



ICU baby[®]

**Optimizing NICU Health Literacy &
Transportation Support**



About Our Organization





Mission

ICU baby unites NICU families and provides emotional, financial and informational support so that babies and families can thrive together.

Vision

To build a community of NICU families who empower each other to be confident and present in their own NICU journeys, leading to better outcomes.

Founded in 2014 out of personal experiences.



3 Pillars of NICU Support

- NICU Parent Mentor
- NICU Pack
- Foster Care Kits
- Bereavement Support
- Meaningful Meals
- ICU Read

Emotional Support

There for families in their greatest time of need.

- Transportation Assistance
- Burial Assistance

Financial Support

Easing life's additional challenges.

- My NICU Baby Book
- NEST Video Library
- Community Resources
- Beyond the Beeps Podcast
- ICU baby App

Informational Support

Sharing what we have learned.

Volunteer Initiatives



Hospital Partners

| 291 beds |





Impact to Date

3,798 NICU Families Supported

6,560 NICU Emotional Support Hours

2,787 NICU Packs Delivered

1,179 TAP Families

178 In-Hospital, Meals of Support Served

- **3,637** NICU Family Members Attend

558 NICU Babies Read

856 Bundles of NEST Distributed

.....

1,864 Community Volunteers



Our Emotional Support for NICU Families





Emotional Support

- > NICU Packs
- > NICU Parent Mentors (tele & bed-side)
- > Meaningful Meals
- > ICU Read
- > Foster Care Kits
- > Bereavement Support

Corner Stone is Individualized Support

Other programs are tools to meet parents where they are in their journey.

Optimize Support



Our Financial Support for NICU Families

| Transportation |



Statement of Need

What's Happening in Our NICUs?

- Parents are not present at the bedside for a variety of reasons
- A **primary, modifiable barrier** = transportation access & affordability
- Transportation is a barrier that can be addressed & ameliorated

Metrics

- Average length of stay > 61 days & 42 days
- Average distance from the hospital
- Average income of TAP families
- Disproportionate # of Black (44%) & Brown (52%) families impacted

Anecdotally

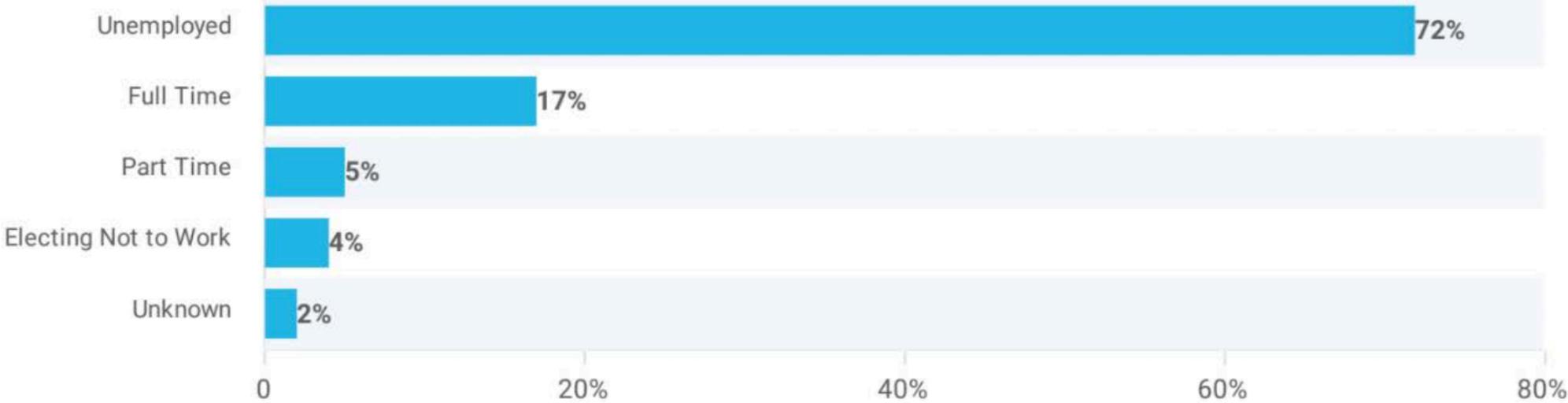
- What we see and hear from the NICU healthcare team
- Limited, reasonable access to public transportation in South Florida
- Only one vehicle per household & parent has to work
- Cost of gas, particularly with traffic
- Parking \$12 per day



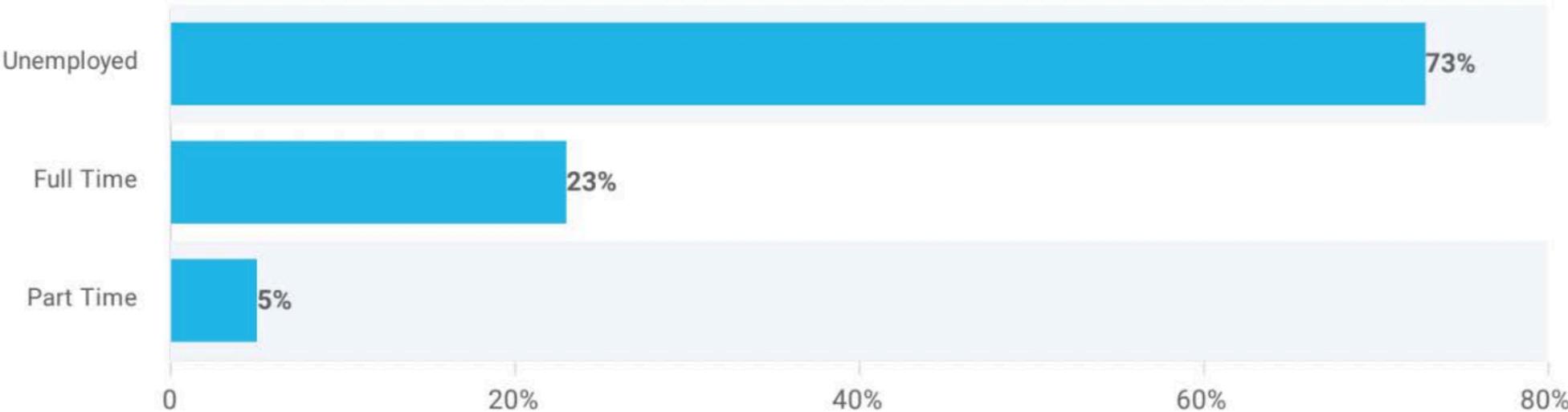
Statement of Need

What's Happening in Our NICUs?

