



COVID-19 SPECIAL EDITION

In this special edition of our newsletter, we are focusing on words of hope from members of the Graham's Foundation community. Please take a few minutes to read their encouraging messages.

Supporting Premie Parents in Difficult Times

As we work together through these challenging times, you may have questions about how Graham's Foundation is supporting our premie parent community. Fortunately, because our support programs have always been delivered virtually, we are equipped to deliver all our programs today, tomorrow, and into the future to continue to meet the psychosocial needs of parents.

Our [Care Packages](#) offer helpful tips for self-care and navigating the NICU and going home (our supplies have been in stock since before the COVID-19 outbreak), our [MyPremie app](#) provides critical premie-related information and helps parents journal their NICU experience, and our three dozen trained [Mentors](#) are available to lend an ear and offer words of advice and encouragement.

In such a difficult time, it is more important than ever that we are here for the most vulnerable members of our community and Graham's Foundation is ready. We are grateful to our volunteers and the individuals and industry partners who make generous donations that enable us to develop and deliver our support programs.

In gratitude,

Nicholas Hall, Founder
Graham's Foundation

I Know We Will Get Through this Together

A neonatologist's message to premie parents

I hope everyone is staying safe and healthy during this difficult time. From a neonatologist's perspective, these last few weeks have felt surreal. On the one hand, we have taken some solace in the fact that it appears that infants and children are not severely affected by COVID-19. On the other hand, we have been watching as our colleagues in the emergency room and adult ICU's prepare for a possible wave of very sick patients to hit the hospital.

There is a palpable fog of anxiety in the hospital, as security guards check visitors and staff, and military-like triage tents appear overnight outside our emergency department. Personal protective equipment is being rationed, and staff is being reduced in order to limit traffic in and out of the NICU. One of the scariest things I participated in was counting how many neonatal ventilators we had in the hospital, and how many could be re-programmed to work on an adult patient.

While NICU babies may not become critically ill from COVID-19, my colleagues

and I remain worried about being able to maintain an excellent standard of care while the rest of the healthcare system is strained.



Nurses, neonatal nurse practitioners, therapists, secretaries, and environmental services workers at WakeMed Health & Hospitals in Raleigh, NC are trying to get the word out: STAY HOME!

Perhaps the biggest stressor to our families has been the significant visitation restrictions put in place at our hospital. The NICU has always been a place that limited visitors, especially during flu and respiratory syncytial virus (RSV) season to protect our babies, but COVID-19 has caused many hospitals to reduce NICU visitation to only mom and dad, or a support person, for the duration of the hospitalization. Combine that with families that are already navigating the challenge of having older siblings at home and out of school, or being worried about job security for themselves or their spouse, and I've felt the anxiety in our moms and dads more acutely these last few days.

How scary to feel alone in the hospital with a critically ill newborn. During my two weeks on service, I've tried to just recognize and validate those feelings out loud. I think for some parents it's actually been good to talk through that.

There have been some positives in this new way of doing medicine. Since we are shifting most of NICU follow-up clinic visits to Telemedicine (using video like Facetime or through other apps), we are finding new ways to engage with families. Our G-tube clinic has been doing "virtual" G-tube checks, which both families and doctors have loved. Will this become the new normal, to help families not have to pack up their preemie for a car ride for every follow-up visit?

The concept of social distancing has made tangible to the general public the usual protective steps we take to protect our preemies when they leave the hospital. Hunkering down like a preemie mom is now in vogue.

Parents of babies in the NICU, or those at home with a recently discharged NICU baby may feel particularly isolated at this time. That's why it's important to use our parent networks to support families, or to check in with moms who may be home alone with a baby during this time.

I hope that programs like the [Parent Mentor](#) or [transition home packages](#) at Graham's Foundation will give families comfort as we navigate this new normal in society. NICU families are incredibly resilient, I know we will get through this together.

Stephen D. DeMeo, DO, MEd
Division of Neonatology-WakeMed Health & Hospitals
Regional Assistant Dean - Campbell SOM/WakeMed

We're ALL In this Together

A Message from our Board

What a strange world we've been thrust into, this time of coronavirus! TIME magazine, quoting a letter from a reader, described it as "...this still moment when we balance on the edge of the abyss and try to apprehend the heights which must be scaled." The word "unprecedented" keeps coming up, as we struggle to grasp our changed reality.

