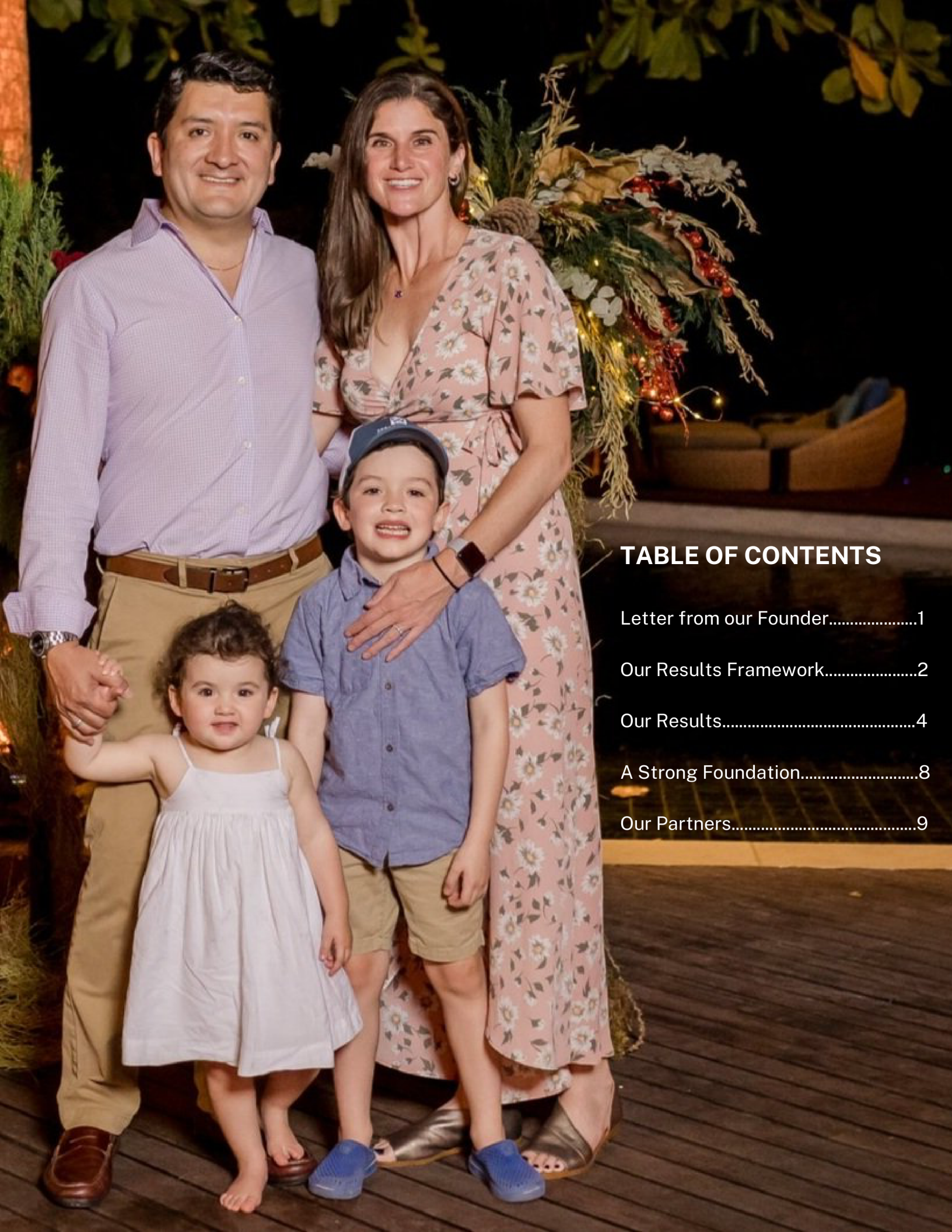




# 2023 IMPACT REPORT

Devoted to the future every  
preterm baby deserves.





## TABLE OF CONTENTS

|                              |   |
|------------------------------|---|
| Letter from our Founder..... | 1 |
| Our Results Framework.....   | 2 |
| Our Results.....             | 4 |
| A Strong Foundation.....     | 8 |
| Our Partners.....            | 9 |

# LETTER FROM OUR FOUNDER

---

My husband and I founded The Iris Fund in 2017 after we suffered the devastating loss of our daughter Iris following an emergency C-section. She was just 28 weeks old. In the immediate days after, we learned two, life-altering things: 1) the stigma and isolation around this kind of loss is crippling, and 2) the basics of how a woman's body works during labor — full term and preterm — have yet to be understood. Not only do we not have enough effective interventions for high-risk pregnancies, but the basic science of labor lags far behind advances in other areas.

