



“The world needs more NIDCAP, and all clinicians and parents need to learn about it.”
—Yamille Jackson

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FAMILY VOICES

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By Yamille Jackson, PhD, PE, PMP

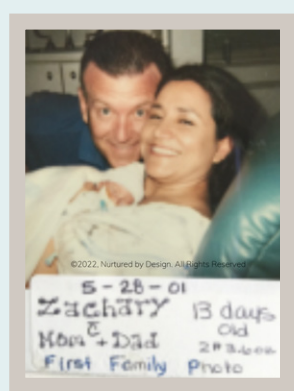
Our True Story of Love, Science, and a Transformative Promise

How it all started

When Larry and I welcomed our son Zachary 12 weeks prematurely in 2001, life changed. It was medically necessary to deliver Zachary early, risking his life to save mine, and while I started feeling better, he struggled. To the NICU staff, Zachary was one of the 13 million babies born prematurely that year, but to us, he was our world.

I owned a consulting firm in risk management engineering for the oil and gas industry. I took an indefinite leave to be with Zach all day, every day, in the NICU (a luxury that, unfortunately, few in the USA have). I was a new and imperfect mother that still believed that nobody should suffer alone. I needed to be there for Zach to nurture and comfort him and,

most importantly, to give him a reason to fight and survive. To this day, my mom has healing and calming superpowers over me, so I figured I had them for Zach too. We were fortunate to be in a progressive hospital, and the staff supported my need to care for our baby.



Our touch turned struggles into possibilities.

The NICU staff encouraged me to ask questions. A nurse shared that when they

grow, former preemies may not like to be touched, and I know isolation is the worst type of punishment. I didn't want that for Zach. Humans learn by association, and I wanted to show Zachary that pain does not always follow touch. Our touch was healing, comforting, and loving. I appreciated it when nurses comforted him verbally before and after painful procedures, as they would with an adult. I appreciated it when they came on their breaks to touch or hold Zachary so he felt loved. Kangaroo Care was introduced the day after he was born as "something nice to do for you and your baby." I remember when the method started when I was a girl in Colombia and heard about it. This started our journey with Kangaroo Care, and we held Zachary daily for hours each day. Kangaroo Care eased my c-section pain and fulfilled my need to nurture my baby as nothing else did. My sadness and worries went away when I held Zachary. Nurses did many interventions while I held him (i.e., blood transfusions, evaluations, change of diapers, heel sticks, and anything I could convince them to do while he was calm on my chest). I fell asleep several times, holding him; it was by far the most restoring sleep since his birth.

The day everything changed.

When Zachary was three weeks old, challenges intensified when Tropical Storm Allison flooded Houston, Texas, and the hospital and life-support equipment lost power we panicked. Larry and I managed to arrive at the hospital, and I held Zachary skin-to-skin for hours, keeping him warm. Larry received a crash course on how to "bag" him and took turns with the staff every 30-45 minutes. In those very dark hours, I promised



Zachary his pain and struggle to survive were not in vain. He was evacuated. A cable television network, TNT made a movie called "14 Hours" about the flood, the evacuation, and Zach's story.

Like most NICU parents, we felt guilt, worry, uncertainty, lack of control, and sadness, among other feelings. Night after night, for five months, we left one of two different hospitals without our baby. My newly found maternal instinct and specialization in ergonomics and human factors engineering helped me be Zach's mom in the NICU.

We were part of a team and had a job to do. The NICU staff cared for Zach's physiological needs for survival. We gave him a sense of security by being present, reassuring, and holding him in Kangaroo Care. Zachary, like every human, likely needed to feel loved to find a reason to fight to survive.

(continued on p. 3)

Editorial



The legacy of Heidelise Als lives on and the breadth of the NIDCAP work represented in this issue is a testament to the strength of NIDCAP. Abstracts from the 33rd NIDCAP Trainers Meeting held in Bad Boll, Germany last October come from nine countries, a truly global effect. Profiles from some of the invited

presenters and their topics raise so many important issues. Kelly Janssens shows how being political can benefit the work we do, and Karl Heinz Brisch, who unfortunately was unable to be with us shares his important work on outcomes. Gretchen Lawhon nicely summarises the meeting in her letter to Heidi highlighting so much of the meeting. I am sure Heidi would love to be kept informed in this way.

