

In Memory of Dr. Heidelise Als

Joy Browne, PhD, Shannon Hanson, PhD, Michael Hynan, PhD

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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Dr. Heidi Als, founder of the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) died last August. Although Dr. Als was most well known for her developmental work, she was also a trained clinician and member of the National Network of NICU Psychologists (NNNP). Members of the leadership of NNNP would like to express their appreciation of the propound impact of Dr. Als' work through a few remembrances expressed here. Dr. Als' influence on many members of NNNP can also be found in chapters of a recently published book, “Behavioral Health Services with High-risk Infants and Families: Meeting the Needs of Patients, Families, and Providers in Fetal, Neonatal Intensive Care Unit, and Neonatal Follow-up Settings.” (1,2) Prior to the remembrances, we have reprinted a few paragraphs from Dr. Als' obituary. ***Heidelise***

Als, PhD, 1940-2022, Professor of Psychology, Department of Psychiatry, Emerita, Harvard Medical School, Director, Neurobehavioral Infant, and Child Studies, Boston Children's Hospital, Founder, NIDCAP Federation International, Inc

Heidelise Als, PhD, of Boston, Massachusetts, and Tunbridge, Vermont, died suddenly on Thursday, August 18, 2022. She is survived by her husband, partner, and research colleague of 44 years Frank H. Duffy, MD (Neurologist at Boston Children's Hospital and Associate Professor of Neurology, Harvard Medical School and Department of Neurology, Boston Children's Hospital), and son Christopher Hopkins Als Duffy of Camphill Village (an anthroposophical community for adults with developmental disabilities in Copake, New York).

Heidelise (Heidi) was born in Krumbach, Germany in 1940, the daughter of Elizabeth Broicher and Heinrich Maria Als, a barrister. Heidi grew up in war-torn and post-World War II Germany. Her experiences during these formative years led her to question how people develop their emotions and inspired her to study how people are shaped by their environment.

During her graduate training and newly married to her first husband, Heidi gave birth in 1965 to her son, Christopher. He was a beautiful infant whose neurological and developmental differences shaped Heidi's career by teaching her to understand that babies communicate and participate in their care if adults would only listen. This understanding led her to create a theoretical model, the Synactive Theory, which became the foundation for the Newborn Individualized Developmental Care and Assessment Program (NIDCAP) in 1982. This caregiving approach quickly became internationally recognized. During this year, Dr. Als established the National NIDCAP Training Center, affiliated with both Boston Children's Hospital and Brigham and Women's Hospital, which provided a formal structure for NICU professionals to become certified in the use of NIDCAP within their own NICUs.

“Dr. Als founded the NIDCAP Federation International, Inc., a non-profit organization (501c3) that ensures the quality of the NIDCAP model of developmental care education, training, and implementation and ultimately improves the future for infants in hospitals and their families around the world.”

In 2001, to coordinate and support NIDCAP training and training center development, Dr. Als founded the NIDCAP Federation International, Inc., a non-profit organization (501c3) that ensures the quality of the NIDCAP model of developmental care education, training, and implementation and ultimately improves the future for infants in hospitals and their families around the world. Today there are 29 centers around the world training in individualized, developmental, family-centered, research-based NIDCAP care.”

“She embodied the definition of resilience, using her personal experience of having a high-risk baby as the guide to create an innovative way to care for patients and families in the NICU. She was approachable and supportive, a true mentor.”

From Dr. Shannon Hanson:

When I think of Dr. Heidi Als, the words that come immediately to mind are passionate, compassionate, committed, and tireless. She was a visionary and an inspiration. She embodied the definition of resilience, using her personal experience of having a high-risk baby as the guide to create an innovative way to care for patients and families in the NICU. She was approachable and supportive, a true mentor. Like the gardener she was at heart, she sowed the seeds of NIDCAP far and wide so that those who work in NICUs worldwide could bloom where we were planted.

“Later she worked with Dr. T Berry Brazelton to develop his Newborn Behavior Assessment Scale. In the consulting call, she said that Dr. Brazelton worried, “If you go into the NICU, I will lose you.” Dr. Brazelton's loss meant an enormous gain for the world.”

