


ORIGINAL ARTICLE OPEN ACCESS

Small Wins for Small Babies: Celebrating Weekly Successes Helps Parents Cope With the NICU Hospitalisation

Béatrice Boutillier^{1,2,3} | Fanny Labelle² | Emilie Lancastre² | Magali Rey-Le Lorier² | Christine Laurin² | Sophie Fournier² | Elisabeth Legault² | Christiane Lachambre² | Annie Janvier^{1,2,4}  | on behalf of the PAF committee (family partnership)

¹Unité D'éthique Clinique et Organisationnelle, Centre de Recherche, CHU Sainte-Justine, Montréal, Canada | ²Division of Neonatology, CHU Sainte-Justine, Montréal, Canada | ³Hôpital Robert Debré, Paris, France | ⁴Faculté de Médecine, Département de pédiatrie, Bureau de L'éthique Clinique, Université de Montréal, Montréal, Canada

Correspondence: Annie Janvier (anniejanvier@hotmail.com)

Received: 10 May 2025 | **Revised:** 10 May 2025 | **Accepted:** 27 May 2025

Funding: This work was supported by Private Funder. M Danny Lacroix (donation) made this study possible with funds donated to the PAF-QI team (partenariat famille quality improvement).

Keywords: balanced information | cellular phone | communication | congenital anomalies | mental health | neonatology | NICU | optimism | parental perspectives | prematurity

ABSTRACT

Aim: To describe the implementation and evaluation of an intervention to celebrate babies' weekly achievements in the neonatal unit (prolonged hospitalisations) and examine parental perspectives.

Methods: In a feasibility study, 92 parents reported the lack of optimism in the NICU, that clinicians often focused on what was going wrong; they recommended weekly celebration of accomplishments. The formats recommended were both physical (certificate given to parents) and virtual (text message). Inclusion criteria were baby > 1 week of life, likely survival, predicted hospitalisation > 1 month and parental consent. Parental perspectives were investigated using mixed methods with a questionnaire after discharge.

Results: The parents of 93 babies received weekly certificates (100% participation). The length of stay was on average 104 days, for a total of 1182 certificates/text messages received. 45% answered the questionnaire. The overall evaluation of parents was 9.1 of 10; 88% reported it helped them cope with hospitalisation. Parental answers to open-ended questions were all positive and invoked gratitude, empowerment, patience and hope.

Conclusion: Weekly text messages and certificates celebrating babies' accomplishments were appreciated and helped parents cope. It is possible to instil healthy optimism in the NICU.

1 | Introduction

Neonatal hospitalisations are frequent: about one in ten babies are born preterm and one in a hundred have a serious congenital anomaly. Parents face many challenges when their children are in the neonatal intensive care unit (NICU), including high levels of stress and anxiety, leading to post-traumatic stress disorder (PTSD) [1–3]. This can have an impact on attachment, bonding,

understanding of the clinical situation, interactions with staff and their baby, which may all be associated with adverse neuro-developmental outcomes [4, 5].

The philosophy of care in the NICU has evolved in the past decades. Parents and families are now considered to be part of the treating team and integrated in the care of their children. Family-centred care and parental support aim at decreasing the

Abbreviations: NICU, neonatal intensive care unit; PTSD, post-traumatic stress disorder.

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Summary

- Parents in the neonatal intensive care unit (NICU) report clinicians were often pessimistic, they suggested highlighting babies' achievements.
- NICU parents received weekly certificates (both physical and texts) to celebrate milestones. Parents appreciated this intervention: it helped them cope with hospitalisation and gave them empowerment, patience and hope.
- It is possible to instill healthy optimism in the NICU. Future studies will examine whether this intervention has an impact on family outcomes.

negative impacts of the hospitalisation [6–8]. Family partnerships, enhanced psychological support and having an optimistic view can improve parent–child interactions, parents' stress levels and rates of PTSD [9–12]. Despite these improvements, many investigations reveal clinicians' perspectives are not aligned with the views of families. The Voice of Parents project has demonstrated that parents are often more optimistic than clinicians [13]. They see the good, not just the bad [14], they describe balanced views such as the positive and negative impacts of NICU hospitalisation [15]. Parents report that clinicians often focus on clinical problems and what to do about them, but rarely on what is going well, or on future steps and the clinical trajectory of their child [16]. Partnering with parents to optimise care and reporting of outcomes [17], as well as providing personalised support are valuable aims [13].