Regular features of the work of the NIDCAP Training Centres is demonstrated by the team at the Edmonton Training Centre in Canada. We also learn about how developmental care and NIDCAP is expanding throughout New Zealand.

A new feature has been introduced in this issue – *In Translation*. Maria Maestro Lopez has expertly translated an article written by Jeff Alberts into Spanish. We would like your feedback on this approach and suggestions on how we could expand this feature. We would like to reach out to those members from different language backgrounds.

Kaye Spence AM

Senior Editor – Developmental Observer
Adjunct Associate Professor / Clinical Nurse Consultant
Australasian NIDCAP Training Centre / Sydney Children's
Hospitals Network / Western Sydney University / Australia

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I kissed him after every stick and painful intervention except when I was not allowed. As bad as we thought we had it as parents, he had it worse, so we kept a positive attitude and concentrated on the good news. There were days when we hung on to the fact that he was breathing.

“I love Zach, but how does HE know I love him?”

I worried that Zachary felt abandoned every night (he didn't know we were not allowed to stay with him at night or how long we would be away). I worried he wondered why I let people hurt him (he didn't know they were trying to save his life). I worried that Zachary felt rejection or guilt when we did not hold him or touch him when he was hurting and needed us the most (he didn't know we were not allowed to touch him). As a human being, he was tiny, but he was a human being nonetheless, and he had the right to be treated with love, compassion, and respect.

“How do you calm a baby?”

Calm humans, especially babies, feel less pain, sleep and eat better, leading to fewer interventions, less medication, better healthcare outcomes, less cost, and increased satisfaction.

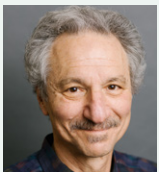
Before a painful procedure, nurses tell adults to relax because “when you relax, it will hurt less.” Since babies do not respond to verbal instructions, I wanted to find ways to calm Zach. Nurses and therapists taught me how to use my hands to comfort him, but who would comfort him when we weren't there?

A turning Point

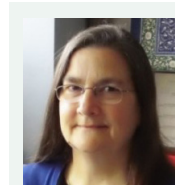
A pair of filled garden gloves simulated the weight, shape, and containment of our hands the way nurses taught me. Larry and I slept with gloves to impregnate our scent so Zachary would feel our presence even when we were not there. The nurses could immediately see the calming effect of “the gloves” on the monitors and how they helped Zachary. However, they could not see how they helped me. Leaving the gloves with our scent made it easier to separate from Zach. A part of us always stayed with him. At night I always left the NICU with the gloves positioned where my hands wanted to stay. The staff also used the gloves to position Zachary and his equipment and soon noticed he was calmer and sleeping better at night or when we were not holding him.

Once at home, a nurse called me requesting “the little gloves I made for Zachary for the rest of the NICU.” This was

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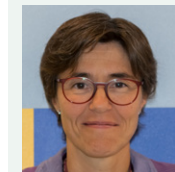
Jeffrey R. Alberts, PhD, is Professor of Psychological and Brain Sciences at Indiana University -- Bloomington (USA). Jeff is also a NIDCAP Professional and blends his lab studies with similar research at Cincinnati Children's Hospital Medical Center.



gretchen Lawhon, PhD, RN, FAAN, is the Clinical Nurse Scientist with Newborn special care associates, at Abington Jefferson Health and a NIDCAP Master Trainer. gretchen has reviewed articles for peer reviewed journals. gretchen has extensive experience as a clinical nurse scientist and has authored numerous articles in her areas of expertise.



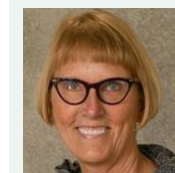
Diane Ballweg, MSN, is the Developmental Specialist at WakeMed Hospital in Raleigh, North Carolina, USA. Diane's writing and editing experience also includes reviewing for several peer reviewed journals and authoring several journal publications and book chapters related to developmental care.



