

# MEET OUR AMBASSADORS

*FAMILY LEADERS IN  
NEWBORN SCREENING*

VOLUME 1

2021-2022



# *I am an NBS* **AMBASSADOR**



## **TARA TANELLA**

My name is Tara Tanella and I am the happiest when I'm with my family - my husband Joe and our three children Joey (11), Victoria (8) and Adriana (1) in our Hometown of Massapequa, NY. As a professional, I am a Risk & Control Officer for Private Banking Operations at Morgan Stanley. As a Rare Disease Caregiver, I am the biggest support to my eleven year old son Joey, who was diagnosed at 3 days old via Newborn Screening, with the Rare Disease, Galactosemia.

Galactosemia is a metabolic disease in which the body is unable to metabolize the sugar galactose. The current treatment for galactosemia is a restricted diet eliminating all galactose products (dairy, organ meats and more). The body also produces endogenous galactose. This endogenous galactose builds up in the body causing neurological issues including learning impairments, speech apraxia, seizures, cataracts and more.

He is a miracle, and he is rare. He is my why...Why I'm passionate about Newborn Screening and Navigate Newborn Screening Ambassador Program. The Ambassador Program has helped me find my voice and learn how to advocate so I can raise awareness about the Newborn Screening System and help educate families. It has given me a sense of community I never would have imagined to be so large and it has helped me find my purpose.

Our families experiences with Galactosemia have shaped our lives in so many ways. After the diagnosis and fear of the unknown, we have surfaced as better individuals with compassion, empathy and a drive to support him and effect positive change in the Rare Disease space.

I am forever grateful for Newborn Screening, without it my life would look very different.



# I am an NBS **AMBASSADOR**

Hello, my name is Chadd Williams. I am a father of two in which one of my kids is a Sickle Cell warrior. I am currently living in NW Louisiana where I'm a native of Shreveport, I spent the past seven years in SW Pennsylvania. While in SW PA I was introduced to the Sickle Cell Foundation where I became a Family Leader with the Foundation. During this time I met multiple families that soon became a support system, and I continue to work with the foundation remotely.

Becoming a NBS Ambassador has been such an eye opening experience. Meeting with the other Ambassadors and learning a about their personal journeys brought about a new perspective. I never knew about all the health complications that were not included on the NBS list. I am excited to continue learning and being a advocate for the NBS group.

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## **LESA BRACKBILL**

Hi! My name is Lesa Brackbill. My husband Brennan and I have three children (Victoria, Isaiah, and Caleb) and we live in Hershey, Pennsylvania.

On February 13, 2015, my firstborn, Victoria (Tori) was diagnosed with Krabbe Disease - a terminal form of leukodystrophy. Her diagnosis changed the trajectory of our lives - and especially my life - in more ways than one. On diagnosis day, we learned that her condition could have been treated had they screened for it at birth, but since Pennsylvania did not screen for it, we were robbed of the opportunity to try to save her life. It was too late. Tori passed away at just twenty months of age. In the midst of devastating grief, my new calling was given to me; my political science education - and prior experience with lobbying - finally made sense! It took six years and three different bills, but our third attempt at reforming our NBS program was a success in November 2020, and Act 133 of 2020 went into effect in May 2021.

As a result of these efforts, all babies born in Pennsylvania are now screened for 63 conditions (and counting), every hospital screens for the same conditions, and we are in alignment with the RUSP. Most importantly for our family, Pennsylvania has already identified four babies with Krabbe (in the first seven months of screening), giving them a chance at life that our daughter did not receive.

I am the Outreach Coordinator for Policy and Advocacy for the Leukodystrophy Newborn Screening Action Network (LDNBS.org) where I am working toward building a coalition with all interested parties as we work toward a world where every baby is screened equally for all possible leukodystrophies. I serve as the co-chair of the Krabbe Stakeholders Group and on the Board of Directors for KrabbeConnect, and I am the Parent Advocate on the LSD Subcommittee of the Pennsylvania Newborn Screening Technical Advisory Board. I am also the author of *Even So, Joy: Our Journey Through Heartbreak, Hope, and Triumph* which chronicles our journey with Krabbe Disease and finding hope and joy in the journey. I am also pursuing a Masters Degree in Strategic Communication so that I can become a more effective advocate and help others do the same.