The goal of this initiative was to cultivate healthy optimism by celebrating weekly achievements during the clinical trajectory of babies in order to help parents cope with the hospitalisation. In this article, we describe the creation and implementation of this project, as well as parental perspectives about the impact of these weekly celebrations.

2 | Methods

The following project was developed in a Level 4 NICU in Québec, a bilingual province where French (official language) and English are spoken. In this province of Canada, neonatology is regionalised, health care is universal (socialised) and parental leave is 1 year. The CHU Sainte-Justine NICU is the largest mother–child NICU in Canada with 75 beds and 30–35 dedicated to intensive care (about 1000 admissions a year). For the past 15 years, the PAF-QI team (Partenariat Famille, quality improvement), an interdisciplinary group of clinicians (physicians, nurses, nurse practitioners, social workers, occupational therapists, pharmacists, physiotherapists, psychologists, unit assistants, volunteers, etc.) and parents (currently 23) [13] created to optimise care in our NICU, has embarked on quality control initiatives and investigations about parental perspectives. This interdisciplinary group reflected on ways to cultivate healthy optimism in the NICU. The goal of this initiative was to address the following parental recommendations: to not only speak about problems and risks, but also to speak about what

is positive, celebrate achievements, milestones and be more optimistic.

2.1 | Needs Assessment, Feasibility and Implementation

This phase of the study took place in 2022; 92 parents of babies who were hospitalised more than 1 month were interviewed in the week preceding expected home discharge (all accepted to participate [18]). We asked parents if the lack of optimism was a problem and how it could be addressed (when, how often, where, how?). All parents confirmed the lack of optimism. One of their recommendations was prevalent: to celebrate milestones regularly throughout the whole hospitalisation. At that time, we already had several (bilingual) certificates celebrating milestones in the unit (*'I weigh 1000g'*, *'my last coffee'*), but they were not distributed in a standardised fashion or for many fragile babies, during periods of stagnation, weeks could separate two milestones. Half the parents recommended daily celebrations, but The PAF team thought this was unrealistic and we aimed at celebrating weekly accomplishments.

Parents recommended the use of certificates, with picture and words and gave examples for more certificates, some of which also celebrated parents (*'I have received my mother's milk for one month'*, *'I had my first kangaroo'*, *'Happy father's day papa: it's our first father's day together'*) (Figure 1). A member of the PAF team, a father partner, recommended both physical (receiving paper 'certificates' that could be placed together as a garland above the baby's bed) and virtual (receiving a text) formats. This father reported that texts would enable the working parent to also receive positive news. We asked parents which format other than paper certificates were optimal: texts, a parent-led app, a passport (with and without stickers of milestones), a brochure, videos or a website with milestones. Most parents ($n = 70$) reported receiving texts as their number one choice. The PAF team developed a protocol to safely send text messages to families; texts were sent from one dedicated phone in the unit. This phone could not receive messages from parents (automatic answer if parents tried to send in a message). The text messages were planned to be sent weekly by one of the investigators.

2.2 | Pilot Phase

The pilot phase took place in 2023. The inclusion criteria for the pilot phase and the prospective study were the same: parents of babies whose hospitalisation was expected to exceed 1 month, where youth protection was not involved (parents are permitted to be at their baby's bedside) and babies who are expected to survive. For example, the majority of babies born at 22 weeks GA die in our unit, and we know the majority of NICU deaths occur in the first week of life. For this reason, parental consent was requested between Day 5 and 10. Parents who agreed were asked to complete a form (including a signature) with their cellular phone number. After consent, the weekly distribution of certificates, both physical and by text (to both parents) started. Single parents were informed that a support person could also receive the certificates. Participants were reminded by text that



Generic certificates from database (from a total number of 55)



Event certificates from database (from a total number of 6)

FIGURE 1 | Example of generic certificates (those with a red line around them were created during the course of the study).

they could stop receiving text messages and certificates anytime they wanted.

Every Thursday, a member of the PAF research team visits the unit to decide which certificates to send to which parents from a bank of numbered certificates (called 'generic certificates' for the purpose of this study) (Figure 1). We quickly realised that for some babies, during periods of stagnation or during difficult weeks, there were no certificates that could be distributed and personalised messages had to be written, such as 'I was brave during my surgery', 'my grandmother visited from France'. Initially, during the pilot phase, 58% of the certificates had to be individually created, which proved time-consuming (Figure 2). We decided to edit some of the created certificates to make them more 'generic' in order to make the process more efficient and to have to create less certificates each week (Figure 3). At the end of the pilot phase, there were a total of 61 certificates, 6 of which

were specific to a particular time of year (New year, mothers' day, fathers' day, valentine's day, Halloween, etc.) (Figure 1).

