

Column Editor: Debra Paul, OTR

Losing a loved one is never easy, especially when the loss is a baby. In this story, we hear from the NIDCAP Trainer that worked with a family as they cared for their baby who was born very premature, and the impact of helping the baby's parents learn how to read their son's behavioral language and provide him support. Following the loss of their son, the baby's mother sent a letter of gratitude to the staff in the newborn intensive care unit and shared how the individualized and developmentally sensitive care their son received profoundly influenced their experience. They described what NIDCAP meant to his family and how it changed their perspective of an intensive care setting. The comforting words that this mother provided to the staff in her letter also challenged staff to expand the NIDCAP work throughout their country so that other babies and families can benefit from this family centered, evidenced based approach to developmental care.

NIDCAP from a Parent's Perspective: An Open Letter from a Family

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Masahiro was born at 22 weeks gestation at the Tokyo Metropolitan Bokutoh Hospital and weighed about 400 grams. Immediately after his birth, Masahiro developed respiratory distress with poor lungs and became seriously ill and needed Nitrous Oxide gas and respiratory support. Masahiro was his parents' first child, and every day they were with their son, they gently touched Masahiro and talked to him affectionately.

Miwa and Teruhisa, Masahiro's mother and father, were able to read Masahiro's behavioral cues so well. During one skin-to-skin care, as Masahiro rested on Miwa's chest, she sensed, based on his expression, that his pain and distress had eased. Likewise, when Teruhisa held him for skin-to-skin, Masahiro's eyes would open, his face would shine, and he appeared delighted with the experience of being close to his father. It was as if Masahiro was enjoying the attention.

Shortly after six months, and Masahiro's half-birthday, it was with great sadness that his parents said goodbye to their son who embarked on an eternal journey in April 2021. Following Masahiro's passing, Masahiro's mother, Miwa communicated to our staff, "Thanks to everyone, we have become a family". These words provided me with a little relief as everyone who had cared for Masahiro was filled with great sadness for his parents. Later, we received a letter from Masahiro's family addressed to our hospital staff. I would like to now share the letter Masahiro's family sent us as it provided us with a great deal of courage and energy.

*To everyone at Tokyo Metropolitan Bokutoh Hospital NICU
Dear Doctors and Nurses,*

For medical professionals, I presume that the days will continue to be unrelenting.

I am full of respect and gratitude to everyone who is working hard every day in the midst of anxiety and great tension. Thank you again.

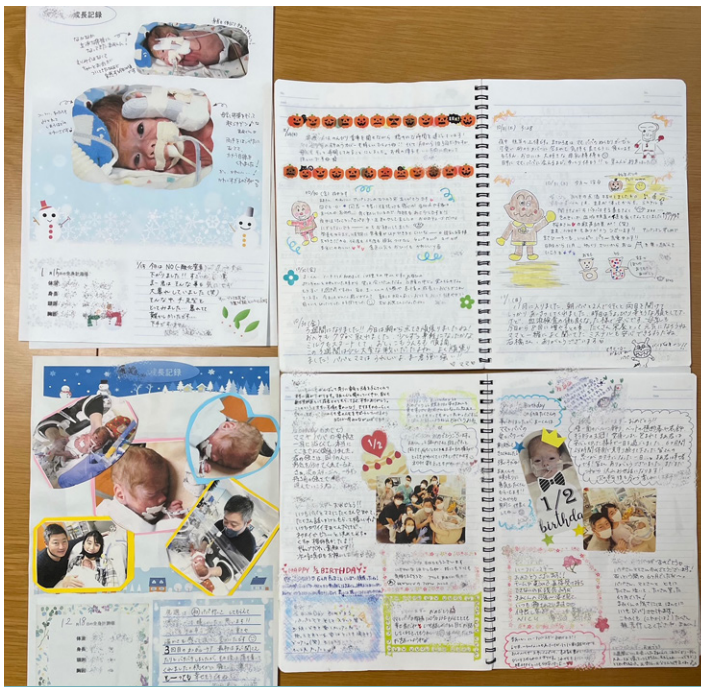
Thank you to everyone for taking care of our son Masahiro while he was in the newborn intensive care unit. I was able to complete the forty-ninth day of the memorial service^a without delay.

It seems that the six months spent in the NICU were short, but I think it is more than enough time for our family. Masahiro did his best. The six months my son was alive was in the midst of widespread fear of COVID-19 infection.

I think there were various difficult decisions in the hospital, such as protecting the bond between parents and children and protecting the safety of everyone involved. Under such circumstances, you allowed us to visit our son 24 hours a day, encouraged active skin-to-skin care, and provided care that was close to our hearts until the very end.

