



Mattis Pfeiffer, right,  
with his sister Marlene

“Every single caregiver must enable parents to be parents not only cognitively within the framework of the rules but also intuitively.”  
—Frierer and Elena Pfeiffer

## ▶ INSIDE

- Family Voices ..... 1
- Editorial ..... 2
- NIDCAP Training Centers ..... 6  
Worldwide
- Educating, Training, ..... 8  
Recruiting, and Retaining  
the Best
- Global Perspective—Australia ..... 12
- Science Desk ..... 15  
Through an Ethical Lens
- Congratulations to ..... 18  
Dr Bjorn Westrup
- NIDCAP on the Web ..... 19
- NIDCAP Training Centers ..... 21

## FAMILY VOICES

DOI: 10.14434/do.v16i2.36197

By Frierer and Elena Pfeiffer

### A small newborn, a whole person

Our son Mattis was born in Tübingen, Germany, almost five years ago. Way too early at week 24. A small, tiny human being of 550 grams, but a whole person at the same time. It took us a while to understand that. When Frierer was allowed to visit him a few hours after he was born, he returned to Elena inspired. “He is so beautiful. It’s a long way. But everything will be all right.”

The third verse of the German lullaby “Der Mond ist aufgegangen” became Mattis’ baptismal motto. Its truthfulness still touches us today:

*Behold the moon - and wonder  
why half of her stands yonder,  
yet she is round and fair.*

On the 1st of July 2018, our lives changed from one day to the next in a different way for each of us. Giving birth so prematurely was the negative culmination

of very worrying weeks with a lot of problems leading up to the delivery. The pregnancy had not lasted. From Elena’s point of view, being born extremely premature posed the greatest possible danger to her son’s life. At first, she was just terrified. For Frierer, former worries turned into the chance to take an active role in Mattis’ development, providing some relief to Elena in a way. Frierer was optimistic. Our feelings about our son’s early birth were different. However, we both felt confused, overwhelmed, and inexperienced.

#### A multitude of emotions

We were overwhelmed by our emotions. A new kind of fear, a new level of loss of control, a state of constant alertness, and, on top of that, the search for understanding from the medical staff, “are we right in the way we feel?” And, more importantly, the question of positioning oneself: Too

little optimism takes away hope and instead may paralyze you. Too much optimism makes you vulnerable and afraid of too much hope and, consequently, too big a fall.

Access to our child was difficult early on. There were so many medical procedures and hospital protocols around Mattis. So, we had to act counterintuitively. In addition, we naturally lacked medical understanding. Added to this was the challenge of self-organization and logistics (e.g., pumping, visiting times) and of course the constant goodbyes. Sometimes these were a relief, but more often they were dreadful. We also found it difficult to realize that touch, which is so important to us, can lead to breathing cessations. This situation was one example of so many dilemmas we found ourselves in. Therefore, it takes time to adjust to the situation and to actively take action. Especially if you already have experience as a parent of a first child. You feel - positively or negatively - the constant dependence on the nurses and doctors.

### Another level of sensitivity

For us as parents, it was helpful when the staff showed a psychological understanding of what we were experiencing.

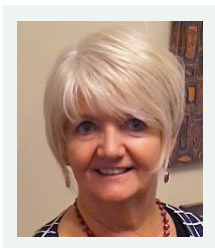
(continued on p. 3)



Learning to adjust to the new environment

## Editorial

DOI: 10.14434/di.v16i2.36195



Families are a great source of inspiration, and their approach enables professionals to adapt and use knowledge in different ways. Frierer and Elena Pfeiffer whom we met at the NIDCAP Trainers meeting in Germany last year write a beautiful story of their journey through the NICU with Mattis and illustrate how

the NIDCAP approach made a difference to their journey. There is a lot to consider as you read their story. Kylie Pussell from Miracle Babies in Australia tells us her story and how attending the International Kangaroo Mother Care conference in Madrid helped her champion the implementation of kangaroo care.