We meticulously described the several steps (checklist) that were required after entering parents in the database with their cell phone number: 1) deciding which certificate to send from the generic list of certificates, 2) when no generic certificate was appropriate, an individualised one was created, 3) printing the created certificates, 4) distributing the certificates at the bedside, 5) sending the certificates via text, 6) removing parents from the database when the baby has been discharged and adding new patients in the database. On Fridays, the preset certificates are prepared to be distributed at the bedside. They are then attached to a garland above the baby's bed. The same certificates are also sent to parents via text. All steps are done by clerical staff, except Steps 1 and 2. At discharge, the physical certificates are bundled and given to the parents.



FIGURE 2 | Example of created certificates when none of the generic certificates fit the clinical situation of the baby.

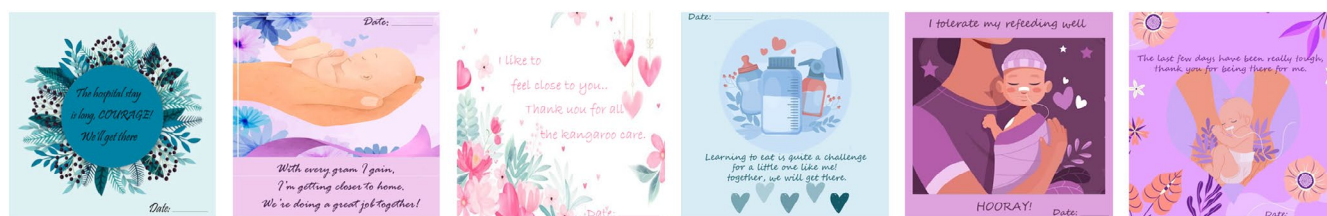


FIGURE 3 | Example of certificates that became generic ones after the pilot phase, in order to be more efficient in the prospective phase.

2.3 | Prospective Study Period

From January 2024 to September 2024, a questionnaire was sent via text at the end of the hospitalisation to evaluate parental satisfaction and their perspectives. For families with two parents, they were requested to answer as a couple (so there would be one questionnaire answered for each baby). The questionnaire focussed on parental satisfaction: how they evaluated the initiative, the frequency, themes and format of the certificates. Three open-ended questions were also asked for parents to give their perspectives on the initiative (positive and negative points), possible improvements and recommendations for new parents.

2.4 | Data Analysis

The quantitative results were analysed using Excel software and are presented in the form of descriptive statistics. Open-ended questions were analysed using mixed methods and thematic analysis. The themes and sub-themes were rigorously defined by two independent researchers. Two independent investigators then independently coded all the data. A mixed-methods specialist supervised each stage of the analysis and assessed the coding reliability. Any divergences were resolved by consensus. Each participant parent provided consent to participate. The project was approved by the Sainte-Justine Hospital Research Ethics Committee as part of the QI projects developed by the Family Partnership Group of the neonatal unit (PAF-QI).

3 | Results

For the duration of the study, 101 neonates satisfied inclusion criteria and were alive at 5–10 days of life, at which time their parents were met to be part of the study; 100% of parents agreed to participate in the project; 8 couples did not receive certificates because their baby died shortly after giving consent (the questionnaire was sent to the 93 parents who received certificates). The demographic factors of the 93 children were the following: the majority ($n=82$) were preterm (range 22–32 weeks, average 29 weeks) and the other 12 were born with a congenital anomaly. The length of stay was on average 104 days (30 to 226 days); 34 newborns were the result of multiple pregnancies (17 twins (including 3 surviving twins after perinatal loss) and 1 quadruplet).

A total of 93 parent/couples received certificates. The average number of certificates/texts sent was 12 per parent (range 3–40), for a total of 2364 certificates received during the study period (1182 certificates sent via text and 1182 distributed at the bedside). After the creation of new 'generic' certificates during the pilot phase, only 24% of the certificates had to be created each week.

