisciplinary Guidelines and Recommendations for NICU Discharge Preparation and Transition Planning. DOI: <https://doi.org/10.1038/s41372-022-01313-9>
- Covid-19 and the Need for Perinatal Mental Health Professionals: Now More Than Ever Before. DOI <https://doi.org/10.1038/s41372-020-0696-z>
- The Neonatal Intensive Parenting Unit: An Introduction. DOI: <https://doi.org/10.1038/jp.2017.108>
- The Transformation of the Neonatal Intensive Care Unit:

A Father's Perspective over 36Years. DOI: <http://dx.doi.org/10.1053/j.nainr.2016.09.021>

- Interdisciplinary Recommendations for the Psychosocial Support of NICU Parents. DOI: <https://doi.org/10.1038/jp.2015.141>

#### Organizations You Should Know:

- National Perinatal Association (NPA) [www.nationalperinatal.org](http://www.nationalperinatal.org)
- National Network of NICU Psychologists (NNNP) [www.nationalperinatal.org/psychologists](http://www.nationalperinatal.org/psychologists)
- NICU Parent Network (NPN) [nicuparentnetwork.org](http://nicuparentnetwork.org)
- Wisconsin Association for Perinatal Care (WAPC) [perinatal-web.org/page/history](http://perinatal-web.org/page/history)

#### Events:

- National Perinatal Association's 42<sup>nd</sup> annual interdisciplinary conference, "Perinatology at the Intersection of Health Equity and Social Justice" May 2-4, 2022 in Aurora, Colorado [www.npaconference.org](http://www.npaconference.org)
- Save the date for the Gravens conference on the environment of care for high-risk newborns, "The Future is NOW for Babies, Families and Systems" March 8-11, 2023, in Clearwater, Florida

*Disclosure: The National Perinatal Association [www.nationalperinatal.org](http://www.nationalperinatal.org) is a 501c3 organization that provides education and advocacy around issues affecting the health of mothers, babies, and families.*

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