



## November 2009 Newsletter

We're proud to introduce our November Angel of the month,

# Nikki

Take a moment and read her story...

she proves once again that our Angels are our inspirations and joy!



Angel Foundation®

Dear Friends of BBAF:

This month, I am grateful for so many things. My treasured friends, my wonderful family. My beautiful Goddaughters.... and YOU. Reading your stories, hearing your thoughts, watching your courageous actions, it truly has been a gift in ways that I cannot even express. Thank you. Thank you for reaching out to others even through your struggles. YOU matter, YOU inspire, YOU are the heart and soul of Thanksgiving.

In addition, I want to take this moment to put on record how very, very proud I am of Renee. And while she will want me to take this out of this letter, I will not. I watch Renee, daily, in her efforts to be there for you, to help with your needs, to assist, care, and strengthen our BBAF family. I see a dedicated woman with a purpose that is beyond ego, beyond self. She sets a wonderful example for her daughters, my son, and all of us. I am proud of you Ren, and I thank you for always inspiring me. I am thankful for all you bring to my life, and the beautiful girls you have given me the chance to love.

To Jill, Laura, Dante, all of you are truly family. You give of yourselves beyond expectations and through extreme hardships. You too are inspirational and gifts that we are deeply thankful for.... So on to business....

### SET YOUR TIVO'S - WATCH YOUR LOCAL LISTINGS!!! RENEE AND SCOTT ARE APPEARING ON "THE DOCTORS"!

This week, Ren and Scott are taping a segment of the daytime show **THE DOCTORS**. We are not yet sure of the airdate, but it should be soon. What a wonderful chance to truly spread the word and work of BBAF! As soon as we know the airdate, we will post it on the site, and we ask that you share it with everyone you know!

### URGENT ACTION NEEDED:

Our dear partner and welcoming committee member, Jill Levy-Fisch, President, Save Babies Through Screening Foundation - one of our affiliates, has this message for everyone. It is of such importance, that we wanted to share it again. PLEASE TAKE ACTION. WE CAN MAKE A CHANGE! "We need your help. Families, adults with Inborn Errors of Metabolism, and medical professionals have come together in an incredibly energetic and focused manner this past year to work on creating federal legislation to mandate that insurance companies provide coverage for medical foods and supplements (i.e. formula and low protein foods). Our efforts are beginning to pay off with a proposed bill called the Medical Foods Equity Act of 2009 through the leadership of Senator Kerry's office. We now need to help Senator Kerry's office by finding co-sponsors for this groundbreaking legislation. Senator Kerry will be introducing the Medical Foods Equity Act very soon, which is based on recommendations from the HHS Advisory Committee on Heritable Disorders in Newborns and Children. **Please call your Senators TODAY and ask for their leadership on this bill by agreeing to become a co-sponsor. Calls are much more effective than emails in this situation!** If you decide to call, please ask to speak with your Senator's Health Liaison. If the Senator needs more information or has additional questions, please direct them to Megan Thompson in Senator Kerry's office. Thank you so much for your help as we move forward in ensuring that all of our loved ones have access and coverage for their medical foods and supplements, no matter where they live in our country."

### WE ARE ALWAYS LOOKING FOR SUGGESTIONS!

We are always interested in ways that you think we can improve our site and our efforts. Please email and/or send us a note through the forum!

### DON'T FORGET TO INVITE THE UNAFFECTED SIBLINGS TO JOIN THEIR FORUM SECTION.

This is a place for unaffected siblings of children with metabolic disorders to connect with each other as well as connecting with parents of metabolic children to offer support and advice.

### A REMINDER OF HOW TO FIND OUR ANGEL'S OF THE MONTH:

Go to the MEDIA AND EVENTS page and look down on the left.. you will see each month with the associated Angel story!

**DO YOU KNOW ANYONE WHO OWNS / OPERATES A LOCAL RADIO STATION?:** As you know, we have a :60 second spot promoting the web-site performed by our very own foundation **Daddy, Scott (Baio)**. If you have a friend that works in radio and that might be talked into running some PSA's in their 'remnant' space, please email me at **BaileyBaioAngels@aol.com** and we can send you an MP3 right away! NOTE: THANKS TO SOME VERY SPECIAL ANGELS ACROSS THE COUNTRY we now have BBAF spots playing in over 80 markets!!! Thank you so much!!

And HAPPY 2nd Birthday BAILEY!!! I LOVE YOU SO MUCH! xoxoo  
Marcia "Marcy Mama" Beverly  
Treasurer, Bailey Baio Angel Foundation and proud Godmother to Bailey



### A GENEROUS EFFORT BY A VERY SPECIAL ANGEL FAMILY!

After their family's experience with Alexia's false positive diagnosis, Brandi McCormack decided to hold a fundraiser to benefit BBAF and families affected by metabolic disorders to celebrate Alexia's first birthday. Brandi worked for several months, getting companies to donate items for a silent auction and she asked for donations to BBAF in lieu of birthday gifts for Lexi. The fundraiser was quite successful! Brandi raised much awareness for Expanded Newborn Screening and was able to raise a substantial donation for BBAF! **THANK YOU LEXI and BRANDI!... AND HAPPY FIRST BIRTHDAY!!**