María López Maestro, MD, is a Neonatologist at the Hospital 12 de Octubre in Madrid, and is a NIDCAP Trainer and Member of the National Committee for the implementation of Developmental Centered Care in Spain. Maria has 10 research works. <https://orcid.org/0000-0002-0545-6272>.



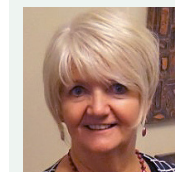
Deborah Buehler, PhD, is a developmental psychologist with expertise in developmental care within newborn and infant intensive care nurseries. Her work has focused on NIDCAP research, education and mentorship, and awareness. Deborah has authored and co-authored papers and manuals pertaining to NIDCAP care.



Debra Paul, OTR/L, is an occupational therapist and NIDCAP Professional at Children's Hospital Colorado in Aurora, Colorado and the Column Editor for the Family Voices section for the *Developmental Observer*. Debra writes policies and guidelines which requires succinct writing and an eye for editing.



Sandra Kosta, BA, NFI Executive Director of Administration and Finance, has been an Associate Editor for the *Developmental Observer* since 2007. As a Research Specialist at Boston Children's Hospital, Sandra has co-authored several papers on the effectiveness and long-term outcomes of NIDCAP Care.



Kaye Spence AM is a clinical nurse consultant and clinical researcher with numerous publications in peer reviewed journals and several book chapters and is a peer reviewer for eight professional journals. She is a past Editor of *Neonatal, Paediatric and Child Health Nursing*. <https://orcid.org/0000-0003-1241-9303>

a turning point...I found a way to give back and solve a need of families and staff in the NICU; however, as a risk engineer, I knew that my homemade and hand-made version had many risks. I could take risks for my baby but not for other babies, so I founded “Nurtured by Design.”

I was in a unique position because I was solving a problem that I lived with, and I had the drive, the education, and the experience to do it. After three and a half years of research and development and the involvement of thousands of stakeholders, we finished our first NICU device, and I called it “The Zaky®.” A pair of The Zaky HUG® extends the touch and scent of the parents and provides a calming and predictable micro-environment for all babies regardless of size, medical condition, or developmental stage. It virtually replaces all developmental care devices and provides a simple and effective tool for NIDCAP as a non-pharmacologic pain management solution, family-integrated care, and effective for babies experiencing opioid withdrawal and for Safe to Sleep.

I first met Dr. Heidelise Als at the Gravens Conference in Florida when she presented information about NIDCAP, and it made sense to me.

Our passion for paying it forward and improving the lives of infants and families

In 2007, Nurtured by Design became my full-time job. I decided to add kangaroo care (KC) to my advocacy work. My research showed two main roadblocks for KC: Safety and Awareness/Education.

To provide safety, we spent three years engineering The Zaky ZAK®, starting with my own experience holding Zachary – I wanted a device that is safe, hands-free, comfortable, easy to wear, unisex, that provides constant containment and a predictable experience for the staff, the parent, and the baby. It offers easy, quiet, and immediate access for transfers, breastfeeding, pumping, and interventions. The stability provided by The Zaky ZAK® reduces risks, prevents injuries (like unplanned extubations and falls), and, as always, considers the entire supply chain (inventory, ordering, storing, maintenance, training, quality control, etc.) It is also the backup for when incubators lose power and evacuations.

In 2010, I was certified as a professional Kangaroo Care-giver by Dr. Susan Ludington and the United States Institute for Kangaroo Care. Soon after, I started the International Kangaroo Care Awareness Day on Zachary’s 10th birthday (May 15th), which is now celebrated globally. www.kangaroo.care provides free resources and information for a fun, non-threatening, non-judgmental way to celebrate Kangaroo Care and increase its Awareness/Education.

In 2014, Oprah met Zach, and she featured our story. The video is on our homepage www.thezaky.com. The Gates Foundation funded us to develop a mobile app for parents called The Zaky® to track kangaroo care and other activities and facilitate Kangaroo-a-thons.