I am doing all that I can to advance Newborn Screening for leukodystrophies so that no one has to endure what we have. That's why I became an ambassador! Diagnosis Day is traumatic, but when it comes through NBS it is trauma with hope. That's what we want to give parents. Hope.

"The depth of my love for my daughter is not measured by the number of tears I have cried, but rather by the life I choose to live in her absence." - Lesa Brackbill

# *I am an NBS* **AMBASSADOR**



## **BETH VANNOY**

Hi, my name is Beth Vannoy. My husband, Jay, and I have two sons (Tate and Alec) and two fur babies (Bella and Gabi). I am a corporate attorney by trade, serving as Chief Legal Officer and a member of the Board of Directors at Window World, Inc. I also own Fruit of the Vine Boutique, a women's boutique and gift shop located in my hometown of North Wilkesboro, North Carolina. Jay's and my youngest son, Alec, was diagnosed with the metabolic disorder, MCADD, through North Carolina's Newborn Screening Program six days after he was born in 2012. In hindsight, I believe that we were quite close to a metabolic crisis on Day 3 of Alec's life. Signs and symptoms were there, but I knew nothing about this deadly rare disease until Alec's diagnosis. In his honor, I started the non-profit organization, Minutes Matter - MCADD in 2018.

My journey with NBS began when my son, Alec, was diagnosed with the metabolic disorder, MCADD, six days after his birth in June of 2012. Despite the fact that Alec was my second child, I knew very little about NBS before receiving Alec's abnormal results. Alec and I were discharged from the hospital just after his NBS heel prick.

In the first few days of life, he was sleeping most of the time and he wasn't urinating frequently. I quickly became concerned that in trying to nurse Alec that he wasn't getting the nourishment and hydration that his body needed. Our hospital had given us a can of baby formula as we were discharged. I contemplated giving him a bottle, but I really struggled with the decision because of admonitions not to give a baby a bottle in the early days if you're planning to nurse. Ultimately, we gave Alec a bottle, and thankfully, he sprang to life like never before. In hindsight, I have no doubt that the bottle of formula saved his life. It was not until 3 days later that we were notified by UNC Children's Hospital that Alec likely had a genetic metabolic disorder. It was Alec's diagnosis and our near metabolic crisis that fueled my desire to become an advocate for more timely newborn screening. I have met families within our organization that had eerily similar stories about lethargy and lack of urination in the early days, but sadly, their stories didn't end like ours. Children are lost in the early days of life because they suffer a metabolic crisis prior to the return of abnormal screening results. It is my mission to more timely screen for this condition so that intervention can occur earlier and prevent the unnecessary loss of life.



# *I am an NBS* **AMBASSADOR**

A Warm Welcome from Liz Carter

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Hi, I'm Liz! I live with my husband and 2 boys in Lexington, South Carolina. I am a mom, a former Spanish teacher of 14 years and now, an advocate for those living with Rare Diseases as well as a Newborn Screening Ambassador! While my journey has not always been an easy one, it's led me to exactly where my passion lies and where I feel I'm supposed to be. I'm happiest when I'm spending time with my family and our dog, and when I can use my experiences and my voice to help others and to create positive change. Becoming an Ambassador for Newborn Screening has been an opportunity for me to both walk alongside other families as they navigate their own Newborn Screening journeys, as well as provide an avenue to learn more about a system that has been proven incredibly effective for many, but through the sharing my family's own experiences, I am able to advocate for improvements.

In 2013, I gave birth to our first son, Grayson, who passed his newborn screening tests with flying colors. 3 years later, our family welcomed baby Elliott, who from the moment he came in to the world, lit up our lives. Just like his brother, Elliott aced his newborn screening tests! (Or so, we were told in the hospital after his arrival.). We took Elliott home, and just like that, our family was complete. In 2018, our family took a trip to the beach. When we returned home, Elliott (age 2 1/2 at the time) became very sick. We thought he had a virus and watched and waited for it to pass. It didn't.