Every day, everyone was thinking and discussing what was the best that could be done at that time. You listened sensitively to the words of our family and worked together to provide care and treatment. And above all, you treated Masahiro and our family with love. I'm really grateful. Thank you very much.

We cherish the growth record with photos that you gave me as well as Masahiro's diary that we wrote together and value. Thank you for the many messages you wrote while you were so busy. It is an important treasure for us.



Masahiro's diary



Masahiro's team

Without each and every one of you, we wouldn't have had six months with Masahiro.

Ma-kun. Ma-kun ...

I still can't forget how hard he responded to many calls. We laughed and rejoiced together in Masahiro's small changes and growth, and thanks to everyone, our first child-rearing became fun and happy. I can't heal my sadness and pain, but when I remember your faces, it still makes me feel better! I am really grateful to have met all of you.

I can't forget how you understood the feelings of a newborn premature baby and how to respond to them. In the midst of all the confusion, your voice and actions towards my son served as a model for us, and each word brought us closer to our baby.

I was really surprised to find that facilitated tucking and skin-to-skin care also gave Masahiro the best experience that we could imagine. Putting my hands in the incubator all day and talking to my son, singing a lullaby, and so on. Thank you for watching over Masahiro with warm eyes.

One day, I learned that "NICU is not just a place to treat." I understood that the NICU is a place to help families learn about their baby's responses and language as well as their child's development and on-going care. I remember feeling relieved as until then I thought it was special place to treat baby illness in every way. I was very happy to feel that nurses are not only for treatment, but also for helping us raise our children.

I think situations will vary depending on the baby and family, but please continue to be a friendly place that is

supportive of the premature baby and family. And we hope that the efforts of NIDCAP will be taken for granted throughout Japan in the future. We look forward to seeing how you continue to you create an ideal environment for babies' development, care and growth.

*Best regards,
Miwa
June 2021*

- a This is a Japanese custom. The memorial service will be held 49 days (7 weeks) after death. The day of the final decision on whether to go to heaven is 49 days after death.

NOTE: The below is the mother's letter in original format.

【家族コラム原稿案】

まさひろくんは22週、四百数十グラムで、私たちの病院で生まれました。彼は生まれた直後から肺の状態が悪く重症でした。NOガスと呼吸器のサポートをずっと必要としていました。ご両親にとって初めてのお子さんと、毎日、まさひろくんに手で優しく触れ、優しく語りかけてくれました。そして、ご両親は彼のしぐさを読み取れるようになりました。

あるときのカンガルーケアでは、ママの胸の上で彼の表情は安らぎました。そして彼の痛みや苦痛が和らいでいることをママは察知しました。パパのときは目も口も開けて表情が輝き喜んでいました。それはまるでアトラクションを楽しんでいるかのようでした。

ハーフバースデーを迎えて間もなく、2021年4月、永遠の旅に出た優裕くんとお別れは大きな悲しみでした。しかし、優裕くんのお母さんが「皆さんのおかげで私たちは家族になれました」とおっしゃってくださったことに、大きな悲しみの中で少しの安堵感を覚えました。後日、私たちの病院スタッフへご家族からお手紙をいただき、私たちは大きな勇気とエネルギーをもらいました。そのお手紙をご紹介します。

墨東病院NICUの皆様へ
拝啓

医療関係者の皆様にとっては、まだまだ気の抜けない日々が続くことと推察いたします。

日々、不安と大きな緊張感の中、尽力されている皆様には、心から尊敬と感謝の思いでいっぱいです。今日もありがとうございます。

息子、優裕の生前中は大変お世話になりました。四十九日の法要も滞りなく済ませることができました。

NICUで過ごした6か月は短いようですが、私たち家族にとっては十分過ぎる時間であるようにも思います。よく頑張ってくれましたから。

息子の生きた6か月はまさにコロナの感染への恐怖が広がる中にありました。

院内では親子の絆を守ること、関わる人すべての安全を守ることと、いろいろ難しい判断があったと思います。

そんな中で、24時間の面会を許可してくださったり、積極的なカンガルーケアを実施してくださったり、私たちの心に寄り添ったケアを最後の最後まで行ってくれました。

その時できる最大限のことを皆さんが日々考え、話し合ってくださっていたこと。家族の言葉に敏感に耳を傾け、連携してケアや治療に力を尽くしてくださったこと。

そして何より、優裕と私たち家族に愛情をもって接してくださっていたこと。

本当に感謝の思いでいっぱいです。ありがとうございました。

皆さんからいただいた写真付きの成長記録や皆さんと書き綴った優裕ダイアリーもそのひとつです。忙しい中、たくさんのメッセージをありがとうございました。大切な宝物です。

