

Sample Email Letter, Sent to a Chief of Staff for Assembly Representative, April 2009

Dear XXX,

Hello, my name is Rachel Goldberg, and I am following up from our phone call last week. I am writing to you to request a meeting with Assemblyman XXXX regarding a bill to test newborns for congenital heart defects.

In June 2008 my daughter Talia was born at XXX Hospital. The hospital and nursing staff were fantastic, but before we were released that Friday morning, the pediatrician told my husband and I that she appeared to have a heart murmur and we should schedule an appointment with a pediatric cardiologist for the following Monday. He did not explain why, and told us that it was probably not something we needed to worry about.

The first 48 hours home were somewhat typical. Sunday afternoon, around 3 o'clock, Talia started to cry. Over the next hour, her crying increased. An hour later, her breathing changed and we noticed that her feet had begun to turn purple. We immediately rushed her HUMC, where she was immediately intubated. The doctors and nurses at HUMC worked feverishly for the next 5 hours to stabilize her for transfer to St. Joseph's in Patterson. They were not sure what was wrong, but it was clear that she was in critical condition.

Upon transport to St. Joe's, we learned from the pediatric cardiologist on call that her condition was life-threatening, and they needed to transfer her to Mt. Sinai in New York City, where a pediatric cardiology team could attempt to save her life. We were told that she was suffering from at least two severe heart defects and was in cardiogenic shock at her arrival, and that if she survived, she could have severe internal organ damage. We were asked repeatedly about the conversation with the pediatrician that released us from the hospital, the prenatal sonograms in an attempt to find out if we had any prior knowledge of this condition.

Once again, she was stabilized enough for transport, and a team of over 20 doctors and residents began working on her when she arrived to the Mt. Sinai NICU. She remained in the NICU for 10 days and had open heart surgery when she 14 days old to repair three of her five heart defects.

Today, she is vibrant 10 month old, and everyday we are thankful to the teams that saved her life. At the same time, we often shudder to think at what a few more minutes could have cost us, or what thousands of other parents throughout the nation and the world may have to deal with, without the access to healthcare facilities that we so often take for granted.

This is why I am writing you today. As the New York Times article linked below points out, Talia's condition should have been identified before she left Palisades hospital. In

fact, there is a very simple and low cost way to spot congenital heart defects such as Talia's, but because it is not required, it is not done.

I would like to find out what we can do to introduce this into New Jersey legislation. The State of New Jersey, along with New York, does some of the most rigorous blood tests to screen for infant illness in the country. With a simple addition to the hearing and vision tests, we can save a few more lives. I will never forget the moment that I was told my daughter was going to die. I pray that this simple test can save at least one more mother from that terrible experience.

I am coming to you first, because I understand Assemblyman XXX's commitment to healthcare and to New Jersey's children. If you do not think this is something he will pursue, please let me know so that I can reach out to other area legislators.

Warm Regards,  
Rachel Goldberg  
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