We ended up in the Children's ICU, where Elliott was placed in to a medically induced coma. We were told that he was having seizures and that they needed to stop the seizure activity to give his little brain a chance to rest. We soon found out that the seizures were a result of extensive clotting throughout Elliott's brain. But WHY? Doctors told us that we may never find out the cause. They told us to brace ourselves; that we could lose Elliott to this. Grasping at straws and racing against the clock, doctors dug deep to determine what was going on. 14 days later, we got the news. "A recent blood test shows a very high level of blood Homocysteine, and we think Elliott has something called Homocystinuria. It's a rare, genetic metabolic disorder. The good news is, it can be managed with a Low protein diet, medical formula and medication." ....And that's where our 'new normal' began. I share our story as often as possible, with anyone that I can. Becoming a NBS Ambassador has given me the opportunity to support other parents that maybe have had a similar experience with a missed diagnosis at screening. It's also allowed me to lean on other moms/caregivers when I need the support myself! I can't say enough about the positive impact that joining the Ambassador Program has had on my life, and hopefully has allowed me to leave a positive impact in the lives of others.



# *I am an NBS* **AMBASSADOR**

A Warm Welcome from Twaina Williams

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Hi! My name is Twaina Williams from Pittsburgh, PA. I wanted to take a moment and introduce myself. So please lean in and take a moment to get to know me. Throughout the course of my life, I have carried many titles: a daughter, a sister, a niece, and a friend. In my professional life: an Accountant, Senior III Sales and Service Consultant, Coach, Executive Director of Finance, Lead Community Health Worker, and Family Consultant/Leader. Yet, one of the most important titles I hold is, MOM. I have three wonderful children who strive daily to make me proud, live out their own dreams and defeat adversity. I have two 18yr olds fraternal twins (Nyjae & Nijere) and an 11 yr old (Nisaun). Therefore, I have to lead by example and make a difference in MY world. That's where my real life journey began. While living to make a difference in my own world, I began to realize that my true calling was helping to make a difference in others' worlds. I have an 18 year old son who was diagnosed with Sickle Cell Disease at birth. This Sickle Cell journey has brought many tears, joys, challenges and blessings. Little did I know that the little heel prick would change my life forever.

Over the years, while living and creating a life for them, I also strived to support, build relationships, and advocate for families who may not have quite found their voice. This is where I began to make a difference. This is how I got to become a part of The Children's Sickle Cell Foundation that later led to an amazing opportunity with Expecting Health's Steering Committee and helping to lead this wonderful Ambassador program. Realizing that life is bigger than me, my needs and wants, how can I be a blessing, continue to grow and always remain open to learn something new? This is the constant question for my life. In my family, we live by 2 things: "Teamwork makes the Dreamwork" and "You make the disease, don't let it make you". This is me in a nutshell! Come be an Ambassador where not only can you learn how to help others but it also provides you with a support system that can last a lifetime!!! Remember that troubles don't always last and there is hope available. Hope to see you soon.

# *I am an NBS* **AMBASSADOR**

A Warm Welcome from Nicole Guysi



**I am Nicole Guysi; wife of over 12 years, mom to two, and dog mom to two! I am a Transition Technician which means I help high school students who receive special education services transition out of high school. Our family is used to the medical world and while we haven't experienced it all; my husband's cancer, daughter's rare genetic condition, and son's delays have allowed our family to make connections and gain resources in a variety of different areas. It's not something we would have asked for and yet, we feel immensely blessed for the privilege to navigate these journeys. We are an Arizona family and we are absolutely family first as we have sacrificed financially over the years to be able to spend more time with family and less at work.**

**I was blessed to get connected with NBS through our states parent training information center, Raising Special Kids. I was somewhat personally invested in that a childhood friend's son passed from a genetic condition that if had been caught before he was symptomatic, could have been treated. I wanted to know more; for her, for others. I wasn't sure how/if I could contribute as our daughters genetic condition doesn't really qualify to be on a screening, but the Navigate NBS Ambassador Program graciously allowed me to participate and I could not be more appreciative for the opportunity. I have "met" amazing women, been connected to awesome resources that I have immediately shared within my network, gained a wealth of knowledge and find myself in an area I wouldn't have imagined. I am passionate about helping families by improving systems of care, working with those systems and working with families to navigate the systems themselves and get involved in advocacy if desired. NBS has given me that opportunity and I am better for it. A better advocate, mom, woman.**





