



A newsletter of *Be Not Afraid...*  
a network of concerned parents and professionals who have experienced or worked  
closely with issues surrounding prenatal diagnosis.

## If You Have a Pulse, You Have a Purpose

Jason Peetz is the father of Jonathan, a nearly seven-year-old boy whom doctors had pronounced “incompatible with life” before his birth. Following a complex prenatal diagnosis of encephalocele and hydrocephalus, among other concerns, Jonathan’s doctors had told his parents, Jason and Lauren, that it was unlikely their baby would survive the pregnancy. Little did they know that Jonathan had other plans!

After their OB referred the Peetz family to those of us at *Be Not Afraid*, Tracy Winsor and Sandy Buck were honored to support Jason and Lauren throughout their pregnancy and birth. When Baby Jonathan was born on July 11, 2011, he exceeded all prenatal prognoses. After less than a month in the NICU, he was strong enough to go home with his family.

Jason blogs about his experiences as Jonathan’s father at *If You Have a Pulse*, inspired by the words of their pastor: “If you have a pulse, you have a purpose.” Jason and his wife Lauren live in North Carolina with their sons Tyler, Jonathan, and Colton. They also have a daughter in heaven named Eliza.

We interviewed Jason about Jonathan’s prenatal diagnosis, seeking to learn from a father’s point of view:

*Tell us about Jonathan’s prenatal diagnosis.*

Jason Peetz: We were experiencing a normal pregnancy with Jonathan through the first trimester. One month into the second tri-



mester we were at a routine OB visit. Once we found out we were having a boy, I left the appointment for work. On my way to work, Lauren called and said there was something wrong, and we needed to see a specialist the following day. At the maternal fetal medicine appointment, we were told Jonathan was diagnosed with hydrocephalus, a posterior encephalocele, clubbed feet, cleft lip, a possible lower spinal defect, and an unclear issue with his hands. The prognosis was that Jonathan would likely die due to the combination of the encephalocele and hydrocephalus. He was deemed “incompatible with life.”

*What was the experience of the diagnosis like for you?*

JP: The experience was devastating. We left thinking Jonathan had no chance at survival

whatsoever. There was a feeling of helplessness and isolation.

*Was an abortion ever a consideration for you and Lauren? Please explain.*

JP: Yes. We initially left the maternal fetal medicine appointment having scheduled an induction [editor’s note: medical professionals frequently offer “early induction” following prenatal diagnosis as a euphemism for abortion]. After a lot of talking, and even more praying, we realized how unsettled we were about ending the pregnancy. By that night, we made a choice that if Jonathan was not going to survive, then it would be by God’s choice...not ours. We had no idea how to proceed beyond that decision, but we felt an immediate peace and a heavy burden lifted from our shoulders.

*When did you decide to start your blog and why?*

JP: I don’t think I can pinpoint a moment in time when I made the decision. (continued on page 2)

---

### Inside this issue:

BNA Funding for 2019 Uncertain	2
Meet BNA’s New Prayer Coordinator	3
BNA Article Published in Ethics & Medics	4
2018 BNA Parent Survey Results	4

## ...If You Have a Pulse, You Have a Purpose (continued)

One of my best friends kept pushing me to tell Jonathan's story. He felt a blog format was a great way to start. I then did a little research about blogs involving children with special needs and was struck by the absence of blogs written from a father's perspective. I thought that the blog had impact potential on two fronts. By sharing our experience in my words, I might be able to reach another father who is thinking he is the only one going through something like this. I'm better at expressing myself through writing versus verbalizing my feelings, so I also felt like it would be cathartic for me.

*What advice would you give to other dads experiencing a prenatal diagnosis?*

JP: You're going to feel helpless. You're going to feel isolated. Be willing to talk with people about your situation...you'd be surprised with where you might find connections and support. Be okay with accepting help from others. You will likely need it, and people really do want to help when they see a need. Most importantly, pray faithfully, and be an indomitable team with your spouse.

