

How To Become a

PHENOMENAL

ADVOCATE

for Your Premature Baby



By Tami C. Gaines

In the world of ringing bells, alarms, and sick babies, at first it may seem that advocating for your baby is impossible and unimportant – especially because most of us have no medical training. Advocating in the purest sense of the word is speaking on behalf of someone else, typically someone who cannot speak for themselves – in this case, your child.

Why Do I Need to Advocate? I Trust Doctors.

While your baby's caregivers are highly skilled and qualified, they are not staring at your baby day in and day out, watching his every move, hanging on her every breath. In many cases, you will know before they do that something just "isn't right." You will have an instinctual sense for what is right for your child. Do not ignore what you know to be the case just because you can't package it in medical terms.

Your reality is staring at your baby for hours on end. Your sense of what is right and wrong with your baby's care is stronger than you can imagine. When you acknowledge and embrace this fact, you become a powerful advocate.

Speak with confidence on behalf of your child because she can't speak for herself. The goal is to be sure that everyone is acting in the highest good of the baby. Advocating is not a power struggle nor is it an opportunity to feed egos. Advocating is a respect-based, rational conversation between adults that results in an advancement of the baby's health, growth, and development – one that leads to a healthier baby who's able to come home sooner.



That Sounds Great. How In the World Do I Do That?

To be a successful advocate, you have to be impossibly objective and unemotional when assessing the status of your baby. As a parent, you are emotional, stressed, distracted, angry, sad, confused, helpless, and happy (did I miss any?). Every emotion you feel as a parent of a N.I.C.U. baby is justified and should be acknowledged. However, as an advocate, you must embrace those emotions and put them in a box so that you can listen clearly, process fully, and ask the right questions. Be thoughtful, reflective, and patient. If you don't understand something, ask for clarification. If you still don't understand something, ask again or ask someone else.

Steps to Becoming a Strong Advocate for Your Baby

1. **Remember that your baby's life is on the line.** It is that serious.
2. **Information must be gathered before opinions are rendered.**
3. Your baby is different from his/her neighbor.
4. Pick your battles.
5. **Fall on your sword for that which you care about most deeply.** This is worth expanding on. My obsession was with my babies' nutrition and development. During every conversation, including those around surgery, I wanted to know when they would start feeding the babies again and how the procedure would affect them developmentally. Pick a "theme" (feeding, nutrition, breathing, development, long-term health) and stick with it. You can't be an expert in everything.
6. **Be an excellent student of the N.I.C.U.** but remember that you are not a teacher.
7. **Choose the right time to advocate.** Never during the doctor's "rounds", in a crowd, or during a casual conversation in the hallway.
8. Find a champion to support your cause (another neonatologist or a nurse, for example. Never another parent!).
9. Go out of your way to be sure that all key players are on the same page (doctor, nurse, therapist, nutritionist, spouse, etc.).
10. **Know when to say "when."** Always remember that you are on the same team as the doctors and nurses. When advocating for a particular issue, it is a battle fought in the larger war. The war is won when your baby is home. Losing a few battles will not change the definition of victory.
11. **Thank the loser.** Give them another chance to help you with something else.