Yet for families of preemies, the experience may feel eerily familiar, like déjà vu. As Nick Hall, the founder of Graham's Foundation, said in an email, "The rest of the country is beginning to understand what we preemie parents endured for months on end with our babies in the NICU and bringing them home." And I realized, indeed, that's true:

- You've already had life as you knew it suddenly upended. You've cancelled treasured plans and lived with uncertainty, not knowing when normal life would resume.
- You've experienced overwhelming anxiety; practiced constant vigilance; learned new behaviors; and throughout it all, been bombarded with medical information, including ominous predictions that might or might not happen.
- "Stay at home." "Avoid large gatherings." "Wash your hands." Been there; done that! You're an old hand at social distancing, like when you first took your baby home or during RSV season. And feeling isolated may be all too familiar - not just physically, but emotionally - because your parenting experiences weren't what you expected and what everyone else was going through.
- Not least, it is definitely nothing new to have your whole world taken up by one very scary concern.

Of course, you don't want to go through all this again. It wouldn't be surprising if you're experiencing some post-traumatic stress as this coronavirus situation unfolds. Or maybe it's the opposite - you're feeling relatively calm because you've faced huge threats before and learned to live with them. Either way, as someone who has loved a preemie, don't ever forget or doubt that you have drawn on reserves of courage, endurance, and resilience that are still there. Be sure to remember that familiar experience, too.

The other day I heard a Norwegian proverb: "It will either get better, or it will pass."

If those words speak to you, take heart. And if they don't, still know that you always have people here in our wonderful Graham's Foundation community whom you can rely on to understand and help where we can.

As families of preemies, you are more aware than most of life's fragility. People feel lost right now. But you know how to maintain hope while learning to accept reality. Maybe you have some advice, some tips on living with uncertainty and how to tap into resilience. You've practiced this; you have the skills. Maybe you can show us the way.

And hey, at least this time around, we are ALL in this together!

Mia Doran, MD, retired

Author of *Preemies: The Essential Guide for Parents of Premature Babies* and

Co-author of the MyPreemie App

Member, Graham's Foundation Board of Directors

Graham's Foundation Makes Wall Street Journal

Graham's
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Fighting for Premature Babies

ONE IN TEN BABIES IS BORN PREMATURELY

THAT'S ONE TOO MANY
YOU CAN MAKE AN IMPACT IN THE LIVES OF PREMIE PARENTS TODAY!

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We need your help!
Join us, in collaboration with the healthcare community, in providing parents with real and immediate support as they fight alongside their premies.

WITH YOUR SUPPORT, WE CAN OFFER FAMILIES

- Informative Care Packages
- Trained Peer Mentors
- Useful MyPremie App
- Valuable Online Resources
- Supportive Community

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Graham's Foundation was recently featured in an ad in the Wall Street Journal. Thank you, WSJ, for helping us raise awareness about our services and reach even more premie parents!

Words of Hope

Share your
Words of Hope
for our parents
currently in the
NICU

Graham's
FOUNDATION
Fighting for Premature Babies

Parents of premature babies are all very familiar with uncertainty. Feelings of anxiety, unease and fear are running through our newsfeeds, neighborhoods, and within us right now. But through all of this, we know to have HOPE. We have fought beside the tiniest and fiercest people. We now have the opportunity to share some of that hope. The rest of the world is being called to live as we lived when we sat beside our baby's isolette or carried them out of the NICU for the first time.

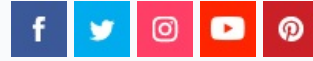
Let's take this opportunity to fill the world with Words of HOPE. It's time to share our strength and wisdom with parents who are currently terrified by what this all means in the NICU and those who have never experienced a premature birth or the isolation of caring for a medically fragile child. Let's share words that will lift others up in times of uncertainty.

Share a quick note or a video to wordsofhope@grahamsfoundation.org. We will start sharing posts with your Words of Hope in graphics and emails to our community. And you can also help spread the word by widely sharing our posts. We can be a light in this uneasy time and encourage each other!

Heather McKinnis
Director of Development, Preemie Parent

[Read parent stories here](#)

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