Employment Status



Employment Status



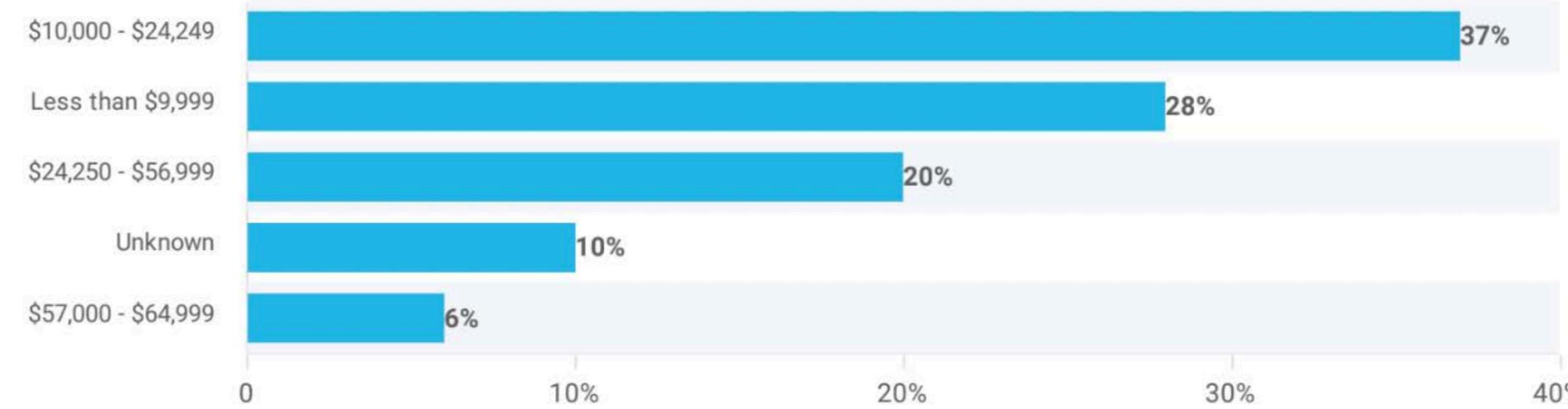
Hospital 1

Hospital 2

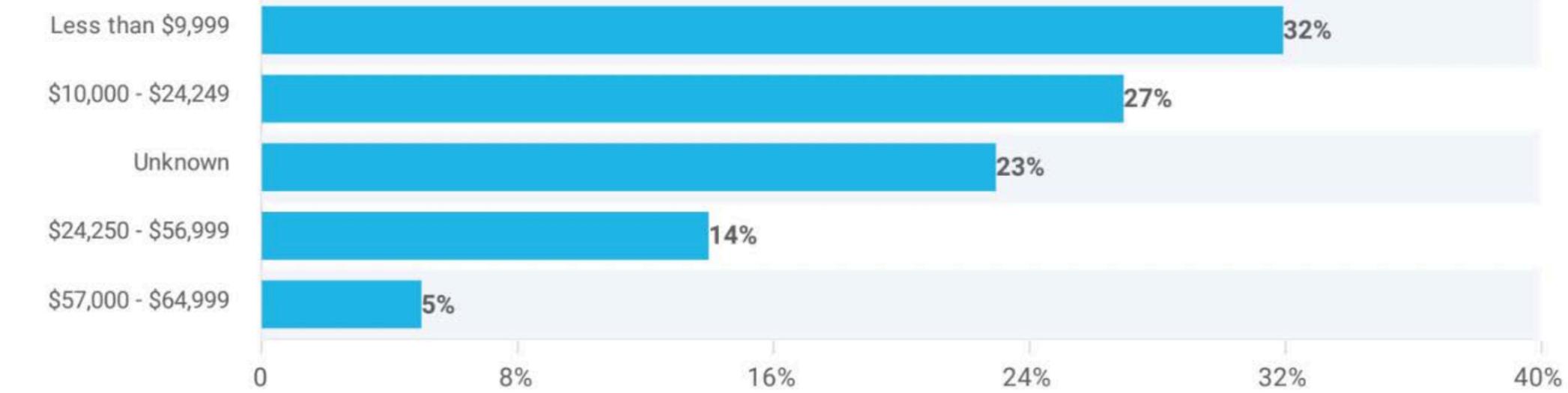
Statement of Need

What's Happening in Our NICUs?

Yearly Income

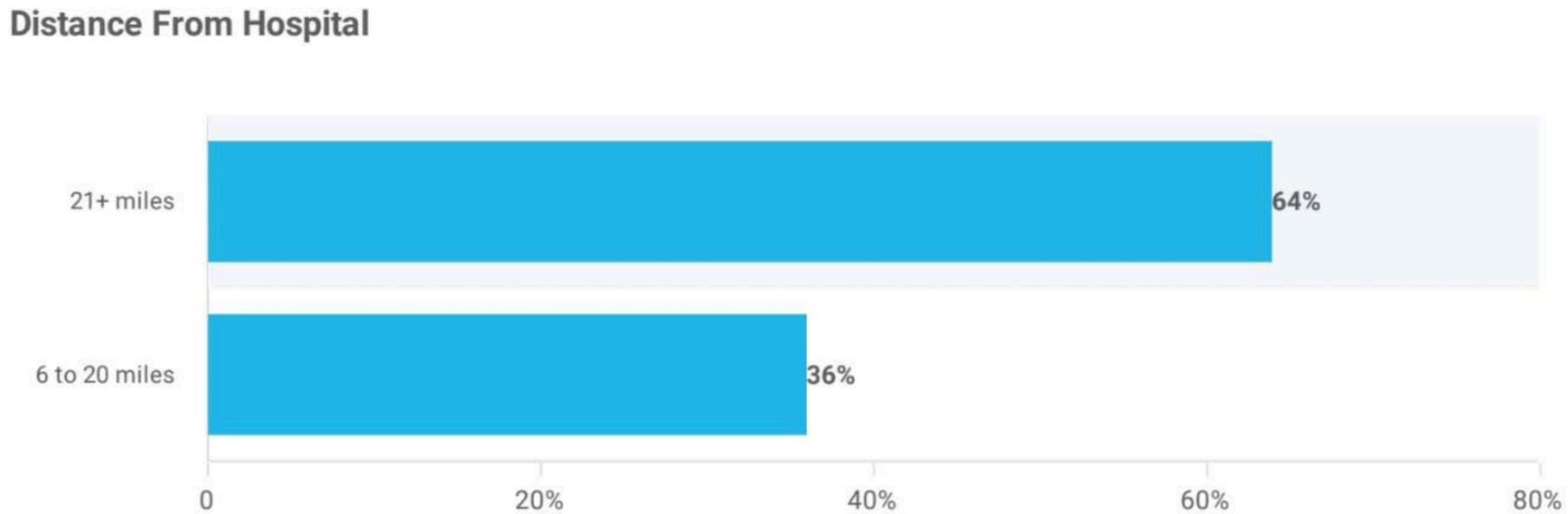
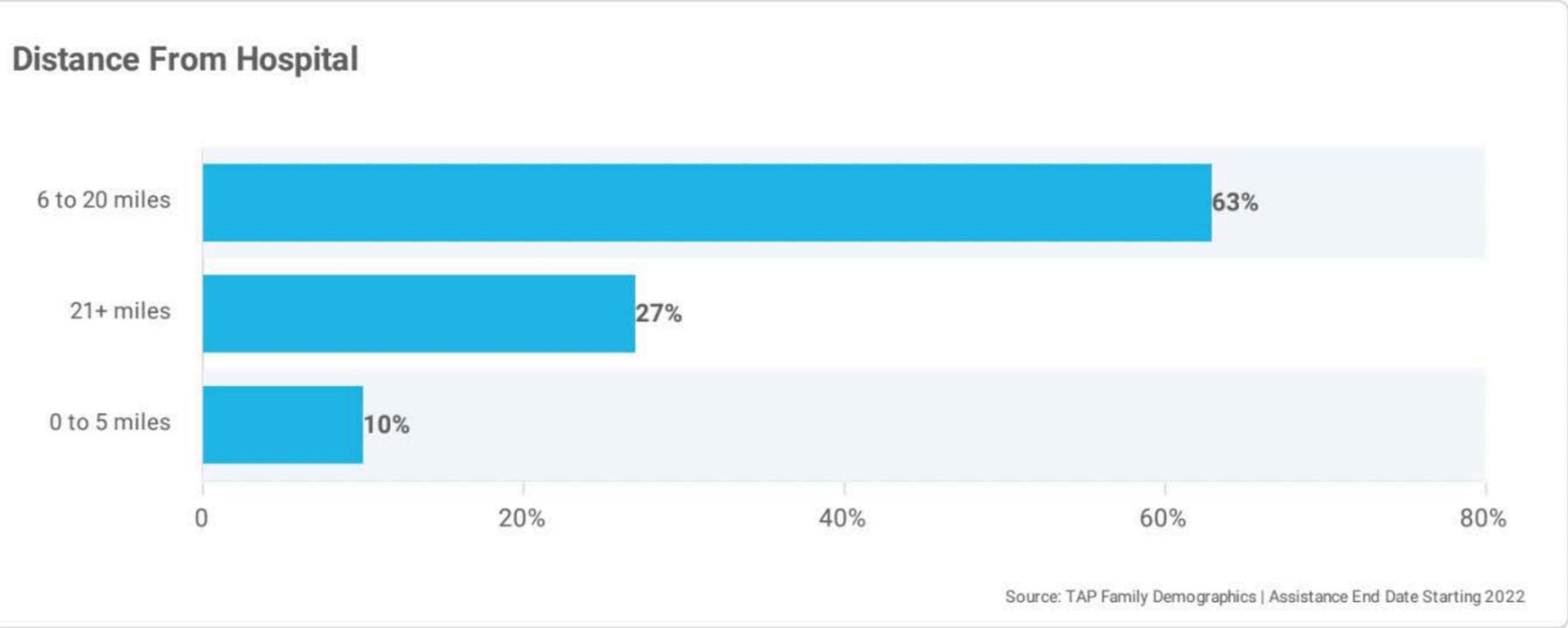