As NIDCAP and APIB training continues to spread we are challenged to see how we can continue to improve the training and the process. In this issue, Roman Chabba and Juzer Tyebkhan, a leader within the NFI ask if NIDCAP is ready for Gen Z. Working with different generations can give us insight into how others see the world, and by listening to younger generations we can learn how to make changes.

In this issue, we introduce a new feature – An Ethical Lens. Jeffery Alberts and David Smith give insightful commentary on an article on moral distress in the NICU. We hope to make this a regular feature raising awareness of the many ethical issues facing parents and healthcare professionals.

The NIDCAP Training Centers continue to inspire us in their work. Natascia Bertone gives us insight into the development and work of the Italian Modena NIDCAP Training Center. I am happy to receive updates from any of the NIDCAP Trainers Centres as this column continues to celebrate the work of NIDCAP and APIB.

I would like to hear from the readership and membership on what features you would like to see in the Developmental Observer. Of course, I would love to receive submissions on your NIDCAP work so we can continue to share the joy of working with newborns and their families.

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

Cover photo used with permission

We were especially helped by the nursing staff who understood that, with us, a soft approach was necessary. The nurses were empathetic, spoke an understanding language, and wanted to build an individual connection with parents. Not necessarily only through medical competence, but as engaging, compassionate people.

Many nurses and doctors showed this level of sensitivity and helped us a lot, especially when NIDCAP came into play. The NIDCAP Professional helped us to understand the medical framework and its effectiveness on the infant and additionally understood our personal framework as parents and individuals.

### The NIDCAP Professional as a mentor

Parents need to be intrinsically motivated and accept that NIDCAP Professionals have a special role as mentors - in a way that parents who already have an older child are not used to. From our point of view, parents should therefore be psychologically met at their level and supported in different ways. For NIDCAPers this means that they have to establish their standing with their various stakeholders, find access and let parents have a say in what their baby tries to communicate to

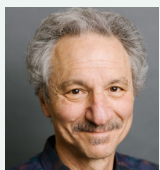
the world, and how it “ticks”.

### NIDCAP as a gamechanger

After about a week of the greatest emotional challenges and of feeling overwhelmed more often than not, we became aware of NIDCAP for the first time. With NIDCAP came the change from having different observers of Mattis to having only one person observing him who stayed by our side for the rest of our time in the NICU. A reference observer, so to speak. This was incredibly helpful and comforting to us. The NIDCAP Professional was a knowledgeable observer who followed Mattis and knew him well, and we accepted her as a mentor for us. We gained confidence through this NIDCAP Professional, who gave us security, structure, and trust in the process.

This NIDCAP Professional got to know us and was able to relate to both of us in different ways. For Frieder, she served mostly as an observer providing structure and chronicling important insights and events that revolved around Mattis and his environment. With Elena, she was a sensitive interlocutor who helped Elena find her own intuition after the traumatic experience of becoming a mother. It helped to observe her

## Editorial Board



**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.



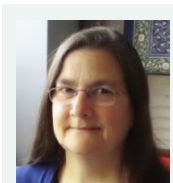
**Diane Ballweg, MSN**, is the Developmental Specialist at WakeMed Hospital in Raleigh, North Carolina, USA. Diane's writing and editing experience also includes reviewing for several peer reviewed journals and authoring several journal publications and book chapters related to developmental care.



**Deborah Buehler, PhD**, is a developmental psychologist and a NIDCAP Master Trainer 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.



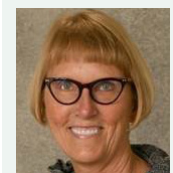
**Sandra Kosta, BA**, NFI Executive Director of Administration and Finance, has been an Associate Editor for the *Developmental Observer* since 2007. As a Research Specialist at Boston Children's Hospital, Sandra has co-authored several papers on the effectiveness and long-term outcomes of NIDCAP Care.