*What advice do you have for other parents carrying to term?*

JP: It was important for us to start with independently educating ourselves on what Jonathan's diagnosis meant, but what helped me the most was praying

for clarity and peace with our decisions. The next most important step was having a resource like Be Not Afraid in our



corner. Because it can be such a helpless and isolating experience, BNA was able to lead us to resources and give us non-judgmental support down whatever path we were taken.

*What advice do you have for parents raising a medically fragile child?*

JP: Advocate for your child because you will know what is best for them above anyone else. Network. Seek out organizations that help families with medically fragile children. Talk with friends who have either had this experience or know others who've gone through it. Our first "networking" success was finding BNA through Lauren's OB. That success created a domino effect of resources for us.

*What has Jonathan taught you?*

JP: I don't know that I can articulate in writing what Jonathan has taught me. It's unquantifiable. He has taught me what it means to be a survivor and never give up even when odds are against you. He has taught me what it means to look beyond our physical differences to find unconditional love. I see this love not only with interactions between him, his brothers and other family, I see it with his teachers and even with people who've only gotten to know him through CaringBridge, his YouTube video, or my blog.

*How do Jonathan's siblings experience him?*

JP: Jonathan has an older and a younger brother. His younger brother's experience is just that...a younger brother that fusses about Jonathan touching him in the back seat of the van. Colton also loves jumping on Jonathan's bed and making him crack up. Since Tyler was two and a half and met Jonathan in the NICU, he has connected with him. It seems Tyler has always been aware of his fragility and is Jonathan's protector. I've never seen so much compassion and empathy come from an eight-year-old. Having Jonathan in his life has positively influenced his ability to interact with other children/adults with disabilities or that might look different. It's truly a gift to witness it.

*Would you recommend BNA to others?*

JP: Without hesitation.

## BNA Funding For 2019 Uncertain

BNA's ministry (which provides direct service for parents carrying to term following a prenatal diagnosis) has not secured continuation funding for 2019. As the ministry does not receive any annual allocations from churches, dioceses, or foundations, the ongoing funding of the ministry from year to year can be uncertain.

"Often we have carry-over from December into January, but this year an unsuccessful fundraiser impacted that," explains Sandy Buck, BNA Director. "We have one major request for funding being considered, but if we do not receive a positive response to that request, we will have to stop offering direct service to parents sometime this fall."

BNA has provided support for parents carrying to term for ten years and has welcomed over 130 babies. Anyone interested in making a donation to the ministry should visit the BNA website at [www.benotafraid.net](http://www.benotafraid.net).

## “Prayer is Our First Resort” — Meet BNA’s New Prayer Coordinator

“God knows the sound of my voice, and I know He knows the voice of the prayer warriors.”

When Lauren Whittaker retired, she knew that the Lord would be calling her to something new. She divested herself of her assets so that she could be free to go wherever He sent her; one of His first assignments turned out to be very close to home. Ms. Whittaker’s friend—BNA co-founder Tracy Winsor—was looking for the right person to revitalize BNA’s prayer ministry, and she knew that Lauren’s energy and gift for intercession were exactly what was needed.

Every family that BNA serves is offered “prayer warriors” (formerly called prayer sponsors) to pray for their baby. Since starting with BNA last fall, Whittaker has revamped the format of the prayer ministry from one sponsor per family to a team of prayer warriors praying for every baby. As Lauren said, “If it was my baby, I’d want the whole world to pray for her!” Although it was a new way of doing things, the prayer sponsors agreed to pray for all the babies and their families, and the feedback from the ministry has been very good. In addition, the number of prayer warriors has doubled since Lauren became the prayer coordinator. The team includes two priests, many lay people in different stages of life, and a nun who prays for each baby by name every morning as she prepares the altar for Mass.



The new format is simple but effective. Every week, Tracy provides Lauren with updates on prayers that are needed, which Lauren then sends out to the prayer warriors in a single comprehensive email—giving each baby’s name and their specific needs at that moment. BNA volunteers pray for babies who have been born, babies currently carried, and “rainbow babies,” the name for a child born to a family after a loss. Parents and the medical personnel are also covered in prayer.