Yearly Income



Statement of Need

What's Happening in Our NICUs? Urban County



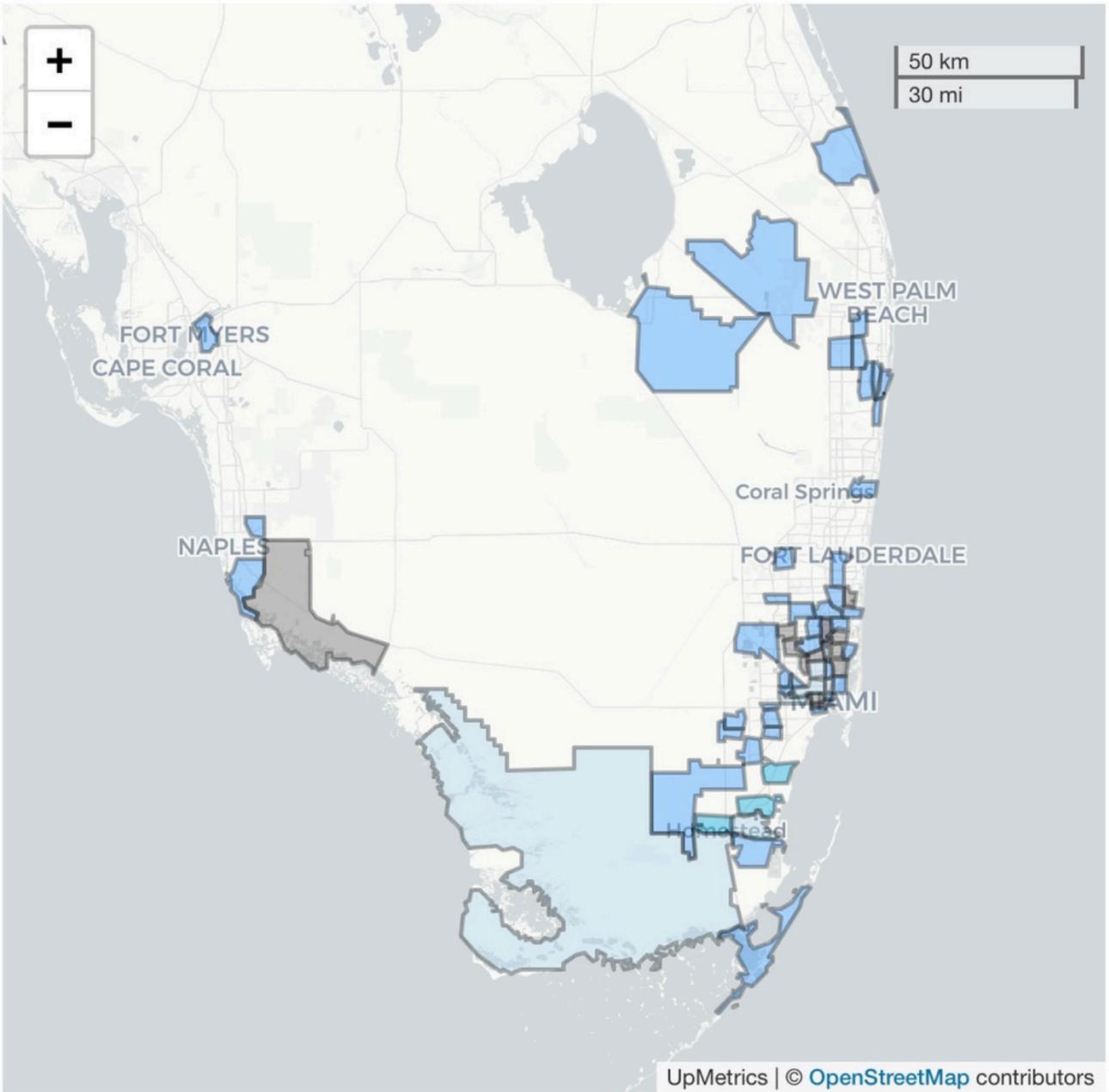
Hospital 1

Hospital 2

Statement of Need

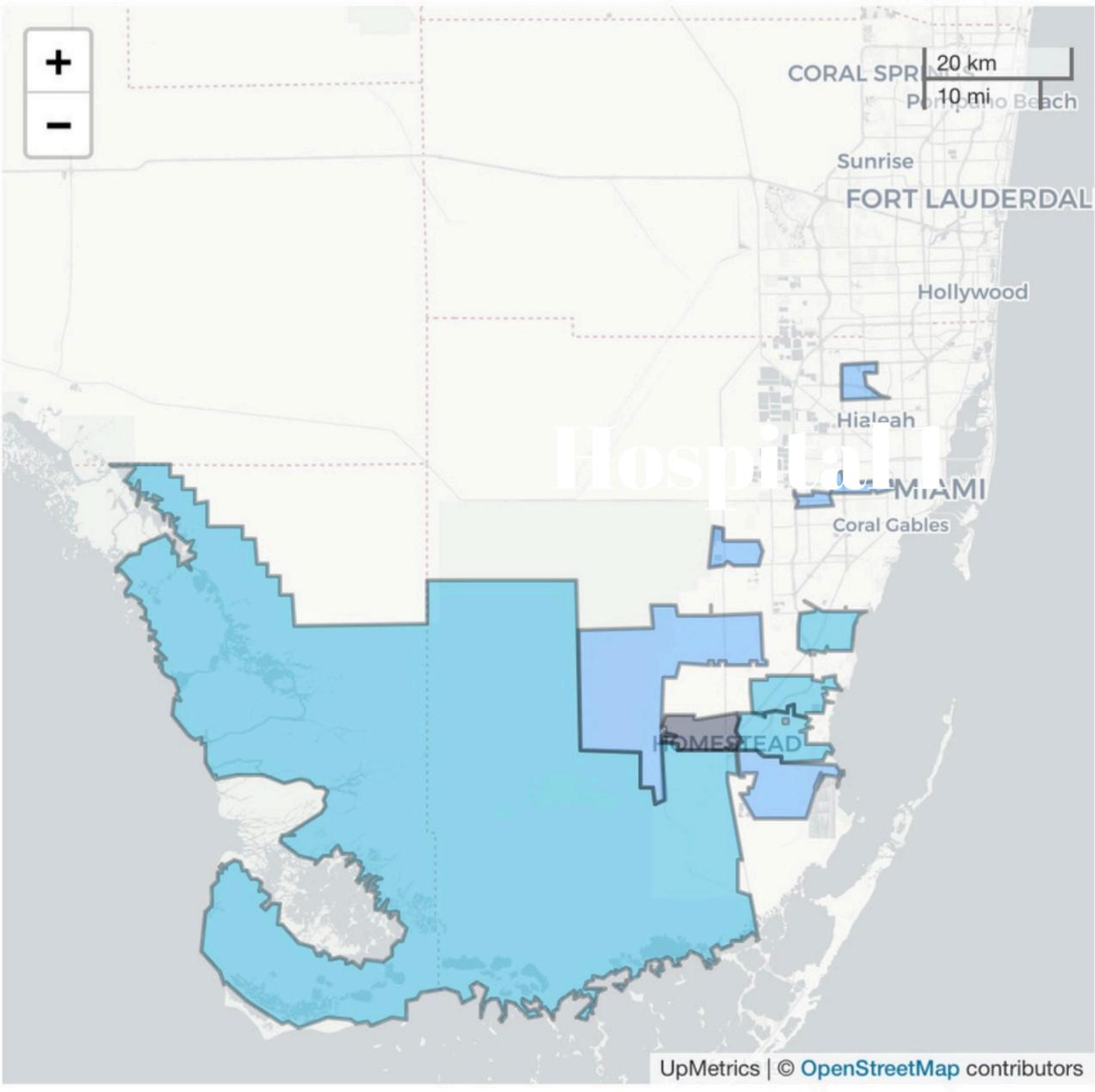
Hospital 1

Number of Families by Zip Code



Hospital 2

Number of Families by Zip Code



The Solution

ICU baby's Transportation Assistance Program designed to ...

Impact racial disparities

Impact ethnic disparities

Impact socioeconomic disparities

Impact disparities generally (etc)

.....

Parents increasingly at the bedside

Improves medical outcomes

Increases mothers' ability to bring breast milk

Increases access to health literacy & healthcare teams

Increases access to emotional support structure

Improves parents discharge readiness



The Solution

ICU baby's Transportation Assistance Program (TAP)

Step 1: Financial Determination

Social worker identifies qualifying family

Step 2: Application Provided on ICU baby's CRM

Social worker provides family with ICU baby's Transportation Assistance Application

Step 3: Application Review

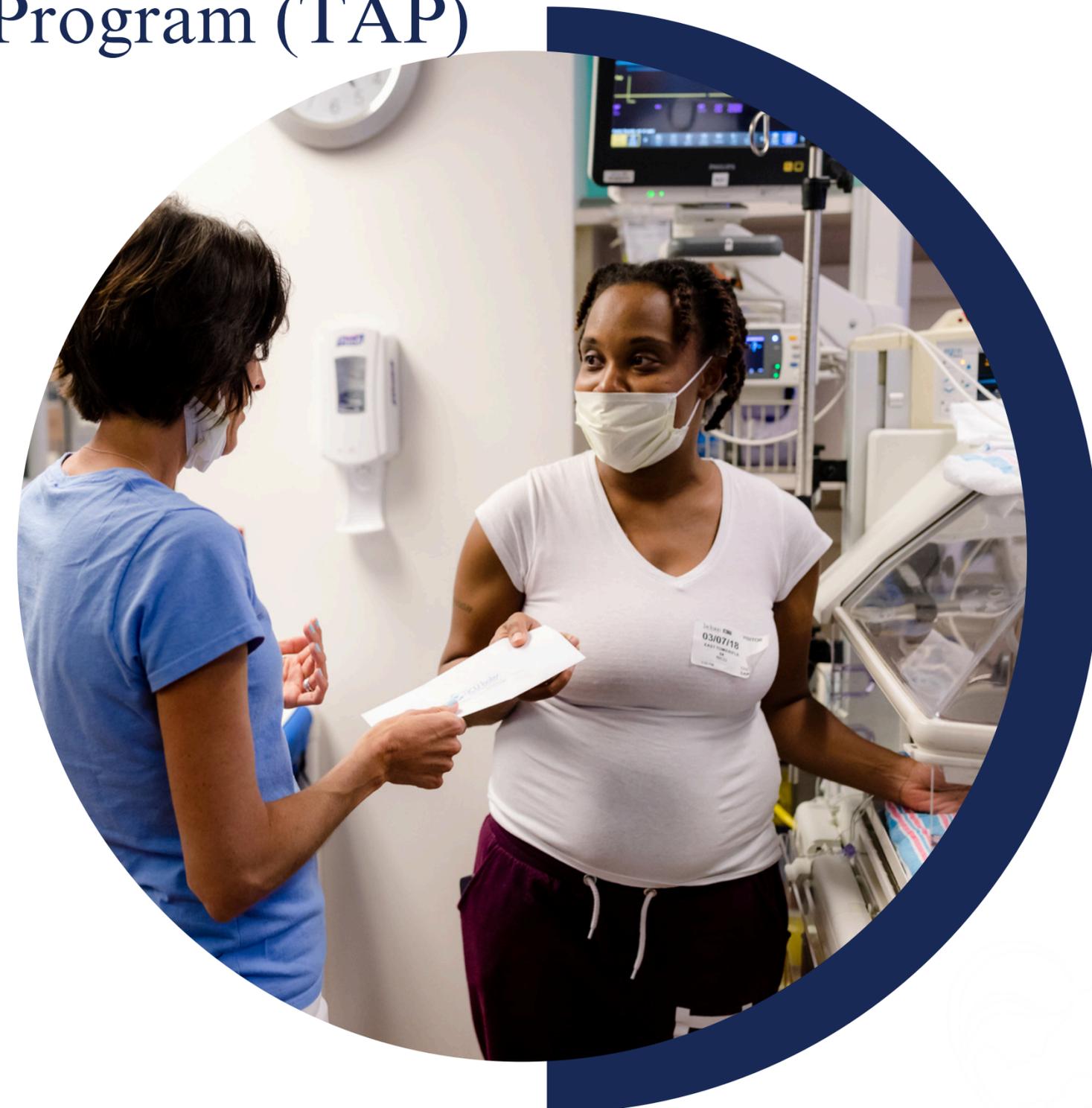
ICU baby's TAP Coordinator review

Step 4: Interview

ICU baby's TAP Coordinator speaks with the parent to determine a transportation solution

ICU baby considers:

- (1) whether transportation costs are an excessive burden that prevent hospital visits, and
- (2) whether transportation assistance will increase parents' visits.



The Solution