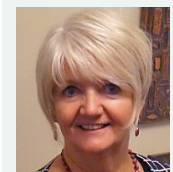
**gretchen Lawhon, PhD, RN, FAAN**, is the Clinical Nurse Scientist with Newborn special care associates, at Abington Jefferson Health and a NIDCAP Master Trainer. gretchen has reviewed articles for peer reviewed journals. gretchen has extensive experience as a clinical nurse scientist and has authored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



**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>.



**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.



**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>



The importance of family



Mattis as a healthy five year old

and Mattis together and helped Elena learn to feel and realize her self-efficacy as a mother. In doing so, this helped to slowly build up the self-confidence needed to stand up for our child's concerns, on the one hand, and the implementation of the NIDCAP Professional's recommendations on the other hand. This allowed us to function for Mattis in our own way, but also for both of us in the best way for all involved.

### Problem Parents

This self-awareness was important because our own actions could also lead to us being perceived as 'problem parents' on the ward. For some caregivers - but explicitly not for all - Mattis, the "King of the jungle", who needed a lot of attention, got company from his "Jungle parents", who also demanded a lot of attention. Parents who had to put up with the fact that some of the jointly developed NIDCAP recommendations were not taken into account by everyone involved according to the guidelines.

Standing up for a child's needs at the expense of one's own reputation, sometimes became a test of strength.

### 360° Empowerment

Every single caregiver must enable parents to be parents not only cognitively within the framework of the rules but also intuitively. This means empowerment regarding the child and their surroundings. Besides the goal *that* the child survives, it is equally important *how* the child survives. Structured observation with its clear guidelines and support helps here.

It is important to give everyone involved a good feeling by taking care of the child's and the parent's needs. Then, they

realize, *It is being taken care of*, but also, *I can do something*. This approach works wonders. Self-confident actions that follow structured assistance ensure further self-confidence and further bonding with the child. However, it is important to remember that each person must be approached differently.

### The power of reading Mattis' behaviors

Together with NIDCAP, we noticed after one observation, Mattis was no longer hungry after cuddling. It seemed like he still needed something. Our impression was that he still wanted to suckle something. That he might even be nursed to sleep. As a result, contact was made with the breastfeeding counselor. A visit was then very quickly implemented with the breastfeeding counselor which was successful, and things moved forward very quickly. It was a very liberating experience for us. Because an observation was made, empathetic thought was given, and the right conclusions were drawn. Mattis' delicate medical situation made individual caregivers refrain from taking this step towards breastfeeding. This is where NIDCAPers supported reluctant caregivers with empowerment.

The child we have today is also the child we had in the NICU and the one we recognize today when we read through the structured NIDCAP observations again. Just as he didn't like position changes in the past, he still has a hard time with major changes today. This means that, in our opinion, an individualized, observational approach to the child from the beginning is incredibly important and a great opportunity for the child to be seen as a whole person.

## Learning a new role and thinking like a lawyer

We had to learn a new role as parents in the NICU. To be an advocate for our child, we remember the quote from our self-selected caregiver "there is no other advocate for your child here but yourselves". Embedding and teaching this fact was crucial. It enables a momentum of self-efficacy as the most important driver of resilience in the NICU. At the same time, the excessive demand of being able to perform this task seems too great, especially in such a medical environment, which is sometimes very foreign to non-professionals. Having a NIDCAP Professional by our side in this mammoth task was probably the decisive factor for us to stand up for Mattis in the right places. We were not alone. In the NICU and in society, premature babies deserve a voice. For parents to support this, they must first find their own voice.

## Without doubt and fear

After 88 days, Mattis came home, three weeks before the estimated date of birth. He is now a bright, cheerful boy who throws himself into life and is full of basic confidence. Mattis is developing better than we ever dared to wish. He loves cars and role plays, music, and running. He is proud of his new bicycle with gears. And he enjoys the big family that has been so sensationally supportive all this time. For his great-grandmother's 98th birthday recently, Mattis sang a song together with his sister. Loud and full of joy. Without doubts and fears. Just as he entered this earth almost five years ago. We first had to learn this feeling from him. But now we know it. Mattis is round and fair. A small newborn, a whole person.