In fact, between 1989 and 1993, inclusion of women in clinical research was the policy of the National Institutes of Health (NIH), but it was not law. It was not until 1993 that Congress wrote the NIH inclusion policy into Federal law through a section in the NIH Revitalization Act of 1993 (Public Law 103-43) titled Women and Minorities as Subjects in Clinical Research. Most of what we know about how the human body works is based on a man's body. And there is no time that we are more vulnerable to this fact than while pregnant.

Today, because of supporters like you, we are accelerating the pace of research that will improve outcomes for vulnerable preterm babies. In just six years, The Iris Fund has raised more than \$800,000 from over 2,000 supporters in 37 states and eight countries.

## **This Is Our Moment.**

We are thrilled to have obtained standalone nonprofit status this past year — after many happy years housed in our local community foundation. We are poised to raise even more funding from individuals, foundations, and corporations to accelerate our progress.

As we continue to turn our shared vision into a reality, I speak for everyone at The Iris Fund — our investors, advisors, and friends — in saying we are proud, and honored, to be helping other families move through their preterm and loss journeys while also fueling the work to make it less common tomorrow. We would not be making progress across our key objectives without your commitment and visionary support. Iris' legacy lives in each of us.



With Gratitude,

A handwritten signature in cursive script that reads "Brittney Crystal". The ink is dark and the signature is fluid and personal.

Brittney Crystal

Iris' Mom

Founder and Executive Director of The Iris Fund

# OUR RESULTS FRAMEWORK

---

The work of The Iris Fund is grounded in a Results Framework. This approach, adopted by USAID in the 1990s, outlines the underlying logic to programming; it defines measurable objectives, helps us monitor our activities, identifies critical resources and activities, and assists with adjusting our strategy when necessary.

Going forward, we will continue to prioritize partnership with practitioners, research institutions, and community groups to realize our vision — where no family endures the heartbreaking complications and loss due to prematurity.

## DID YOU KNOW...?

**10,000,000** preterm babies have died over the last decade.

**400,000** babies are born too soon in the U.S. each year; that number increases to **15,000,000** globally.

**21,000** babies are born still in the U.S. each year; that number increases to **1,900,000** globally.

**0** women can be told how their body works during labor. **0**.



**GOAL**

Reduce the incidence of prematurity and stillbirths at scale.

**STRATEGIC OBJECTIVE**

New, improved, and existing evidenced-based pregnancy-related care is widely known and used by health care providers, pregnant mothers, and other caregivers.

**INTERMEDIATE RESULTS**

**RESEARCH:**

New or improved pregnancy and delivery care practices are designed, tested, evaluated, and disseminated.

**BEHAVIOR CHANGE COMMUNICATIONS:**

Messaging developed and disseminated to providers, mothers, and caretakers to encourage use of evidenced-based best (or better) practices.

**IMPROVED DATA COLLECTION AND ANALYSIS:**

The incidence of stillbirth and prematurity and its causes better quantified.

**ADVOCACY:**

Investments in maternal and newborn health increased; government policies enhanced; and access to information and programs that support improved care broadened.

**A STRONG FOUNDATION OF:**

BEST-IN-CLASS TALENT

MONITORING & EVALUATION

STRONG GOVERNANCE

AGILE SYSTEMS

RESOURCE MOBILIZATION

BRAND BUILDING

# OUR RESULTS

Since our founding, The Iris Fund has fueled multi-disciplinary work that will save babies through improved clinical care.

## RESEARCH

New or improved pregnancy and delivery care practices designed, tested, evaluated, and disseminated.

### The Reality

The greatest advances for babies born preterm has been made by neonatologists, the specialists who care for babies after they're born. The only two interventions for preventing preterm birth, cerclage and progesterone, are ineffective, perhaps because there have been no changes in the past five decades except that the intramuscular form of progesterone lost its FDA approval last year. Cerclage, a technique to sew the cervix shut, was first used for preterm birth prevention in 1902 and the technique hasn't been changed since the 1950s. Progesterone was first used in the 1970s. There is a single imaging biomarker for preterm birth – cervical length – and its predictive value is approximately equal to a coin flip. A mother today has **no more or better** options than did her mother, grandmother, or great-grandmother. Practical improvements, such as ensuring inductions are not scheduled too early and innovations in steroids and magnesium to support a preterm baby's lungs and brain development before birth, while critical in leading to improved outcomes for babies, do not target the mother. The Iris Fund was founded on and remains invested in the maternal side of this equation where early intervention, before birth, will have the biggest impact.

