2020 ANNUAL RECAP

Expecting Health
Though 2020 has brought unimaginable challenges, it has also spurred something many of us have been working toward: increased attention to the health of our nation and the disparate care and outcomes that different communities face. Though most of us have never experienced quite a sweeping change in life as we’ve seen and continue to live with today, drastic changes tend to provide the opportunity for realignments. As we evaluate what it means to have access to care as more institutions commit to equity in all aspects of their work, we continue commit to centralizing the lived experiences of women and families as we build a more inclusive healthcare system.

To our partners who have worked with us throughout the year on everything from creating timely content addressing being pregnant and giving birth during COVID-19, to exploring the use of technology for real-time health education, to expanding learning opportunities regarding newborn screening, to highlighting the importance of considering young children when determining the dietary needs of the nation – thank you.

While this recap highlights our efforts over the past 12 months, it also shows what we are poised to do in the new year. From shifting to virtual forms of connecting to launching new training programs, our efforts are all aligned towards one goal – putting families at the center of their healthcare experiences. And we know this can be done through authentic partnerships. Now more than ever, it is clear how important working together is to making real, and long-lasting change for families across this country.

To a hopeful 2021,

Natasha F. Bonhomme | Founder
OUR MISSION

We aim to alleviate pain points, pressure, and confusion faced by families planning and/or experiencing a pregnancy, and during those early motherhood years by: breaking down the barrier between science-based information and the real life experiences of families, pushing for a culture change to have the clinical setting oriented toward family needs, and building the capacity of individuals to connect and advocate for themselves and their communities.

OUR VISION

The fear and confusion individuals and families face during pregnancy and parenting is replaced by confidence and agency to make the best healthcare decisions for their lives. With their providers, health systems, and communities, they are able to make confident, evidence-informed, and unified decisions about reproduction, pregnancy, and parenting.

WWW.EXPECTINGHEALTH.ORG
In 2020, we supported families to have *more guidance, more support, better health.*

- **266** individuals participated in our online training courses.
- **725** individuals attended our online learning sessions.
- **3.8 MILLION** individuals were reached through our annual newborn screening awareness campaign.
- **710,688** individuals accessed our online resources.
We are health communicators committed to providing actionable, relatable science-based information. During this year of changing health information and uncertainty, we continued our work of educating and supporting new and expecting families. To alleviate any anxiety or confusion related to COVID-19, we created a variety of timely COVID-19 materials and connected with partner organizations to meet families where they are.

Our COVID-19 Resources

- **Website articles** that covered topics from the prenatal to postpartum period
- **Webinar** to support family needs during the pandemic
- **Infographics** to share important COVID-19 information
- **Educational module** about COVID-19 and newborn screening

We are maternal health advocates committed to fighting for equitable healthcare and accessible health education. Rooted in social justice, our programs aim to provide access to important health information throughout the prenatal and early motherhood years.

- We attended a local community health fair for low-income families and connected with over 50 moms to share the benefits of healthy eating, including eating seafood during pregnancy.
- We developed a free, online newborn screening module so families have access to critical information about the test that every baby gets with 266 course sign-ups to date.

We celebrated Black History Month to raise awareness for the unique history, experiences, and contributions of Black women in America in the reproductive and maternal health space generating 18,042 social media impressions.
We are leaders at the intersection of family health and genetics. With our expertise in elevating the family experience in the rare disease and newborn screening communities, we collaborate with advocacy and professional organizations across the nation.

We lead the content development on 2 federally-funded programs focused on newborn screening and family support.

We are community partners for 2 national initiatives focused on improving health services and outcomes for women and children, specifically through reducing maternal mortality and improving telehealth services.

We leverage and support the work of organizations to ensure that new and expecting families are getting actionable, digestible information to feel empowered in their healthcare decisions.

We have a growing partnership program with 12 partner organizations to expand our reach to new and expecting families.

We co-hosted a 5-part training series with the EveryLife Foundation to educate and engage newborn screening stakeholders.

We submitted public comments to support updated guidelines on dietary needs of women and children.
We listen, value, and amplify the family voice. Across all of our programs, families are at the center of all that we do. We utilize different strategies to integrate the family voice throughout our programs.

Family **Connected**
Families serve on our steering committees and workgroups.

Family **Generated**
Families share their input, review, and test our program content.

Family **Informed**
Families share their healthcare experiences through surveys and stories.

The Mays Family Story
Susan Mays, our Family Ambassador, shares the story of her daughter, Indie, who has Maple Syrup Urine Disease. Susan was not aware of newborn screening before her daughter was born. Susan is interested in advocacy for the metabolic community, including advocating for the Newborn Screening Saves Lives Reauthorization Act, and feels that it’s her personal responsibility to educate others about newborn screening. Susan hopes to work towards a landscape where all parents know what to expect from newborn screening.

“That was the blood draw that would reveal Indie had a life threatening TREATABLE metabolic disorder called Maple Syrup Urine Disease. Because of this public health program we were able to get a timely and accurate diagnosis, begin treatment, and prevent irreversible brain damage. *We are forever thankful for newborn screening!*

*Susan Mays, mother of Indie*