皆さんお一人おひとりなくして、優裕との6か月はありませんでした。

まーくん。まーくん…。

たくさんの呼びかけに、一生懸命こたえる姿が今でも忘れられません。

小さな変化や成長と一緒に笑い、喜び合ってください、私たちにとって初めての子育ては皆さんのおかげで楽しくて幸せなものになりました。

まだまだ悲しみやつらさは癒えませんが、みなさんの顔を思い出すと今でも元気が出ます！

皆様との出会い、本当に感謝しています。

早産で生まればかりの赤ちゃんの気持ちをどう汲み取り、どう接したらよいのか。

とまどいの中、皆さんの赤ちゃんに対する声かけや行動は私たちのお手本となり、言葉の一つひとつが赤ちゃんとの距離を縮めてくれました。

ホールディングやカンガルーケアも、私たちが想像する以上に、赤ちゃんにとって最高の時間を与えられるということも実感し、本当に驚きました。

保育器に一日中、手を入れて話しかけてはウトウトしたり、子守歌を歌ったり…。そんな姿も温かい目で見守ってください、ありがとうございました。

「NICUは治療する場ではありませんよ」とある日、教わったこと。

NICUは家族とともに赤ちゃんの子育てを手助けする場所なんだ、と理解しました。それまでは病気をあらゆる方法で治療する場所で特別なんだと思っていただけに、気持ちが和らいだことを覚えています。そして、皆さんと一緒に子育てを手助

けて応援してくださっているんだと感じ、とてもうれしかったです。

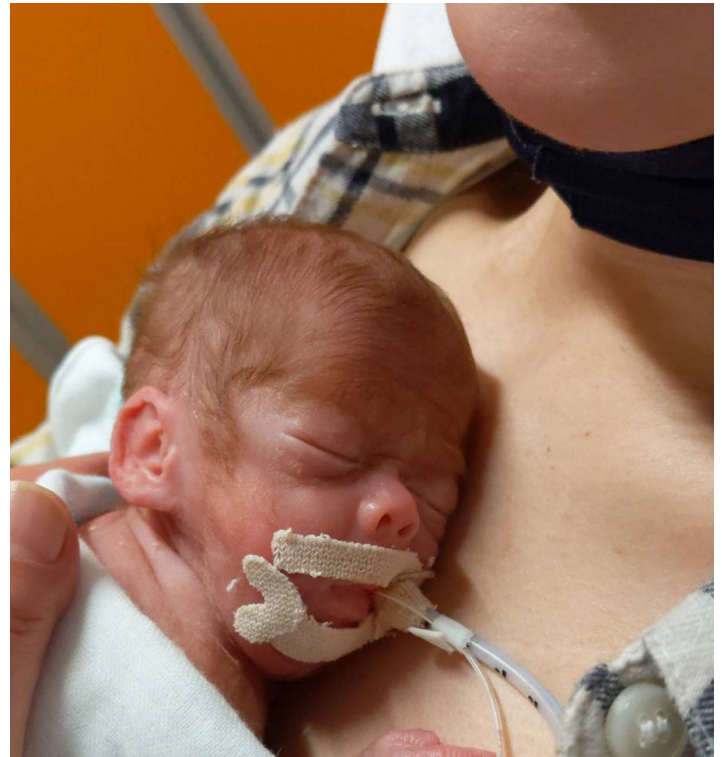
状況は赤ちゃんやご家族によっても様々だと思いますが、これからも赤ちゃんやご家族に寄り添った優しい場所であり続けてください。

そして、NIDCAPの取り組みも、今後、日本中で当たり前に取り入れられることを私たち家族も願っています。赤ちゃんの心のケアと、成長と発達のために理想的な環境づくりを今後も期待しています。

敬具

2021年6月

優裕の父、母



Masahiro with his mother, Miwa



Mission

The NFI promotes the advancement of the philosophy and science of NIDCAP care and assures the quality of NIDCAP education, training, mentoring and certification for professionals, and hospital systems.

Adopted by the NFI Board, July 1, 2019

Vision

The NFI envisions a global society in which all hospitalized newborns and their families receive care in the evidence-based NIDCAP model. NIDCAP supports development, enhances strengths and minimizes stress for infants, family and staff who care for them. It is individualized and uses a relationship-based, family-integrated approach that yields measurable outcomes.

Adopted by the NFI Board, October 20, 2017