## NIDCAP Federation International Board of Directors and Staff 2022–2023

### PRESIDENT

#### **Deborah Buehler, PhD**

NIDCAP Master Trainer  
APIB Trainer  
Director, West Coast NIDCAP and APIB Training Center  
**email:** [nfipresident@nidcap.org](mailto:nfipresident@nidcap.org)

### VICE PRESIDENT

#### **Dorothy Vittner, PhD, RN, FAAN**

Senior NIDCAP Trainer  
West Coast NIDCAP & APIB Training Center  
**email:** [dvittt8@gmail.com](mailto:dvittt8@gmail.com)

### TREASURER

#### **Gloria McAnulty, PhD**

National NIDCAP Training Center  
**email:** [gloria.mcanulty@childrens.harvard.edu](mailto:gloria.mcanulty@childrens.harvard.edu)

### CO-TREASURER

#### **Jennifer Hofherr, MS, OTR/L, CNT**

National NIDCAP Training Center  
NIDCAP Trainer  
Children's Hospital of University of Illinois NIDCAP Training Center  
**email:** [jennifer.hofherr@nationwidechildrens.org](mailto:jennifer.hofherr@nationwidechildrens.org)

### SECRETARY

#### **Jean Powlesland, RN, MS**

NIDCAP Trainer  
Director, Children's Hospital of University of Illinois NIDCAP Training Center  
**email:** [nidcapchicago@gmail.com](mailto:nidcapchicago@gmail.com)

#### **Fatima Clemente, MD**

NIDCAP Trainer  
Co-Director, São João NIDCAP Training Center  
**email:** [clemente.fatima@gmail.com](mailto:clemente.fatima@gmail.com)

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

Family Representative, Dublin, Ireland  
**email:** [mandy.daly@yahoo.co.uk](mailto:mandy.daly@yahoo.co.uk)

#### **Jennifer Degl, MS**

Family Representative, New York, USA  
**email:** [jenniferdegl@gmail.com](mailto:jenniferdegl@gmail.com)

#### **Dalia Silberstein, RN, PhD**

NIDCAP Trainer  
Co-Director, Israel NIDCAP Training Center  
**email:** [daliasil1960@gmail.com](mailto:daliasil1960@gmail.com)

#### **Apoorva Sudini, BS**

Healthcare Associate  
PricewaterhouseCoopers, New York, NY  
**email:** [asudini@outlook.com](mailto:asudini@outlook.com)

#### **Charlotte Tscherning, MD, PhD**

Division Chief of Neonatology  
Oslo University Hospital, Norway  
**email:** [charlottecasper66@gmail.com](mailto:charlottecasper66@gmail.com)

#### **Juzer Tyebkhan, MBBS**

NIDCAP Trainer  
Director, Edmonton NIDCAP Training Centre  
**email:** [juzer.tyebkhan@albertahealthservices.ca](mailto:juzer.tyebkhan@albertahealthservices.ca)

### STAFF

#### **Rodd E. Hedlund, MEd**

Director, NIDCAP Nursery Program  
NIDCAP Trainer  
**email:** [nidcapnurserydirector@nidcap.org](mailto:nidcapnurserydirector@nidcap.org)

#### **Sandra Kosta, BA**

Executive Director of Administration and Finance  
**email:** [sandra.kosta@childrens.harvard.edu](mailto:sandra.kosta@childrens.harvard.edu)

### FOUNDER OF THE NIDCAP FEDERATION INTERNATIONAL, INC.

#### **Heidelise Als, PhD 1940–2022**

NIDCAP Founder, Past President 2001–2012  
Senior NIDCAP Master Trainer  
Senior APIB Master Trainer  
Director, National NIDCAP Training Center, 1982–2022