Forty-two parents answered the questionnaire (45% participation rate). The mean evaluation (on a scale of 0–10) of parents for this project was 9.1; 88% of parents reported it has probably or certainly helped them cope with hospitalisation. 78% thought that the weekly frequency is appropriate; the rest would want more

certificates. Parents all liked the format of certificates (both via text and physical). There were no negative impacts reported.

3.1 | Answers to Open-Ended Questions

3.1.1 | Recommendations and Steps Taken to Improve the Initiative

Parents gave recommendations to improve the study. We removed the certificates that were not appreciated by parents. For example, many parents disliked one of the certificates that celebrated fighting an infection, which was removed from our database (Figure 4). Some fathers were unsatisfied that there were many positive certificates only mentioning mothers, but few for fathers or both parents. We indeed realised there were several certificates relating to mother's accomplishments (receiving mom's milk for over a month, first breast feeding, kangaroo care, mothers' presence and touch), but only one for fathers' day. We then created certificates specifically highlighting the participation of fathers and their bond with their baby and adjusted some of the certificates to include both parents (e.g., for kangaroo care) (Figure 5). Parents also recommended adding the date on the physical certificates, which was done.



FIGURE 4 | Example of one of the certificates that was removed from the bank of certificates (because it was disliked by parents in the questionnaire).



FIGURE 5 | Example of additional certificates created to celebrate the role of fathers in the NICU.

3.1.2 | Positive Points About the Study

When parents described positive points, four themes were invoked: 1) they thanked clinicians and expressed gratitude for the project; 2) they described how the project helped them cope and gave them hope; 3) they highlighted how much support parents need; and 4) many proposed new initiatives. Examples of parental quotes can be found in Table 1.

3.1.3 | Advice Parents Would Give to New Parents

We asked parents what advice they would give to new parents whose baby had just been admitted to the NICU. Parents invoked four themes in their messages: 1) hope and encouragement; 2) reassurance and trust; 3) patience; and 4) practical advice (rest, skin to skin ...). Examples of parental quotes can be found in Table 2.

4 | Discussion

The aim of this study was to describe the implementation and evaluation of a weekly celebration of babies' accomplishments during their neonatal hospitalisation. To our knowledge, we are the first to report such an initiative in the scientific literature. On the other hand, some parental blogs and parent associations encourage parents to celebrate milestones, and several milestone cards can be found and printed [19].

Our first finding is that parents were enthusiastic about the intervention and all of those who reached study criteria agreed to participate. Parents evaluated this initiative highly and reported it helped them cope with the hospitalisation and gave them hope. Their answers to open-ended questions were full of gratitude. When adults who were born preterm report what it means for them to be preterm, several report that their parents had both positive and negative stories [20]. These certificates are also mementos the family can keep, one day possibly telling the child his/her story in positive terms. No negative impacts of the study have been found. On the other hand, it is possible that some parents whose babies did not reach entry criteria were disappointed. We wanted to be realistic and started this project at a smaller scale, knowing that the length of hospitalisation is associated with more psychological impacts on families. In several studies, parents report the lack of optimism in the NICU, and that clinicians focus on problems and diagnoses, as opposed to what is going well and functional abilities [12, 14, 15, 17]. When parents describe wanting more optimism, they do not provide an operational definition. Rather they describe only hearing about problems and worst-case scenarios. Indeed, as early as the prenatal consultation,

TABLE 1 | Parental quotes: Feedback about the project.

<p><u>Thanks and gratitude (n=19)</u></p> <p><i>'Very positive experience, I want to thank all of your staff for all the work they do for humankind.'</i></p> <p><i>'Everything is perfect like that!'</i></p> <p><i>'The support provided to parents is excellent. Many thanks! 🙏❤️'</i></p> <p><i>'Honestly you guys are doing great. I love getting these messages it makes my day.'</i></p> <p><i>'You are all magnificent, the kindness of the nurses made our stay very pleasant. We are very grateful'</i></p> <p><u>Coping and Hope (n=5)</u></p> <p><i>'It made us smile every time'</i></p> <p><i>'We love getting these messages it makes our day'</i></p> <p><i>'It's such a pleasure to receive them'</i></p> <p><i>'It helps us hold on to the light at the end of the dark tunnel!'</i></p> <p><i>'It's nice to receive a message of encouragement and hope from time to time.'</i></p> <p><u>Parents need support (n=4)</u></p> <p><i>'There needs to be more extensive psychological support for parents'</i></p> <p><i>'Social workers should be more quickly available'</i></p> <p><u>New initiatives (n=8)</u></p> <p><i>'Increase the frequency of messages because it's such a pleasure to receive them'</i></p> <p><i>'It would be interesting to have a date, the number of days in hospital and/or the baby's age.'</i></p> <p><i>'Games or songs. Because we forget the nursery rhymes'</i></p> <p><i>'Send pictures of the child directly'</i></p> <p><i>'Create a WhatsApp group with volunteer parents'</i></p>
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TABLE 2 | Parental quotes: Recommendation to 'new NICU parents'.