### The Research

Since 2017, the team we support has updated, for the first time since the 1940s, our understanding of what proteins make up the cervix, the organ that measures just inches and is the practical gatekeeper to labor. Throughout pregnancy and then rapidly accelerating during labor, the cervix goes from the consistency of a rubber eraser to that of butter, from 3" long to zero, and from closed to open, so that the baby can deliver. Within a few minutes of delivery, the cervix starts returning to its original form. This must all occur "on time" and in unison with other transitions for a normal delivery. When this occurs early, it can cause preterm labor.



Drs. Kristin Myers and Joy Vink\*

“The Iris Fund is a vital source of support that enables us to continue our research into understanding how a woman's body supports a normal pregnancy and how premature activation of the uterus and cervix leads to adverse outcomes such as preterm birth. Without The Iris Fund we would not be able to continue to fill this vast knowledge gap. —Dr. Joy Vink

In addition, the team has developed the first-ever protocol for quantifying maternal anatomy, and is now exploring new potential biomarkers of timing of delivery.



Dr. Mirella Mourad, Co-Director of the Preterm Birth Prevention Center and a Maternal-Fetal Medicine specialist at Columbia University Irving Medical Center

This past year, The Iris Fund expanded its support to fund additional work at Mount Sinai Hospital in New York, and joined a research team that also includes University of Wisconsin, and University of Hawaii. This multidisciplinary team, consisting of clinicians, physicists, engineers, and mathematicians, is leveraging AI to accelerate the pace of research, using innovative, noninvasive techniques to understand how and why a woman's body determines when a baby will be born. This will lead to understanding the triggers of preterm birth and then development of novel therapies targeted to the individual.

### **BEHAVIOR CHANGE COMMUNICATIONS**

Messaging developed/disseminated to providers, mothers, and caretakers to encourage use of evidenced-based best (or better) practices.

Women continue to face stigma and shame when they lose a baby and talking about it is rarely encouraged. As a result, many women are trapped in their own personal grief, which leads to isolation and disconnection. Most will tell you they did not know another preterm or stillbirth mother until they went through it, which is astounding considering this happens over 400,000 times a year in the U.S. This compounded pain is unacceptable and does not need to be so.

In late 2023, we prepared (with partners) a pregnancy after loss training that we anticipate delivering in 2024. This training is targeted to practitioners and staff that interface with preterm and loss parents as they navigate the difficulties of a subsequent pregnancy. This training will be delivered to doctors and staff at Columbia University Irving Medical Center's Preterm Birth Prevention Center, Rainbow Clinic, Labor and Delivery and NICU, as well as sonographers.

## DATA COLLECTION AND ANALYSIS

The incidence of stillbirth and prematurity and its causes are better quantified.

The multidisciplinary team funded by The Iris Fund is currently focusing on developing and refining AI algorithms for quantifying maternal (cervical and uterine) anatomy from clinical ultrasound images. We are currently designing a very ambitious project, in partnership with GE Healthcare, who will provide equipment and engineering support, and global colleagues. We plan to acquire data in a standardized manner from pregnant women all over the world under a novel agreement that would grant ownership to any of the stakeholders – the countries, academic institutions, industry, and of course the pregnant women themselves. The standardized ultrasound setting to obtain cervix images will be called **The Iris Setting**. The goal over the next two to three years is to develop a predictive model of birth timing, via understanding the biomechanics of birth, so that a pregnant woman can be offered a personalized risk assessment of preterm birth, right there during her routine ultrasound visit.



Dr. Helen Feltovich\*

## ADVOCACY

Investments in maternal/newborn health increased; government policies enhanced; and access to information and programs that support improved care broadened.

Beyond the loss of life, the financial and psychological impact of losing a baby is devastating. The Iris Fund was the organization that brought to our legislature and helped pass HB 5103, a \$2,500 stillbirth tax credit in Connecticut in 2022, which provides parity to families with the financial resources needed to pay for funeral and burial expenses, genetic testing that may not be covered by insurance, and access to mental health or other critical services. In 2023, we partnered extensively on the implementation and communication of this bill.





Because real change depends on implementation, we are proud to report that this year we have:

- Ensured information regarding the tax credit is in materials shared with loss moms in all 50 CT hospitals.
- Met with the CT Hospital Association, Connecticut Funeral Directors Association and the Department of Revenue Services to ensure mothers were informed of this credit at these three critical touchpoints.
- Secured a commitment from TurboTax to install a prompt alerting users about the credit.
- Worked with multiple U.S. senators to assess the feasibility of passing a federal tax credit.
- Wrote a technical op-ed in [Bloomberg Tax](#) outlining why this credit is critical and should be federal.
- Presented at a national NICU conference with our sister organization Saul's Light in Louisiana on how we passed bills in our respective states and are supporting other states seeking to pass similar credits.



Debbie Haine Vijayvergiya, author of The SHINE For Autumn Act and mother to Autumn Joy.

