The Right Doctor Can Make All the Difference: One Family’s Story

Jeremy and Risa Alt found out their twin daughters were conjoined at a routine 16 week ultrasound. The big news that day was supposed to be if they were expecting boys or girls or one of each. The news that their twin daughters shared a heart as well as possibly other organs was devastating. Risa remembers fear and sadness, crying in the doctor’s office with Jeremy, and hoping that maybe it wasn’t as bad as it looked. The Alt’s were told abortion was an option, but declined.

A consultation with a high risk doctor at a major pediatric center within a couple of hours of their home followed the next week. His opinion was that the girls would not survive to birth and as compromised as they were he thought a termination was a good option. A subsequent appointment with a pediatric cardiologist at the same center resulted in the third offer to abort. Over the next couple months, there were additional consults with children’s hospitals with experience with conjoined twins in four other states, but little hope was offered for the Alt’s daughters.

As the pregnancy progressed, an introduction to a neonatologist arranged by BNA provided the opportunity for the Alt’s to revisit one birth option they had set aside. Over a series of phone conversations, they found a doctor who would not ultimately be able to save the girls, but whose care and support would make all the difference in the world as Jeremy and Risa welcomed their precious daughters and then lifted them to heaven. He was there on the morning Ally and Addy drew their first breaths and remained a dedicated advocate for the family until their death thirteen days later.

We asked Risa about her experience of prenatal diagnosis, her daughters, and what advice she would offer to parents newly diagnosed.

How did you and Jeremy approach the diagnosis?
We approached it with a fight attitude. We spent hours educating ourselves and researching. We contacted four other hospitals that had dealt with conjoined twins and sent our records to get second opinions. We wanted to make sure we did everything possible for the girls if they could be saved. We did not want to ever look back and say “what if.”

As the pregnancy progressed and you realized that treatment options were limited, how did you manage that?
We started shifting our mind set to them being born and that we would not fully know their condition until they were born. We focused on the fact that God was in charge...we knew that ultimately God would decide what would happen to Addy and Ally. We prayed for a miracle and trusted that no matter what happened God would be with us. We trusted Him.

What was your biggest challenge as you approached your due date?
In our home community, we had a supportive OB, but we had not found a pediatric provider who seemed committed to our intention to take the girls to term...not to mention our intention to make one final assessment of their heart at birth. We were very uncertain of where we would deliver.

What made the biggest difference for you in deciding where to give birth?
The absolute biggest difference for us was meeting the neonatologist who became the girls’ doctor. He was part of the support we were offered by BNA. They contacted him on our behalf...asking if he would call us to help us sort through our options...particularly birthing at the hospital at which he worked. We hadn't had great consultations there. He was different to the extent that he wasn’t confused by our decision to carry to term and listened to our perspective and our questions with understanding and compassion. We could tell he was willing to work with us...offering us his clinical expertise while recognizing our need as parents to make certain that we provided the best care for our daughters. We could also see that he was advocating for us and for the girls...helping other doctors understand our intentions and what we wanted to do.

Continued on page 4.
**BNA Growth Continues**

2013 has brought continued change to BNA. First founded as a parish-based ministry in the Charlotte Diocese in 2009, BNA incorporated as a private non-profit with a Board of Trustees in December of 2011. The organization’s mission (to provide support to parents experiencing a prenatal diagnosis and carrying to term) remains unchanged although the scope has grown beyond the Diocese of Charlotte.

BNA’s work is peer-based, informed by the ethical teachings of the Catholic Church, and founded on a commitment to provide pastoral care to parents while offering a witness to the beauty of every life no matter how brief or how frail.

Over the last two years, BNA has been featured in national Catholic press and in a webinar sponsored by the National Catholic Partnership on Disability and the US Conference of Catholic Bishop’s ProLife Secretariat. The organization was also featured in “Ethics and Medics,” a publication of the National Catholic Bioethics Center.

Increasingly, the organization has been asked to support service development in Catholic communities in various parts of the U.S. BNA is currently supporting service development in the archdioceses of Omaha, Philadelphia, and NY as well as in the dioceses of Rockville Centre, Brooklyn, Allentown, Harrisburg, and Raleigh.

BNA published a comprehensive pastoral care manual in 2011 and hopes to have a service development guide completed by the end of this year. The organization hosts an active Facebook page, and a new website with updated features including videos of BNA families, referral capability, and a password protected section for service providers.

Late last year, the Supreme Council of the Knights of Columbus provided a $50,000 grant to BNA. Encouraging service development in Catholic communities has become a major interest of the Knights of Columbus. BNA will use Knights funding to develop an online training program to increase access to BNA messaging and materials. Knights funding will also help BNA serve parents outside of Charlotte in communities in which there is not similar support for carrying to term or in communities where developing services need BNA assistance. In addition to North Carolina, BNA has provided support to parents in New York, Georgia, California, Illinois, Missouri, Rhode Island, South Carolina, Pennsylvania, Massachusetts, Virginia and Florida.