ICU baby's Transportation Assistance Program (TAP)

Step 5: Award Distributed

\$160 = \$40 per week

\$320 = \$80 per week (hardship fund)

Monthly Bus & Metro-Rail Passes

Gas Stipends

Partnering Gas Stations Receive ICU baby Stipends

Bill Us or Advance Pay

Monthly Parking Passes

UBER

Locked Location

Hybrid Award

Transportation solution customized to the family's needs



The Results

ICU baby's Transportation Assistance Program (TAP)

Step 6: Ongoing Monitoring to Ensure Desired Outcomes

Parent is present, as determined by their personal life circumstances

- Increasing the frequency of their visits with their baby
- Delivering breast milk
- Participating in their in-hospital care
- Engaging with medical teams

Monthly renewal

Since Fall 2017

7,926 Transportation Stipends Distributed

1,179 TAP Families



What We've Observed

How TAP Helped: {Survey Responses}

- talk to the nurses and doctors | 62/81 ppl
- be with my baby when I wanted | 65/81 ppl
- bring breast milk to the hospital | 47/81 ppl
- participate in my baby's care | 61/81 ppl
- do skin-to-skin contact | 45/81 ppl
- feed my baby | 43/81 ppl

How TAP Helped: {Parent Testimonials}

“The assistance I got from ICU baby helped me so much! I was able to go see my baby Rosalee everyday. I've been able to change her diaper. Sing to her and read books to her for as long as I want. It helped so much relieve some stress and weight off my shoulders. I appreciate all the help I was able to get from ICU baby.”