In 2014, Zach met Oprah Winfrey, who featured Zach’s story

In 2018, I was honored to sponsor Dr. Als to present at Mary Coughlin’s conference in Belgium. I saw her again at my first NIDCAP Trainers meeting in October 2019 and met many professionals who told me they love The Zaky®, which warmed my heart. What I remember most about Dr. Als is when she said, “you are one of us,” and she also wrote a letter of support for me for a grant. Her life was well lived, and her legacy will continue to be multiplied by phenomenal professionals worldwide that give every baby the best possible chance of life, not just survival.

I achieved the Trauma Informed Professional (TIP) certification from Caring Essentials, Inc., and realized that The Zaky® was aligned with all the elements of trauma-informed care. I also became more active in research, and the list of publications is on our website.

Our philanthropy includes donating The Zaky® products to the most vulnerable. The most recent large donation of The Zaky® packages went to every baby in seventeen NICUs in Ukraine, where parents and babies are experiencing more than usual trauma and are fighting for their survival and their country. We collaborated with the NIDCAP Federation International, other parent organizations, and the March of Dimes for logistics and delivery. I also host the “In touch with experts: LIVE,” where we talk in layman’s terms with experts about topics that interest parents.

Zachary will never remember, but Larry and I will never forget.

Zach is our CIO (Chief Inspirational Officer) and grew up to

be a loving, intelligent, witty, handsome, funny, caring, talented, and hard-working adult. He has visited over 20 countries with me, takes fantastic photos, and is gifted and creative. Zach is now in college and is passionate about cars.

Our story was possible because we were part of the NICU community caring for him. I am grateful for the work behind the scenes by researchers like Dr. Als. I am aware that she and thousands of professionals influenced the NICU staff that cared for Zach. Globally, we are mourning her loss, but I am confident that NIDCAP will only strengthen.

Dr. Als was an exceptional woman and teacher, who was inspirational, com-



"Zach is our CIO (Chief Inspirational Officer)"

passionate, and approachable. Those who met Dr. Als realize what we lost and feel honored to have been touched by her life. Dr. Als inspired us, taught us, and gave us the knowledge to treat every baby as a human, as someone's child that is part of a family that deserves compassion, respect, and individualized nurturing care.

The world needs more NIDCAP, and all clinicians and parents need to learn about it. My commitment is to continue supporting your work (on behalf of Zach) and offer tools and services that empower you to implement and teach NIDCAP so that every family can have the best possible quality of life for a lifetime.

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email: nfipresident@nidcap.org

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NIDCAP Trainer
Director, Children's Hospital of University of Illinois NIDCAP Training Center
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email: clemente.fatima@gmail.com

Mandy Daly, Dip. H Diet and Nutrition, ACII, DLDU

Family Representative, Dublin, Ireland
email: mandy.daly@yahoo.co.uk

Jennifer Degl, MS

Family Representative, New York, USA
email: jenniferdegl@gmail.com

Dalia Silberstein, RN, PhD

NIDCAP Trainer
Co-Director, Israel NIDCAP Training Center
email: dalia.silberstein@clalit.org.il

Apoorva Sudini, BS

Healthcare Associate
PricewaterhouseCoopers, New York, NY
email: apoorva.sudini@pwc.com

Charlotte Tscherning, MD, PhD

Division Chief of Neonatology, Sidra Medicine, Doha, Qatar
email: charlottecasper66@gmail.com

Juzer Tyebkhan, MBBS

NIDCAP Trainer
Director, Edmonton NIDCAP Training Centre
email: juzer.tyebkhan@albertahealthservices.ca

STAFF

Rodd E. Hedlund, MEd

Director, NIDCAP Nursery Program
NIDCAP Trainer
email: nidcapnurserydirector@nidcap.org

Sandra Kosta, BA

Executive Director of Administration and Finance
email: sandra.kosta@childrens.harvard.edu

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NIDCAP Founder, Past President 2001–2012
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