<p><u>Hope and encouragement (n=24)</u></p> <p><i>'Be optimistic and above all patient'</i></p> <p><i>'Strive to find moments of calm, reflection and affection in the midst of turbulent times, because with the downs there are magnificent successes, and on the other side of unhappy news there will be happy memories that will give you the strength to move forward.'</i></p> <p><i>'Have faith, everything will be alright'</i></p> <p><u>Reassurance and trust (n=21)</u></p> <p><i>'Stay strong. It's only temporary. Your little one will be home soon'</i></p> <p><i>'Ask questions and communicate openly with the medical team. Seek support from family, friends or support groups. Stay hopeful and trust in the expertise of the medical staff.'</i></p> <p><i>'Trust the staff—they know what they're doing and give good advice'</i></p> <p><i>'Stay hopeful and trust in the expertise of clinicians.'</i></p> <p><i>'Hang in there, they're a great team so if there's anything you need to talk about, share your concerns...'</i></p> <p><u>Patience (n=10)</u></p> <p><i>'Be optimistic and above all patient'</i></p> <p><i>'Take it one day at a time; everything is temporary, nothing is eternal'</i></p> <p><i>'Be patient'</i></p> <p><i>'Patience is the most important thing, Babies need time to grow up'</i></p> <p><u>Practical advice (n=7)</u></p> <p><i>'Do skin-to-skin often'</i></p> <p><i>'Staying close to your baby helps a lot'</i></p> <p><i>'Spending as much time as possible in kangaroo with baby worked for us'</i></p> <p><i>'Seek support from family, friends, or support groups.'</i></p> <p><i>'Don't forget to take time for yourself!'</i></p> <p><i>'Share positive energy with your baby'</i></p>
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neonatal academic societies recommend that clinicians describe all potential adverse outcomes to prospective parents [21–23]. These recommendations do not urge clinicians to speak to families about their role in the unit, skin-to-skin, nor

positive aspects of parental bonding, for example. In this project, clinicians see the garland above the babies' bed, they are informed when a new certificate is created and they witness parents' joy when a new certificate arrives. It is possible that

such a programme serves as a remedy leading to a small culture change.

Our second finding is that for some babies, we could not find generic milestones to use. Operationalising optimism in the NICU can be difficult, as some babies have complex hospitalisations, long periods of stagnation and/or intermittent deteriorations before they improve. In these cases, it is important to avoid causing harm. We did not want to create unrealistic expectations and aimed to remain attuned to the clinical situation. For example, when a baby's highlights for her sixth week of life were that she went to the operating room for a second unexpected surgery, there were no generic milestones to celebrate. In such cases, individualised certificates were created, for example *'It was a hard week, but my parents visited me every day'*. We realised that even in the most difficult situations, clinicians could find something positive to highlight despite adversity.

Our third finding was that such an enterprise was more complex than we initially thought and would have been near impossible outside of a research project. The feasibility and pilot phase were essential to know what parents wanted, optimise our functioning and to ensure we could send texts in a secure fashion. Many institutions do not support texting parents, and institutional telephones (land lines) do not support sending texts. Parents investigated in our feasibility trial were offered many choices and the vast majority wanted to be texted. They did not want a website, videos, to print their own certificates, an app, brochures, nor a website. For this specific problem, they recommended a solution for which the hospital did not have the infrastructure, nor any experience, and which raised concerns about confidentiality. By performing this project as a research initiative, we were able to address these issues, demonstrate that parents appreciated the project, and that there were no issues regarding confidentiality. The certificates were also created with parents. Those that were not liked were removed, and parents helped us create and improve those that were lacking. This agility was also cheap and efficient. Several institutions would have requested that certificates be created by a specific group using institutional colours and language. Our PAF-QI team is a quality improvement research intervention team [13] that aims to help parents the way they want to be helped. In this context, regularly seeking parental perspectives is important. Parents in other institutions may have preferred videos. In several years, parents may prefer new ways to communicate. Institutional rules and committees can be slow to adapt to patients/parents needs. We need to remain cognisant of these institutional barriers. This project was labour intensive to develop but once it is developed, it represents about 3 h of dedicated time a week: 1) deciding which certificate to send from the generic list of certificates and when no generic certificate is appropriate, an individualised one is created, 2) printing the created certificates, and distributing the certificates at the bedside, 3) sending the certificates via text, 4) keeping the database up to date and removing parents from the database when the baby has been discharged. All these steps can be done by different groups of people. Step 3 is the most complicated step to develop and perform weekly. We recommend that clinicians who wish to embark on a similar initiative start with the physical distribution of generic