BNA Peer Ministry Training

There is no cause to which the Knights of Columbus is more committed than the cause of life,” observes Stephen Feiler, Administrative Assistant to Carl Anderson, “And the Supreme Council is pleased to partner with BNA in addressing this often overlooked, yet increasingly urgent dimension of the prolife movement.”

This past month, BNA was also awarded a grant for $4,000 from the Catholic Campaign for Human Development (CCHD) from Catholic Charities Diocese of Charlotte to jump-start the organization’s efforts to translate brochures and other resources into Spanish. BNA has received support through the Respect Life Program of Catholic Charities Diocese of Charlotte in the past, but this is the first time the organization has received CCHD funding. Additional funding is being sought for the important work of providing Spanish-language outreach and support to the Latino community experiencing prenatal diagnosis and carrying to term.

Joseph Purello, Catholic Charities CCHD Director, asserts that BNA fits wonderfully the criteria for receipt of a CCHD grant.

“CCHD works to fight poverty and help those who are marginalized in society,” said Purello. “Be Not Afraid exists to be a resource to families who seek support as they affirm the lives of their vulnerable children who face severe disabilities and medical needs. CCHD is glad to partner as a funder of the good work of Be Not Afraid.”

Funding from both the Knights of Columbus and CCHD reflects the increasing organizational development of BNA which is also in the process of creating an Advisory Council, and has added several part-time staff positions.

“Incorporation in late 2011 was a major development for BNA,” notes BNA Board of Trustees Chairperson, Monica Rafie, “and we look forward to continued growth in the years to come.”

BNA peer ministers, volunteers and staff value most their direct support of parents carrying to term. In 80% of cases, parents experiencing a prenatal diagnosis terminate, but when presented with a service of comprehensive support like that offered by BNA, 80% chose life for their babies.

BNA is currently serving parents with the following prenatal diagnoses...Trisomy 21 (Down syndrome). Trisomy 18, various complex heart defects, Potter’s Syndrome, and anencephaly.

Judy Townsend, BNA Project Assistant, notes, “It is an honor and a privilege to share the lives of these babies with their families...to welcome every baby joyfully and to offer support when birth brings death. I have always thought of myself as prolife, but this work provides real perspective on what it means to value even the most vulnerable among us.”

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**Upcoming BNA Programs**

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<th>Date</th>
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<th>Program Description</th>
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<tbody>
<tr>
<td>06/15</td>
<td>Diocese of Raleigh</td>
<td>BNA Peer Ministry Training</td>
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<tr>
<td>06/29</td>
<td>Archdiocese of Philadelphia</td>
<td>BNA Peer Ministry Training</td>
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<tr>
<td>08/03</td>
<td>Diocese of Orlando</td>
<td>Workshop - “Life-Affirming Strategies for Marriages When a Pregnancy is Complicated”</td>
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What Parents Are Saying About BNA...

“When we were given our son’s initial prenatal diagnosis, we felt hopeless and lacking any guidance or support in such an unknown situation. To be told that your son’s prognosis is “incompatible with life” is something that no parent should ever have to hear, but when you hear such words there should be resources to help guide you down the paths that lie ahead. We decided on life and we needed help for all of the unanswered questions. Thankfully, we are told about BNA and that was the answer that we so desperately needed. They were able to help and guide us in so many ways and provide options, perspective and an experienced ear. From the difficult and emotional task of writing a birth plan, to help in finding the right doctor to deliver our son, to general love and support, BNA was with us every step of the way, right up until the day that Jonathan was born.”

Jason and Lauren, Parents of Jonathan
Mooresville, NC

“Our diagnosis day was terrible. Like all babies, we knew Andre’ was a divine gift, but we were afraid. There was no question that we would carry to term, but how would we parent this child and what lessons would his life offer his five siblings? Finding BNA was a blessing because they gave us more insight, compassion and encouragement than any of the medical providers we saw. They listened to our story, our worries, our questions, and gently offered us considerations and ideas for the pregnancy, birth and beyond. They assured us we weren’t crazy for wanting to honor and love Andre, and they helped light a path we will never regret! We will be forever grateful to BNA for enabling us to parent Andre in the most loving way we could while helping us show his siblings that all life is beautiful.”

Dave and Lisa, Parents of Andre
Leemore, CA

Introducing BNA Board of Trustees...

**Bishop Peter J. Jugis** is a native of Charlotte, NC, and is the fourth Bishop of the Diocese of Charlotte. He has a degree from the University of North Carolina in Charlotte, and graduated from the seminary at the Pontifical North American College in Rome. He was ordained to the priesthood by Blessed John Paul II in 1983, and awarded a licentiate the Pontifical Gregorian University in 1984. He received his doctorate in canon law (JCD) from the Catholic University of America in 1993. Bishop Jugis has offered on-going encouragement to BNA in its development particularly as it relates to the important work of serving families and welcoming vulnerable newborns. He was both a sponsor and an attendee of BNA’s conference for service providers, and it was at his urging that BNA incorporated as a private nonprofit in December of 2011. Bishop Jugis serves as Episcopal Moderator on the BNA Board of Trustees.