## *I am an NBS* **AMBASSADOR**

My name is Kiomara Gonzalez, 36-years-old with a bachelor and master degree. I am from Puerto Rico. I live currently in Georgia. My story about ALD; It started 30 years ago when my brother was diagnosed with the disease. Several months later my sister and I were also diagnosed. Since then I have tried to guide myself and others about newborn screening not only for ALD but for all diseases that can be detected and treated, since my brother could not receive treatment due to a late diagnosis. Five years ago my son born, and after his test, now he has the opportunity to fight and win.

My journey started 5 years ago when my son was born and my state Georgia did not have ALD in newborn screening (just a pilot program that did not include my county). When my son was born I asked to have the ALD test done and after the results, the newborn screening staff in Atlanta asked me if they could add the results to the pilot program. After that, I decided to help pass the law in Georgia. I was part of the EveryLife Foundation sharing my story and seeking information with other resources on how to help.

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**Navigate** Newborn Screening  
An Expecting Health Program



## *I am an NBS* **AMBASSADOR**

My name is Raleighn Williams and I'm a mother of five: four girls and one boy. I have nine grandchildren who I love dearly. I live in a small town called Lagrange in Dutchess County New York. I was born and raised in South Jamaica Queens N.Y and move upstate NY after having the four girls and realizing how expensive it was going to be to send them all to private schools. I was a stay at home mom for 20 years before I ventured out to work. I work at a daycare center first as a teachers assistant and I became an advocate for parents who have children with mental health issues. I love what I do and I've been working in this field for about 12 years now it's awesome. I love helping others that's me in a nutshell.

My journey as an NBS Ambassador really begins here. Although I've been advocating in a lot of different areas and helping a lot of families. My journey really begins with NBS ambassador started in 2020 right after COVID-19 began. I knew about it and was indirectly involved meaning I would make a donation when I could. After doing my trainings and meeting the current Ambassadors, I have now started a new journey of helping others and becoming a NBS Ambassador. I'm thankful for them sharing their stories. I thank them for being strong and never giving up. I am here with them and I thank them for having me.

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**Navigate** Newborn Screening  
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# Get to know Susan Mays



## The NBS AMBASSADOR

My name is Susan Mays and I'm the mom of two littles-my daughter Indie who is 8 and my son Lincoln who is 6. I'm married to my high school sweetheart Adrian and together we live in Washington state just north of Seattle. We love spending time together outdoors as a family-biking, hiking, adventuring. Although our daughter lives with a very serious metabolic disorder, we try to never let that define who she is or limit her in any way. Because of NBS she is having the ability to reach her potential and we couldn't be more grateful!

Although I didn't know it, our NBS journey began when Indie was 24 hours old. I vaguely remember someone doing a heel poke on her and when asked it being said that it was part of NBS. I had no idea what that meant but we were simply over the moon in love with our little girl so I didn't think much of it. Fast forward to Indie's two week well child checkup when her doctor mentioned she'd need another heel poke. In WA state, as with many other states, there are two routine NBS performed.

It was this second screen that would reveal Indie was born with a serious rare metabolic disorder called Maple Syrup Urine Disease (or MSUD for short). Remembering back it felt unreal, not possible, she showed no signs of having this or any other condition. But that's why NBS is so important and why I'm such an advocate for it. Most of these conditions are invisible, with there being no known family history but yet they are treatable. And there is community and support upon receiving the diagnosis. This is why I wanted to become an ambassador with Expecting Health because NBS literally saved my daughters life and everyday I'm thankful for it. I don't think we should wait until parents receive a presumably positive result to start the conversation about its importance. Out of ignorance, at the time I questioned if a second NBS was necessary. Of course now I cringe thinking about that, but in-spite of reading the parenting books and taking the birthing classes somehow I missed hearing about NBS. I hope in some small way I'm able to help change that for other families!

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# Navigate Newborn Screening

 An Expecting **Health** Program

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