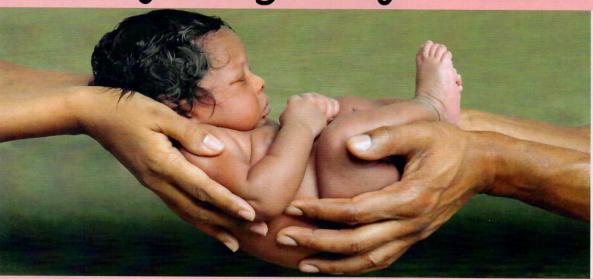
## Everything Baby Guide



#### Ways to be your child's best advocate in the doctor's office

By Kristi Wees, MsChem

ast week, a television in the waiting room caught my eye. It was Doc Baker on an old episode of Little House on the Prairie. He was making house calls to check on the children (and adults and an occasional horse!) of Walnut Grove.

As I snapped back from yesteryear, I sat in the doctor's office waiting room reflecting on just how different medicine is practiced today. House calls and personalized medical care of *Little House on the Prairie* days was undoubtedly the original rendition of "family & patient centered care". Even in today's seemingly complicated medical systems (compared to one doctor per town on the prairie), it is possible to get that personalized care for you and your child.

Below are a few tried and true tips to help you advocate for your child medically.

### Remember that YOU know your child best. Period

Although you adore and trust your pediatrician, it is important to remember that they only spend a fraction of time with your child (national average is 17.4 minutes per visit). Compared to the hours, days months and years that you spend as a parent knowing their every mannerism, non-verbal cue and whimper.

Doctors must rely heavily on the caregiver's information about the child, and some of the best doctors I have worked with, regard the parent or grandparents as the experts that they

truly are on their children and treat them as equal members of the child's medical team.

### You are allowed to ask questions, lots of them if need be

Asking questions is how we learn and clarify what we don't understand. If a physician is bothered or seems dismissive of your questions, it may be that they are running behind schedule and have many more children to see or they may not know the answer. In these cases, ask what is the best way to communicate with them outside the visit time to get your questions answered (phone, email, patient portal, etc).

Don't ever make a medical decision for your child if you have unanswered questions. If you do not feel your questions are being answered by your doctor it is ok to seek a second opinion with a physician who will answer your questions.

### Get copies of everything: labs, records, notes, discharge paperwork

Being your child's best advocate means having access to all the information for your child. Medical records contain a tremendous amount of data, but often it is locked away in the "electronic health record" (EHR) computer system.

By getting paper copies at each point in your child's treatment you can begin to assemble your own copy of the health record that you can access whenever you need it. This will be helpful if you need to see a specialist or seek a second opinion.

# Treat the medical staff with the same respect, kindness and professionalism that you wish to be treated with

The Golden Rule - do unto others. If you want to be regarded as the expert you are about your child and an equal member of your child's team you must treat others on the team with the same respect and regard. While it can be difficult to put emotions to the side when it comes to your child, it is important to retain composure and professional demeanor while communicating clearly and concisely yet firmly regarding your child's healthcare.

#### Know your "patient rights"

Whether you are seeing a pediatrician or a family physician or whether you are being seen in a doctor's office or hospital, there are defined "patient rights" which can guide your expectations and your advocacy. Pennsylvania has a "Patient Bill of Rights" which can be found by searching §5100.53. In the PA code.

The Joint Commission (JHACO), the largest healthcare accrediting body in the United States that is focused on quality and safety, has additional resources on their website through their *SpeakUp* materials (https://www.jointcommission.org/speakup), which can assist in patient advocacy.

If you feel like you or your child's pa-



tient rights have been violated, the best first step is to voice your concerns with the office manager or hospital's patient advocacy department. If you feel like your concerns are not being addressed you may need to elevate your concerns to the next level.

Advocating for your child in the medical setting means keeping your child's wellbeing at the forefront of the decisions you make for them. Ensuring that those decisions are informed decisions with all of your questions answered, all decisions based on data, and having all information available to your child's entire medical team (including you), will help in keeping your child safe and avoiding medical errors.

Above all, there is one piece of advice that I share with all the parents I work with: Trust your instincts as a parent. Don't ignore that voice from within, that gut instinct, or the "hunch"; instead, embrace it, follow it, and remember: You know your child best. Period.

Kristi Wees is the Chief Advocacy Officer at www.EmpoweredAdvocacy. com. She advocates along-side families each and every day for the best quality of life for their children.