From Dr. Michael Hynan:

I heard Dr. Als speak at three conferences, and I was in awe of her knowledge and dedication. Years later, I contacted her with a request to serve as a consultant on one of the phone discussions of the growing group of NICU psychologists, now the NNNP. She agreed to explain her NIDCAP work to the group and answer questions. During our two or three conversations prior to the group call, I always addressed her as “Dr. Als.” I got a very warm feeling when she asked me to call her “Heidi”. The consulting call with Heidi set a record for the number of participants. Heidi described her early work as a graduate student observing preterm infants' behavior for countless hours. Later she worked with Dr. T Berry Brazelton to develop his Newborn Behavior Assessment Scale. In the consulting call, she said that Dr. Brazelton worried, “If you go into the NICU, I will lose you.” Dr. Brazelton's loss meant an enormous gain for the world.

“On a chance trip to a meeting in Boston, I heard a presentation by Dr. Als, who was describing her new Assessment of Preterm Infant Behavior (APIB) and the promise of better medical and neurodevelopmental outcomes for babies such as those with BPD. I was immediately interested in getting trained in the APIB, which was available before NIDCAP was available or even had an acronym.”

From Dr. Joy Browne:

In the early 1980s, I was the Director of a Pediatric Pulmonary Center in New Mexico. We were trying to support preterm infants who had developed bronchopulmonary dysplasia (BPD). Babies we cared for struggled to breathe and had many difficulties with fussing, interacting, sleeping and eating, and development. Most spent their first few months and even years in the intensive care unit. On a chance trip to a meeting in Boston, I heard a presentation by Dr. Als, who was describing her new Assessment of Pre-term Infant Behavior (APIB) and the promise of better medical and neurodevelopmental outcomes for babies such as those with BPD. I was immediately interested in getting trained in the APIB, which was available before NIDCAP was available or even had an acronym. After the emergence of a more structured NIDCAP program, I was fortunate to be guided by Dr. Als to establish the first NIDCAP training center outside of the Boston “mother ship.”

The next decades were full of applications of the supportive NIDCAP approach in NICUs that were not readily accepting of this “soft science.” The NIDCAP Federation International (NFI) was established, and the now global integration of Dr. Als’s vision for professionals and parents to understand the newborn’s voice. Integration of her vision into clinical practice has changed NICU policies, procedures, and outcomes for babies worldwide. There are currently 29 NIDCAP training centers in the United States, Europe, Asia, South America, Australia, and Japan. For more information, see <https://nidcap.org>

“Through thick and thin, her vision was to provide exemplary neurodevelopmental, evidence-based care for babies and their families and support staff caring for them.”

Along the way, I developed a personal and professional relationship with Dr. Als. Her style was exacting, rigorous, and structured, yet warm and supportive simultaneously. Her “good enough” was typically not quite “good enough,” leading the learner to continue striving to be a better observer and clinician. Through thick and thin, her vision was to provide exemplary neurodevelopmental, evidence-based care for babies and their families and support staff caring for them. Her focus was primarily on how babies communicate their needs and strengths and how the professional needs to recognize the goal striving of each and every individual baby. The result was the individualized intervention approach according to the baby’s needs indicated through their behavior.

After days of rigorous NIDCAP or APIB training, Dr. Als morphed into the elegant ballroom dancer, the pony-riding cowgirl, the roar-

ing 20s flapper, or the obstacle course ninja. She definitely knew how to play and always encouraged others to play along with her.

Few leaders in the field have been more committed to supporting babies and families, took on countless naysayers with grace and poise, or showed every person who interacted with her a personal and unforgettable experience.

The philosopher Thomas Kuhn in his groundbreaking “The Structure of Scientific Revolutions” (3), wrote that “scientific fields undergo periodic *paradigm shifts*” rather than solely progressing linearly and continuously and that these paradigm shifts open up new approaches to understanding what scientists would never have considered valid before”. He further notes that the initial rejection of new concepts and approaches is often downplayed or even rejected by the scientific community until enough evidence and change in practice make people think that the initially rejected new practices are “the norm.” His perspective describes Dr. Als’ work succinctly. Her work and evidence were initially rejected as, at worst, detrimental to neonatal care and, at best, “soft” science. She provided a true “paradigm shift” to neonatal care, making neurodevelopmentally supportive care now the norm rather than the exception in global NICUs. Every NICU that practices developmental, family-centered care pays tribute to her dogged determination to provide babies and families with evidence-based, sensitive, and individualized developmental care.

Dr. Als’ leadership, compassion, and personal integrity will be sorely missed. However, she leaves a cadre of committed professionals who join in promoting her vision to provide sensitive, individualized care to every newborn, family, and intensive care professional.

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In summary, we are very saddened by Dr. Als death but very appreciative of how her work has changed newborn intensive care. Members of NNNP have made a financial contribution to Camphill Village for the care of Dr. Als son, Christopher.

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Disclosure: The National Perinatal Association 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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