certificates before they start creating some and before they start sending text messages to families.

Our last finding were the results of the recommendations parents made to new parents. At the end of a long hospitalisation, they were able to reflect on their stay and provided positive messages to new parents. Parents also highlighted the importance of self-care with practical examples, confirming this is an essential component of their psychological health [24]. Parents reported the value of psychologists and social workers who work in our unit. Despite having four full-time positions for these clinicians, many parents found it was insufficient for their needs.

This project has several limitations. We only started to distribute certificates at 1 week of life knowing the majority of NICU deaths happen in that first week. It is possible that for parents who lose their child, these certificates and texts would be precious mementoes. As stated before, only parents whose babies stayed longer than 1 month were included for feasibility reasons. It is possible that parents of babies who are less sick would benefit less from such an initiative. This is a local initiative with limited parental responses and results may be different in other contexts. We also did not obtain quantitative measures of parental psychological state and cannot state that the project had an impact of parental anxiety, depression nor PTSD. On the other hand, it is difficult to imagine scenarios where this project would harm parents. Recently, in the Voice of Parents project, 248 parents (98% of parents coming to follow-up) were asked about their information needs and recommendations in the NICU. When they had such recommendations, 26% reported needing more optimism [16]. This confirms a parental need for balanced and optimistic information. As of now, there are no validated 'optimism scale', 'balanced information scale', nor 'communication scale' measuring this parent important outcome. In some countries, parental leave is nonexistent or less than in our province. In these circumstances, parents could perhaps benefit even more from receiving similar texts. Finally, an important factor to consider is how much time these initiatives consume. They require the mobilisation of clinicians and volunteers who are willing and motivated to develop, support and optimise care. Our group has decided to continue these efforts, for the positive impacts on parents, and also because we feel that it has a significant impact on our unit culture.

5 | Conclusion

Weekly text messages and certificates celebrating babies' accomplishments were appreciated by parents and helped them cope. It is possible to instil healthy optimism in the NICU.

Author Contributions

Béatrice Boutillier: conceptualization, investigation, writing – original draft, methodology, validation, visualization, writing – review and editing, formal analysis, project administration, data curation, software, supervision. **Fanny Labelle:** conceptualization, investigation, methodology, validation, visualization, project administration, data curation, writing – review and editing. **Emilie Lancastre:** investigation, methodology, formal analysis, data curation, resources, conceptualization,

writing – review and editing. **Magali Rey-Le Lorier:** conceptualization, investigation, methodology, visualization, software, formal analysis, project administration, data curation, writing – review and editing. **Christine Laurin:** conceptualization, visualization, data curation, writing – review and editing, methodology, project administration. **Sophie Fournier:** investigation, writing – review and editing, project administration, data curation. **Elisabeth Legault:** conceptualization, writing – review and editing, methodology, visualization. **Christiane Lachambre:** conceptualization, methodology, writing – review and editing, software, project administration, data curation, resources. **Annie Janvier:** conceptualization, investigation, funding acquisition, writing – original draft, methodology, validation, writing – review and editing, formal analysis, project administration, data curation, supervision, resources.

Acknowledgements

We want to acknowledge the contribution of Elisa Lalonde and Julie Ouellet, neonatal nurses who had the idea of the certificates and configured the first ones. We also thank Danny Lacroix (parent of James Lacroix), a father partner who recommended weekly celebrations and had the idea of the texts (thought about for fathers who work). We also thank Steve Turmel, administrative assistant who enabled us to send texts to parents in an optimal and safe manner. We also thank the entire PAF team for their ongoing support and work for all families.

Conflicts of Interest

The authors have no conflicts of interest to disclose.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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