**Amy Daniels** completed doctoral studies at Oblate School of Theology, TX, a Master of Divinity degree, and a Residency in Clinical Pastoral Education (CPE). She is a former U.S. Air Force Chaplain who currently serves as the Director of the Office of Formation & Discipleship in the Archdiocese of Atlanta. She became familiar with BNA while working in the Diocese of Raleigh, and was a featured speaker at the BNA conference for service providers in 2011. Her professional insights regarding pastoral care and needs of parents are informed by her own experiences as the mother of a child with Down syndrome.

**Peggy Gallo** graduated from the University of Scranton with a B.S. in Accounting. She is a Realtor with Helen Adams Realty in Charlotte, NC, and has had extensive board experience supporting community-based organizations in various positions of leadership. Peggy has experienced both perinatal loss and prenatal diagnosis as a mother, and used these experiences in support of others as a peer minister. She was instrumental in encouraging the development of BNA as a diocesan-wide service.

**Susan Guilfoyle** graduated from Western Michigan University with degrees in Early Childhood and Elementary Education. She has taught at Reedy Creek Elementary in Charlotte, NC for 21 years in the 3rd and 4th grade and also as a Literacy Facilitator. Her youngest son was prenatally diagnosed with T18, and so she has both been served by BNA and served with BNA as a peer minister. She is also the chairperson of BNA’s annual fundraiser (the BNA Run for Life, Love and Hope 5K) which will be held on October 12 of this year.

**Maggi Fitzpatrick Nadol** has a Bachelor’s degree from Mercy College of Detroit, a nursing degree from the University of Arkansas at Little Rock, and a Master’s in Counseling from Gordon-Conwell Theological Seminary. She serves as the Respect Life Director for Catholic Charities Diocese of Charlotte and maintains licensure as a counselor in the State of NC. Under Maggi, the Respect Life Office has supported BNA with funding and program sponsorship.

**Monica Rafie**, founder of benotafraid.net, will remain on the Board serving as Chairperson.
Peer Ministry Trainings Offered in NY and Washington DC

Sixty attendees completed BNA Peer Ministry Training in New York City May 18th. They represented the Archdiocese of NY and the Dioceses of Brooklyn and Rockville Centre and included professionals from the medical community, social service, crisis pregnancy and hospice providers, chaplains, diocesan staff, individuals interested in volunteering, and peers who had themselves experienced a prenatal diagnosis and/or perinatal loss.

BNA is supporting the three metropolitan NY dioceses in the development of a service called Diana’s Hope. Baby Diana, for whom this new ministry was named, was prenatally diagnosed with anencephaly. She was the first baby welcomed by dedicated volunteers in NYC in collaboration with BNA. Diana’s parents began the training on May 18th by sharing pictures of their precious daughter.

Diana’s Hope is using the BNA model of care in its development effort, and together with BNA is serving a second family currently.

“I believe the training provided information we need regarding the background and full dimension of the service BNA provides,” offered Bob Lopez, the Diana’s Hope Chaplain, “We have greatly appreciated the support and mentoring BNA has provided to us in the development of this important ministry.”

Two similar trainings were offered earlier in the year in the Archdiocese of Washington for Isaiah’s Promise Ministry. Professionals, volunteers and peers also completed training there.

...I would recommend this peer ministry training to anyone who was hoping to get involved with families that choose to take their pregnancy to term” shared Jeanine McGrath, RN, BSN. McGrath provides professional doula services, volunteers with Isaiah’s Promise and attended the BNA Peer Ministry Training held at Holy Cross Hospital in Silver Spring, MD.

Right Doctor...

What did he do to help you accept the reality of their shared heart?
He made certain we got that echocardiogram at birth, and then because he was always straight forward and honest with us and yet committed to going as far as we wanted to go, we knew we could trust him when he told us we couldn’t save the girls.

What will you always remember about their birth?
I will always remember the many amazing people in the delivery room and our pastor leading everyone in prayer before they started...that was something that BNA and our neonatologist made possible for us. I will especially remember seeing the girls for the first time and touching them. I did not want to leave them.

What is your most precious memory of their thirteen days of life?
My most precious memories will be holding them and trying to breast feed and singing to them, kissing their little heads and rubbing their feet. And I will also always cherish their brothers and sister getting to meet them and touch them.

What would you tell parents who might get a prenatal diagnosis?
Do your research. Educate yourself because you may not be able to count on the first doctor you meet to have all the answers you need. I have heard of so many people that if they would have relied on just the information and advice available to them and given up on second opinions...they would not have their babies today. Find a doctor with whom you are comfortable, and one who will work with you so that you have peace no matter the outcome. Don’t get discouraged with the negative. Remember you are still carrying a baby, safe and alive inside you, and especially when you don’t know how long you’ll have them...that time of pregnancy should be sweet and precious to you. And pray.

Be Not Afraid

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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.

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 skill you have that may benefit the parents we serve.

Financial donations are always welcome. They can be made via paypal at our website. Checks should be payable to Be Not Afraid. You can send your gift to:
Be Not Afraid
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Huntersville, NC 28078