What We've Learned

New Hospital Enrolled

- > Benefits of division of hospital's role & ICU baby's role
- > Reliance on Social Worker as first point of contact

Why TAP Works

- > Empowering parents by including them in customization of transportation plan
 - No waiting for rides
 - No coordination with providers
 - No relying on other people
 - The power of a car ride on emotional well being
- > Most valuable component of program is that transportation solutions are individualized to the family
- > Scalable & Sustainable with **FUNDING**



Our Health Literacy Support for NICU Families

| NEST |



Statement of Need

What's Happening in Miami-Dade County?

- Poor pregnancy outcomes & pregnancy related deaths are in the second tier as the most vulnerable in our country*
- 1/10 babies are born premature*
- 4-8% of full term babies require ICU care
- 14.1% of black babies are born premature in our country

Holtz Children's Hospital (127 beds)

Mercy (25 beds)

South Miami Hospital (62 beds)

Mt Sinai (16 beds)

Nicklaus Children's Hospital (54 beds)

Baptist Main (36 beds)

... Referring hospitals near and far



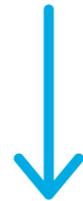
Statement of Need

Impact of Global Environment on Our Work

Bedside NICU Parent Mentor Program
becomes tele-support.

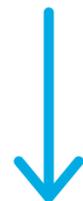
Mentors' relationships with families deepen.

Gaps in resources for families exposed.



Black Lives Matter re-amplifies the spotlight on
racial disparities in maternal and infant health.

Our sphere of influence gives us credibility to
impact change in the NICU.



Society increasingly relies on technology for
information & connection.

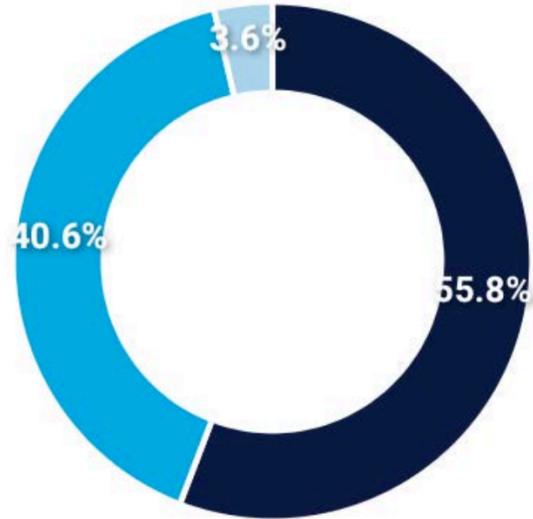


Statement of Need

Who Are Our NICU Parents?*

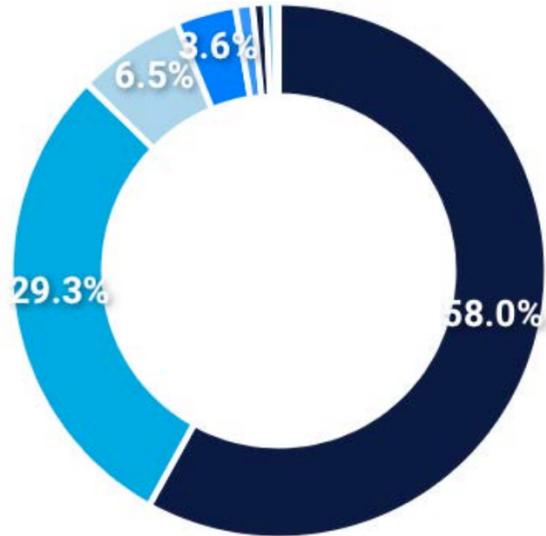
Ethnicity Breakdown

- Hispanic/Latino
- Not Hispanic/Latino
- Prefer Not To Answer



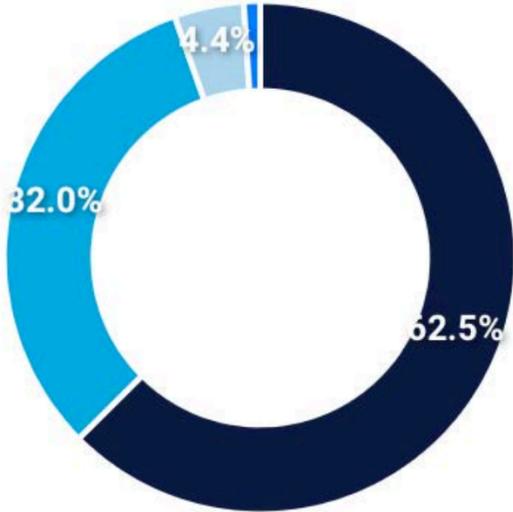
Race Breakdown

- White
- African American or Black
- Prefer Not to Answer
- Race Unknown
- Asian
- Bi-Racial
- Native Hawaiian or Pacific Islander
- Native American or Alaskan Native