If urgent needs come up between weekly emails, another email is sent out with the headline “BNA Storm Heaven!” so that the prayer warriors know to drop everything and lift up prayers for a baby in critical condition. Ms. Whittaker reminds us that “Prayer is not a last resort; it should be a first resort.”

Sadly, the prayers often include a petition that doctors will change their hearts and become more willing to care for babies with disabilities the way they would treat other babies.

Lauren believes that prayer satisfies many things for the ministry. As coordinator, she not only leads others in prayer—she lifts them up in prayer and seeks to encourage the prayer warriors and others in the ministry. “Prayer intensifies the graces that God is bestowing on the ministry,” Whittaker says, and adds, “We have seen miraculous things [resulting from prayer for babies and families]. We know that the Lord can change hearts and situations.”

Not only does the role of prayer coordinator bear much fruit for BNA families and the ministry—the experience is also helping Lauren in other advocacy efforts for vulnerable babies. As a longtime sidewalk counselor outside a late-term abortion center, Lauren has seen firsthand the pressure to abort that parents face following a prenatal diagnosis. She says that the counselors are diplomats for the babies, and that the more she learns about different types of diagnoses through BNA, the more equipped she is to step in and offer BNA as a resource.

Ms. Whittaker concludes that the prayer ministry “blesses everybody, affirms everybody,” and that the stories she hears about the babies shows her that it is truly making a difference. “It’s a beautiful gift, a beautiful privilege to be able to do this.”

## BNA Coordinator's Article Published in *Ethics & Medics*

Bridget Mora, BNA's Community Education and Communications Coordinator, had an article entitled "Prenatal Testing and the Denial of Care" published in the February 2018 edition of the National Catholic Bioethics Center's commentary *Ethics & Medics*. The article describes how a prenatal or neonatal diagnosis is often used to deny these babies the treatment that would typically be offered to other babies. It explores causes for bias, lack of sufficient parental informed consent, and the impact of prenatal testing. Included in the article are the stories of two BNA families whose babies were denied heart surgery following a Trisomy 18 diagnosis. A copy of the article can be read at this link: [www.benotafraid.net/resources/Medical-Professionals](http://www.benotafraid.net/resources/Medical-Professionals)

### 2018 BNA Parent Survey Results Available

In the spring of 2018, BNA completed a survey of parents served by the ministry over the last ten years. Results were overwhelmingly positive. 100% of the parents surveyed said that they would encourage other parents experiencing a prenatal diagnosis to carry to term and that they would refer them to BNA. 97% said that BNA was important to their personal well-being as they carried to term. 97% agreed that BNA peers and volunteers were knowledgeable and sensitive to their needs. 100% said that BNA responded to questions and concerns in a timely manner, with 90% agreeing that BNA had a positive impact on their communications and relationships with their medical provider. Finally, 95% agreed that BNA provided them with support not otherwise available to them. Parents were also given options for written responses, some of which are provided below.

*"The support we received was game-changing. I can't imagine having gone through this without BNA."*

*"The support we received from BNA was invaluable. Their support and resources were instrumental in getting the best care for our baby that we could."*

*"They provided such wonderful care and resources for us and our son. Their love for us and our son was shown throughout."*

*"No one else really knew what I was going through and not everyone understood or was willing to help. BNA was there for me every step of the way."*

*"...They helped prepare us for speaking with our providers. We were told repeatedly by our doctors and nurses that we had such a good grasp of our situation and were so well prepared. I know this is because of BNA."*

For complete Parent Survey results, visit the "News" tab at the BNA website: [www.benotafraid.net](http://www.benotafraid.net)

## Be Not Afraid

[www.benotafraid.net](http://www.benotafraid.net)



**Be Not Afraid** is a network of concerned parents and professionals who have experienced or worked closely with issues surrounding poor prenatal diagnosis. Our free service of practical guidance and compassionate care focuses on meeting the needs of expectant parents as they seek to honor the life of their baby, no matter how frail or how brief it is.

### **We Need You!**

If you are interested in supporting our ministry, there are many ways you can help. Let your experience support another parent; be a prayer sponsor or a Spanish translator. Tell us what skills you have that might benefit the parents we serve.

Financial donations are always welcome, and can be made at our web-