

# The Twin to Twin Transfusion Syndrome Foundation

*“Connecting the World to Fight Twin to Twin Transfusion Syndrome”*

411 Longbeach Parkway Bay Village, Ohio 44140 800-815-9211 [tttsfoundation.org](http://tttsfoundation.org)

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Dear Friends,

Twin to twin transfusion syndrome knows no boundaries. It doesn't care who it affects or where in the world we live. This disease threatens the lives of the most important and precious gifts to us, our children. We fight hard. For many, there are happy endings with healthy babies. For others, there are tremendously painful losses or special needs concerns. This year alone, we have helped parents from all across the United States, Canada, Singapore, United Kingdom, Thailand, Spain, Jamaica, Norway, Germany, Poland, Australia, and Holland. We truly are connecting the world to fight TTTS. We are all the same. We just wanted to have a baby. We never thought we would be thrown into a high-risk medical world and have our lives changed forever. But some parents, maybe you included, had a soft place to fall when they contacted the Foundation. We continue to provide immediate help and hope to families in crisis.

For 17 years, The Twin to Twin Transfusion Syndrome Foundation has devoted all of its time and energy to educating thousands of mothers and fathers experiencing the shock of a TTTS diagnosis. Doctors still need help understanding the urgency in treating TTTS and properly monitoring the pregnancy for the signs of distress that demand immediate action. They should know what to do, but many do not. Women with a monochorionic placenta need weekly ultrasounds from 16 weeks through the delivery of their babies, even when a diagnosis of TTTS has not been made. We continue to make educating doctors a priority and also place emphasis on maternal nutrition and bed rest.

We wanted to share some of the letters that we receive on a daily basis. After reading this letter, we hope that you will make a donation to help us continue to fight this terrible disease. We can't do it without your help. The work is endless, but each day brings us closer to more effective treatments that will save the lives of more babies.

“Please tell me exactly what is happening. I am a young first time mom. My fiancé and I are just 23 years old and this will be our first child. I am alone at home now as he is working in the states. You can imagine I have no shoulder to lean on. I'm still crying myself to sleep at nights and even traumatized at the fact that I will be losing my baby. YOUR HELP IS GREATLY NEEDED.” (Jamaica)

“Mary, we are in a real trouble, Natata is always crying, peace has gone far from our home. So we do need your genuine and professional advise. We also appreciate if your organisation can help us reach any of the centres in Europe who are collaborating with you for medical treatment. Looking forward to hear your urgent reply.” (Norway)

“Thank you for your wonderful, kind support during our diagnosis of TTTS and the loss of our daughter two years ago this month. I continue to think of how amazing you are in the way you handled our phone conversations - how you listened and sympathized while still giving me direction in my fear and grief. You are a blessing to me, and to many others who share our experiences. Because of our conversations, the way we handled our daughter's diagnosis and loss is something we look back on without regret. We have meaningful memories and mementos that we never would have even considered without your prompting. "Thank you" hardly seems adequate.” (United States)

“There are no words that can ever describe my surprise and pleasure when I heard your voice on the phone the first time you called! I was alone, scared and confused by all that was happening. My husband was (and still is) deployed in Iraq. I was forced to resign my position because of my troubled pregnancy, and to top it all, I was confronted with the terrifying fact of losing one or both of my babies. I have to admit, when I e-mailed to The Foundation, the most I expected was some information e-mailed to me in a week or so. I never dreamed I would get to talk to somebody that same evening, and even more, to someone that understood very well what I was going through!” (United States)

“Thank you so much for volunteering to stand by us through this battle. We will be going for another ultrasound scan on Monday. Hopefully the fluid level hasn't gone back to the previous level. I also hope the donor baby will have a normal bladder as she doesn't have any fluid in her sac. I am really so glad to receive your mail. It means a lot to both of us to have someone who can really understand our problems and more importantly, able to advice us along the way as we fight this lone battle to save our 2 daughters.” (Singapore)

The faces and voices are different, but the desperation, panic, urgency and love are all the same. We will never give up the fight against TTTS. Please help us.

From my heart,

Mary Slaman-Forsythe  
Founder and President

PS. One hundred years from now it will not matter how much money you made, the type of clothes you wore or the size of your house. What will matter was how you made a difference in the life of a child. Please make a tax-deductible donation today.