Primary Language

- English
- Spanish
- Creole
- Other

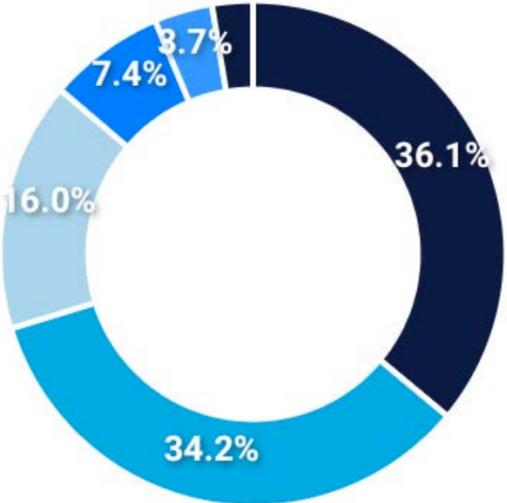


Statement of Need

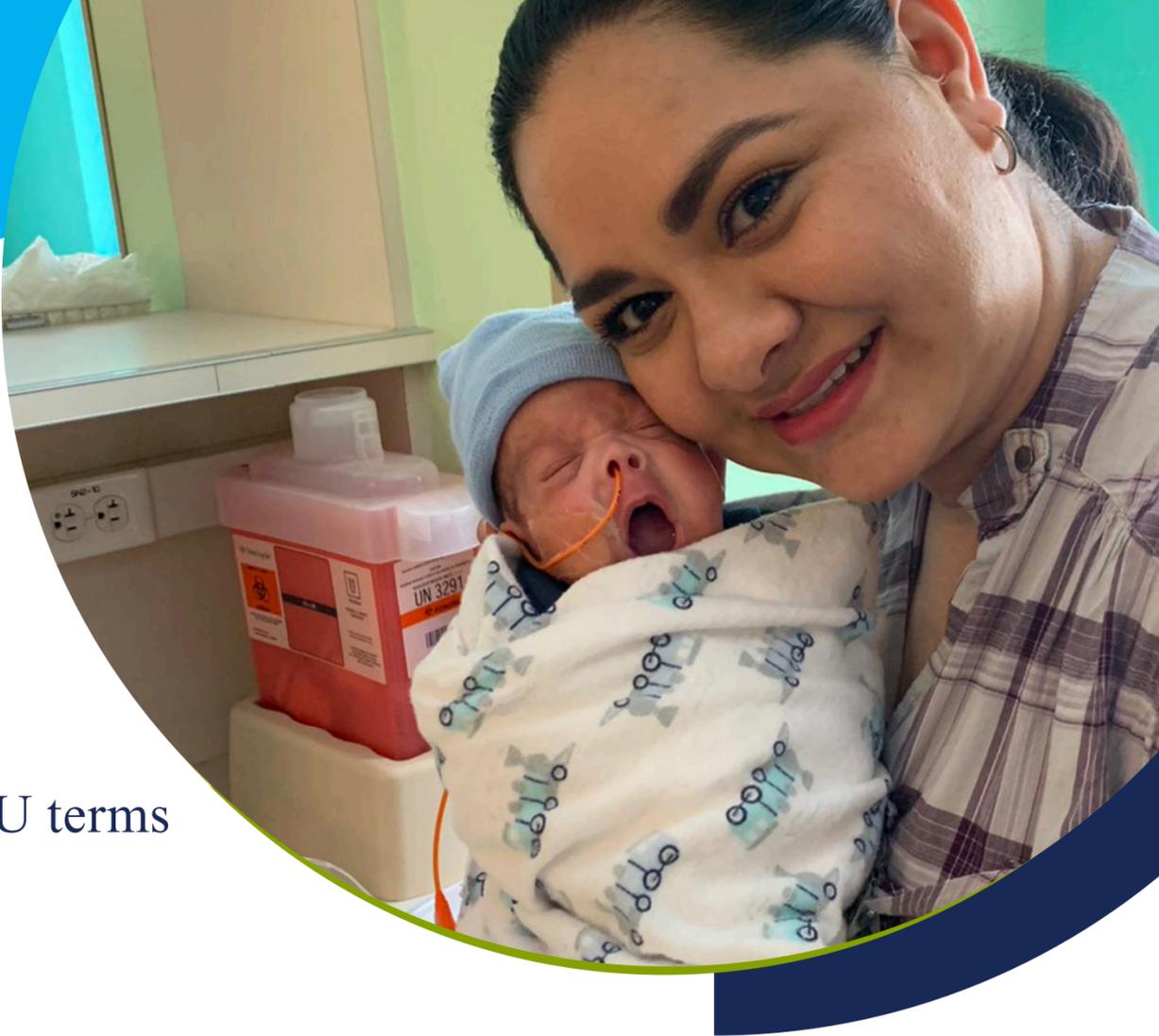
Who Are Our NICU Parents?*

Education

- College Degree or Higher
- High School
- Some College
- Prefer Not to Answer
- Less than High School
- No School

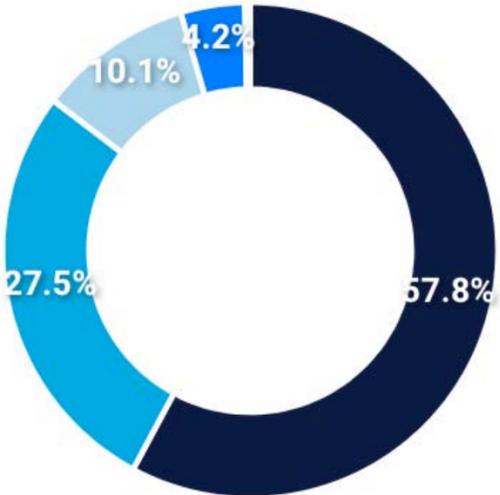


48.2% are of low income levels
24% had never heard of a NICU
20% not comfortable at all with NICU terms



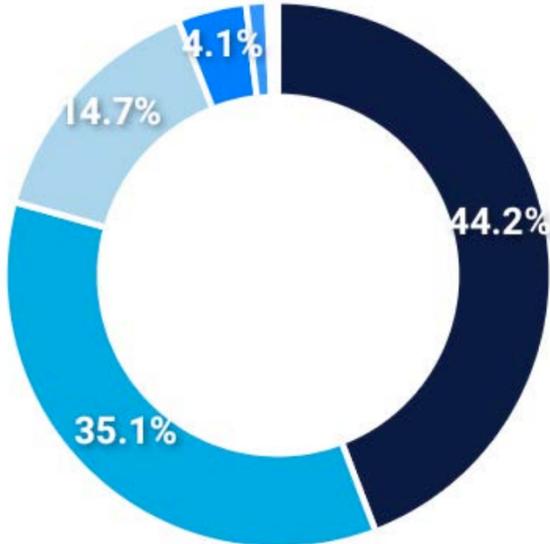
Employment Status

- No
- Full Time
- Part Time
- Prefer Not to Answer
- Unemployed



Marital Status

- Married
- Single
- Unmarried (in a relationship)
- Prefer Not to Answer
- Separated
- Divorced
- Widowed



* Families supported in 2022 at Holtz Children's Hospital & South Miami Hospitals.

- #1 38%-63% of NICU mothers experience depression
- #2 53% of NICU mothers score above threshold for Post Traumatic Stress Disorder
- #3 43% of NICU mothers experience anxiety
- #4 9 out of 10 Americans have limited health literacy

.
● ● ● ● ● ● ● ● ● ● ● ● ● ●
.

No psychologists available in the hospital to parents

Social workers are stretched thin

No formal NICU orientation or classes

What Research Tells Us About Being a NICU Parent?



Let's take a quiz... What do these 5 words mean?

1. NPO

2. Bradycardia

3. Pneumothorax

4. NEC

5. CPAP



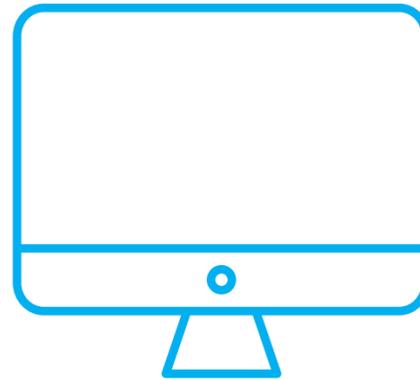


Inputs



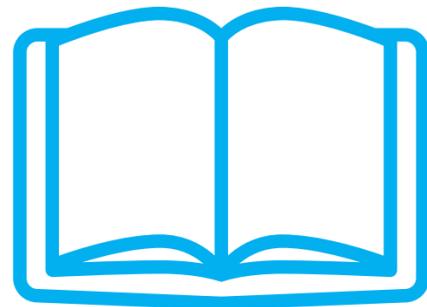
What is the NEST?

NICU Empowerment Support Tools



Parent Portal
A Space for Resources & Information

My NICU Baby Book
A Companion Journal & Guidebook



NEST Videos
5 Minutes of NICU Information

Available in English, Spanish, Haitian Creole



My NICU Baby Book

A Companion Journal & Guidebook



Crafted with Compassion. Constructed with Intention. Created by Community.

a companion journal & guidebook



My NICU Baby Book





Today's Date _____

Hello _____! It's _____.
(baby name) (mom/dad/grandparent/aunt/uncle/nurse etc.)

You were _____ days/weeks old today.

Your day nurse was _____.

Your night nurse was _____.

Your doctor(s) was _____.

The medical team rounds at _____ am/pm.

Your visitors were _____.

Your touch times were at _____.

You were ready for kangaroo care: Yes/Not Today

Goals for Today

You were working on/ learning: _____

I was working on/ learning: _____

Here is What We Did Today

- I fed you
- I rested/took a nap
- I read to you
- I sang to you
- I took your temperature
- I changed your diaper
- We spoke with an ICU baby Supporter
- I watched a NEST video to learn more about caring for you
- I prayed
- I talked with your nurse on the phone
- I watched you on the camera
- We looked at each other
- You had speech/feeding therapy
- We held hands
- We did kangaroo care
- You snuggled in my arms
- I attended a baby care class
- I attended rounds
- You had physical therapy
- You had music therapy
- Other



DATE: (S) (M) (T) (W) (T) (F) (S)

HEALTHCARE TEAM

Day Nurse: _____ Night Nurse: _____
 Your Doctors: _____
 Time of Medical Rounds: _____

Touch Times: _____
 Kangaroo Care: Yes Not Today
 Pumping / Breastfeeding Times: _____