In addition, The Iris Fund supports The SHINE For Autumn Act, which aims to prevent stillbirth through enhanced data collection, research, education, and awareness by creating the first comprehensive, federal-state partnership to reduce the incidence of stillbirth in our country. Similar to the research The Iris Fund supports, The SHINE For Autumn Act takes a root causes analysis approach to a critical maternal health issue. It is named after Autumn Joy, a New Jersey baby who was stillborn in 2011.

### **PATIENT-CENTERED**

High-risk pregnancies and loss families supported throughout their physical and mental journeys.

One of our greatest honors is to sit with families across the U.S. as they work through the realities of infant loss and/or high-risk pregnancy. Whether it is listening on the phone, sitting for a coffee, exchanging a text, sharing resources, or dropping off a much-needed dinner, these are the moments that matter – the moments that often feel so isolating – and The Iris Fund is grateful for the opportunity to support these moms.

# A STRONG FOUNDATION

The Iris Fund is committed to ensuring a strong foundation to support our work as we grow. From best-in-class talent to strong governance, resource mobilization, monitoring and evaluation, agile systems and brand building, we are especially proud of the continuous progress in these areas.

Over the past year, we also **showed up** for moms, babies, and families everywhere — from hospital rooms, to races locally and in NYC — we are there, and always will be.



We provided a first-ever lactation tent at the finish line of the “Run Like a Mother” 5K in Ridgefield, CT..



## RUN LIKE A MOTHER



## VALENTINE'S DAY

Thanks to the generous support of a local Ridgefield florist, Three Roots Floral Design, we delivered beautiful Valentine's Day bouquets to 163 moms in the antepartum, post-partum, and NICU units in five hospitals in Danbury, Bridgeport, Stamford, Norwalk and New York-Presbyterian Morgan Stanley Children's Hospital.

## MARATHONS



Each year, The Iris Fund and our supporters come together at the Ridgefield (CT) Half Marathon and Seven Miler events, as well as the NYC Marathon. These signature events are our biggest community awareness and fundraising events. Since our first race, we've been so moved by the number of supporters who have come out and expressed solidarity with our cause.

“ The only fitting legacy for our daughter — who was destined for a bold, beautiful, and meaningful life — is one that impacts all families long into the future. — Brittney Crystal

# OUR PARTNERS

The Iris Fund is proud to support \*Drs. Joy Vink, Kristin Myers, and Helen Feltovich's ground-breaking research, and multi-disciplinary approach that is changing the trajectory for mothers and babies.

**Dr. Joy Vink** completed her Ob/Gyn training at Georgetown University and her Maternal-Fetal Medicine fellowship at Columbia University Medical Center. Dr. Vink's interest in this area stems from the fact that approximately 1 in 8 pregnancies results in a preterm birth, yet the pathophysiology of preterm birth remains largely unknown. Regardless of the inciting event, the end result in all cases of preterm birth is premature cervical remodeling followed by cervical dilation and delivery of the fetus.

**Dr. Kristin Myers'** solid mechanics research program studies the biomechanics of biological soft tissues with a specific focus on the female reproductive system and pregnancy. Her Columbia research group is one of only a few engineering teams in the world creating biomechanical models of pregnancy to uncover structural mechanisms of preterm birth. Working with Maternal Fetal Medicine specialists, the team is working to identify mechanical risk factors in pregnancy and to develop precise clinical interventions to eliminate those risks.

**Dr. Helen Feltovich** completed her Ob/Gyn training at Oregon Health and Science University and her Maternal Fetal Medicine fellowship at University of Vermont. During her fellowship she first connected with Kristin Myers, who was a PhD candidate at MIT at the time. After two years of telling families that she was sorry about their baby, that medical science has failed them, that nobody knows why preterm birth happens or even why birth usually happens on time, she took a new position as a clinician-scientist so that she could focus on this problem both at the bench and the bedside. She's been working with this ever-expanding team since then.

We are also honored to partner with the following organizations on research, outreach, and advocacy:

Columbia University Irving Medical Center  
Every Mother Counts  
Fairfield County Community Foundation  
Hope After Loss  
Icahn School of Medicine at Mount Sinai  
March of Dimes

Natalie Foundation  
NICU Parent Network  
Saul's Light  
Star Legacy Foundation  
The Tiny Miracles Foundation  
University of Hawaii  
University of Wisconsin



## **OUR MISSION**

We are devoted to the future every preterm baby deserves.

## **OUR VISION**

We make certain no family endures heartbreaking complications and loss due to prematurity.

## **OUR VALUES**

We work in partnership and with transparency, to raise all voices in hope of a better tomorrow.

**THANK YOU.**

**IT'S BECAUSE OF YOU THE FUTURE IS BRIGHT.**