GOALS FOR TODAY

Your Goals: _____
 My Goals: _____

HERE IS WHAT WE DID TODAY

- I fed you
- I rested/took a nap
- I read to you
- I sang to you
- I prayed
- I took your temperature
- I changed your diaper
- I watched you on the camera
- I spoke with your nurse on the phone
- I attended rounds
- I attended baby care classes
- I spoke with an ICU baby Parent Mentor
- I watched a NEST video to learn more about caring for you
- You had speech/feeding therapy
- You had physical therapy
- You had music therapy
- You snuggled in my arms
- We did kangaroo care
- We held hands
- We looked at each other
- Other

Our Visitors: _____

MEASUREMENTS

Length: _____ Weight: _____
 Head Circumference: _____ Belly Circumference: _____

BREATHING SUPPORT

Type:
 CPAP Oscillator
 Jet Ventilator Room Air
 Nasal Cannula Ventilator
 NIPPV Other
 How Much: _____ How Often: _____
 Settings: _____ Oxygen: _____

FEEDING

What You Ate: _____ How You Ate: _____
 Breastmilk IV
 Donor Milk Tube
 Formula Syringe
 Fortifier Bottle
 Nothing Today You Were Resting Breast
 G-tube
 How Much: _____ How Often: _____

MEDICATIONS

PROCEDURES OR LABS

QUESTIONS FOR YOUR HEALTHCARE TEAM



Disclaimer

This information is intended to be guidance from parents for parents. Nothing in this book should replace the medical advice of the NICU healthcare team caring for your baby. The information in this book should also not replace the advice of the professionals caring for you, including but not limited to, your medical, mental health or nutritional healthcare providers.

The information that follows is simply a guide to help you navigate the NICU and it is to be used as a tool in discussions with your baby's NICU healthcare team, as well as your personal care providers.



NICU Orientation

An Introduction to the NICU



www.icubaby.us/nest-video/nicu-orientation

Scan this NEST QR Code to view a 5 minute video with more helpful information & resources on this topic.



Welcome to NEST by ICU baby

NEST by ICU baby provides you with access to information and resources to help you better understand and experience the NICU.

**NEST was created by NICU parents,
for NICU parents.**



NICU Empowerment Support Tools

Video Library

About ICU baby

NICU Family Stories

Community Resources

Hospital Resources

Linking Family to Community Resources



Community Resources



Where to Get Resources for Emotional Wellness

Having a baby in the NICU is an emotional experience for parents and caregivers. These resources may help you learn more about your emotions and get the support you need to feel well. Caring for you is caring for your baby.

[Learn More](#)



POSTPARTUM SUPPORT
INTERNATIONAL



Mammha



National Alliance on Mental Illness
Miami-Dade
County

SHADES of BLUE
PROJECT



NATIONAL
SUICIDE
PREVENTION
LIFELINE
1-800-273-TALK (8255)
suicidepreventionlifeline.org

Additional Community Resource Sections

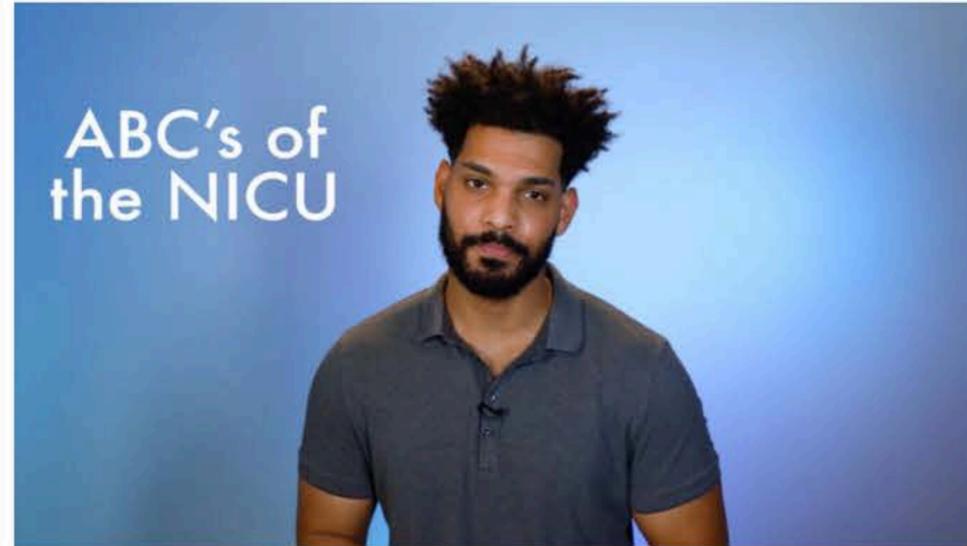
Breastfeeding Support
Resources for NICU Dads
Healthy Start
Government Benefits
Financial Assistance

Food Access
Shelter & Safety
Discharge resources
Bereavement Support
Women's Health



NICU Orientation

 NEST Videos



ABC's of the NICU

 NEST Videos

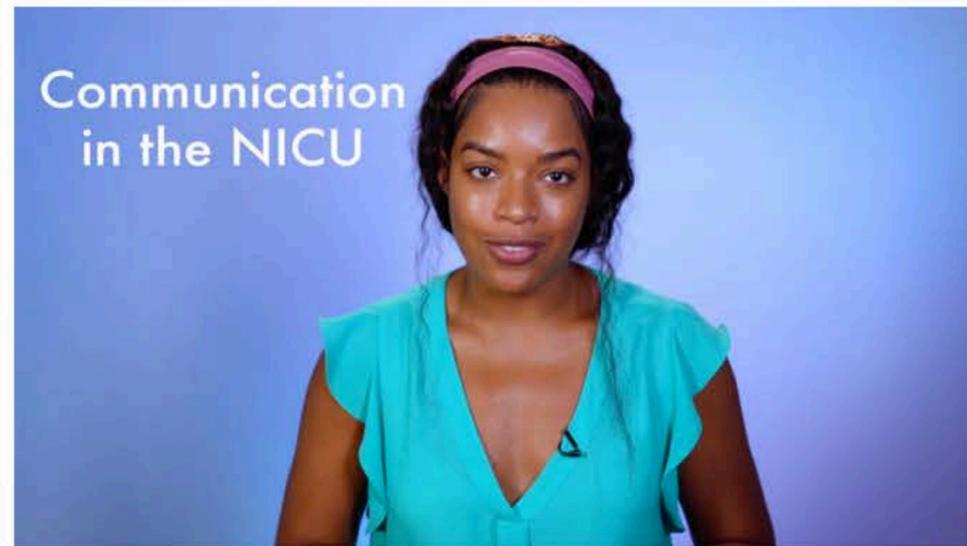


Who's Who in the NICU

 NEST Videos



Caring for Your Baby Throughout Their NICU



Communication in the NICU



Feeding Your Baby in the NICU



Breastfeeding in the NICU

 NEST Videos



Transitioning Home

 NEST Videos



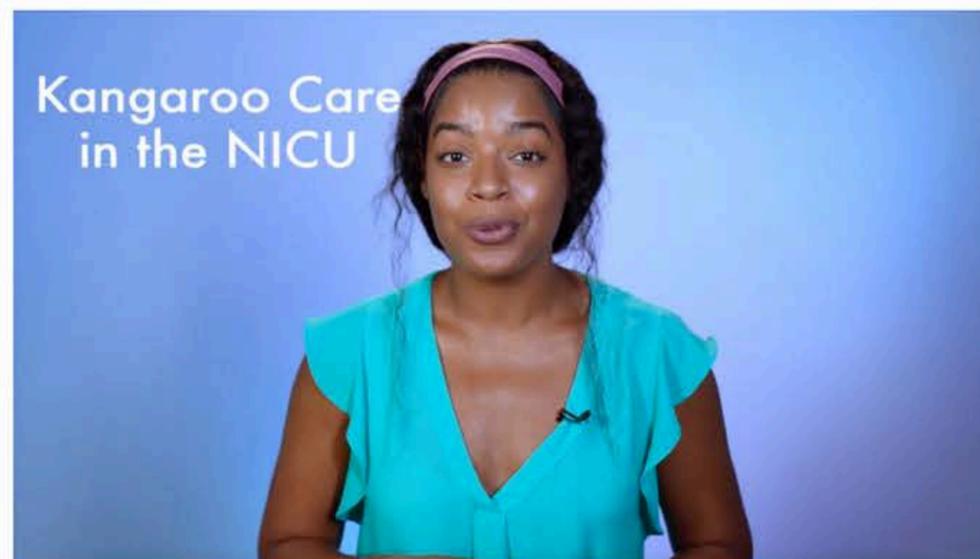
NICU Dads

 NEST Videos



Self Care for Parents

 NEST Videos



Kangaroo Skin-to-Skin Care

 NEST Videos



About ICU baby

 NEST Videos



El Cuidado de Su Bebé Durante Su Travesía por el NICU

 NEST Videos



Comunicación en el NICU

 NEST Videos



Alimentación de Su Bebé en el NICU

 NEST Videos



Lactancia Materna en el NICU



Transición a Casa



Papa del NICU



Lactancia Materna en el NICU

NEST Videos



Transición a Casa

NEST Videos



Papa del NICU

NEST Videos



Cuidado Propio

NEST Videos



Cuidado de Canguro Piel con Piel

NEST Videos



Sobre ICU baby

NEST Videos



Oryantasyon NICU

 NEST Videos



ABC nan NICU

 NEST Videos



Kiyès ki Kiyès nan NICU

 NEST Videos



Pran Swen Bebe ou a Pandan Pakou yo nan NICU



Kominikasyon nan NICU

 NEST Videos



Nouri Bebe yo nan NICU

 NEST Videos



Bay Tete
nan NICU

Bay tete nan NICU

 NEST Videos



Kay Tranzisyon

Kay Tranzisyon

 NEST Videos



PaPa NICU

Papa NICU

 NEST Videos



Swen Pèsonèl pou
Paran nan NICU

Swen Pèsonèl

Swen Pèsonèl

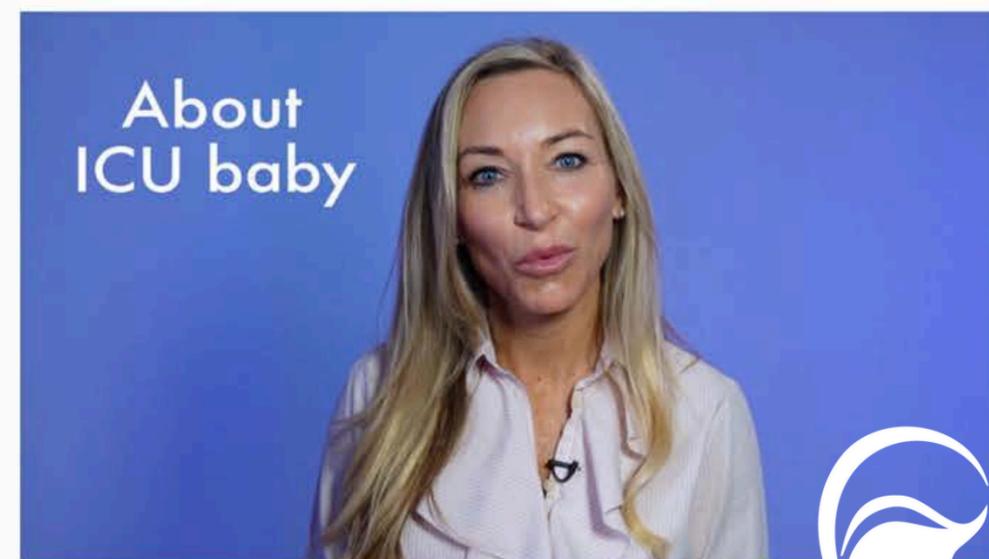
 NEST Videos



Swen Kangouwou
Po-Pou-Po

Swen Kangouwou Po-pou-Po

 NEST Videos



About
ICU baby

KONSENAN ICU baby

 NEST Videos



There's an App for
{ALL of} that!



Activities

An "Opt Out" Program

Access

- > **Deliver** NEST book by Parent Mentor or Healthcare Team
- > **Provide Access** Throughout the NICU

Opportunity

- Opportunity for Use** > No Pamphleting
- > ICU baby's NICU Parent Mentors
- > Healthcare Teams

Give parents:

- **Orientation** to the NEST program
- **Reinforcement** of Use
 - Guide the parent through the NEST weekly
 - Reminder messages sent through CRM
- **Customization** of resources as needed



What We've Observed

How NEST Helped: {Survey Responses}

96% found NEST resources helpful or very helpful

96% After using NEST resources, felt more comfortable or much more comfortable caring for their NICU baby

90% After using NEST resources, felt more comfortable or much more comfortable using medical words and information

90% After using NEST resources, felt more comfortable or much more comfortable speaking with nurses and doctors about their baby's care

How NEST Helped: {Parent Testimonials}

They (the NEST resources) have been very helpful, they provide you with a lot of knowledge and above all they encourage you and help you face this difficult journey through the NICU.



What We've Observed

New Hospitals Enrolled

- > Prioritization from administration and NICU healthcare team is critical
- > Including as part of NICU's orientation and protocol reinforces usage
- > Multiple channels of access to the program drives usage

Why NEST Works

- > Empowering parents by providing with resources that are “on-demand” and culturally and linguistically accessible
- > Most valuable component of program is that NEST provides parents access to health literacy at the start of their baby's life and it carries through to childhood and beyond
- > Scalable & Sustainable, provided usage is reinforced

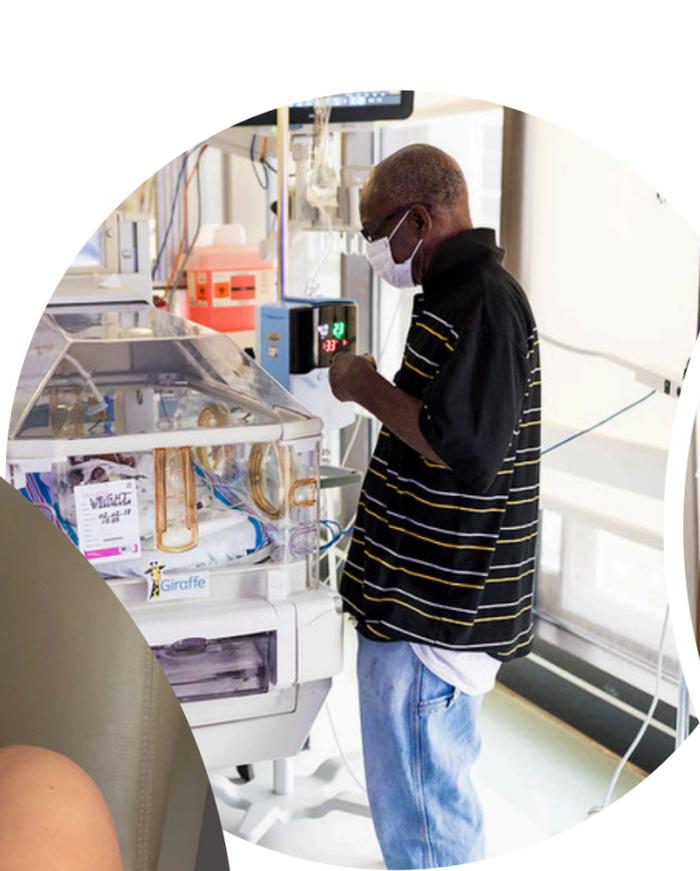




Optimizing Transportation Support & NICU Health Literacy to Support Families

Offers Them the Opportunity for:

Access | Affordability | Advocacy | Autonomy | Accomplishment



Comments & Questions

Contact | elizabeth@icubaby.org

