



## **Advice To Parents Of Living Cherubs**

*CHERUBS – The Association of Congenital Diaphragmatic Hernia Research, Advocacy and Support  
Written 1999, last updated 2007 ~ [www.cdhsupport.org](http://www.cdhsupport.org)*

### **"I Wish Someone Would Have Told Me!"**

- Don't give up your dream of breastfeeding. Unless your child has a severe allergy, there is no reason he/she can't be given your breastmilk when the time comes. Don't let a doctor or nurse talk you into using formula just because it's easier to measure and control.
- If you find you are not able to breastfeed don't worry there are a lot of other good things you can do for your baby.
- Learn how to take care of your baby from the very beginning. Help out the hospital as much as you can. You don't want to delay release just because you haven't learned everything yet.
- After your child comes home, after the phone calls and visitors stop coming so often and you're home alone with your baby, depression very often sets in. It's normal to feel alone and "strange". Don't be afraid to seek help or accept it.
- Your child's immune system isn't as strong as a healthy child's- take precautions, don't go into crowds until your child is strong, and don't be afraid to "monitor" who enters your home.
- Keep records on hand in case of an emergency.
- Notify your local ambulance service and invite them to meet your child- you may need them someday and it will save time to not have to give them your child's complete medical history.
- If your child needs any medical equipment at home, notify the Power Company so that you can be put their emergency list.
- Don't be afraid to call the doctor if you feel anything is abnormal.
- Don't be afraid to do "normal" things, such as tickling, bouncing, going to visit friends and family, taking them to see Santa (of course monitor everyone for viruses first and see Santa on "off-peak" hours).
- Ask your child's doctor about the Chicken Pox, Flu, and RSV vaccines and especially monitor young children that your child may come into contact with.
- Be aware that having a "disabled" child can cause marital problems and sibling rivalry- pay extra attention to family members and seek counseling if needed.
- Don't be afraid to fire nurses, doctors, therapists, etc. that you are not comfortable with- that is your choice, but just make sure your child receives the services that he/she needs.
- Listening to your inner instincts are important. Once we get our babies home we can tell when something is not right and need to convey that to the health care provider. It is important to have a doctor that will listen to and address your concerns. Each child is different so we need to be their advocate in their health care.
- Keep a home medical chart on your child with the dates of past appointments/hospitalizations and which hospital they were at and what was done/said. A list of all medications current and past and what they are prescribed for, a list of all doctors that he currently sees, so that when an emergency does happen whether you transport or you have paramedics transport they have that record because you are not going to remember what exactly is going on during a time of extremely high stress.
- Keep a journal.
- Build a support system of family, friends, and support groups that can listen, answer questions, offer a hand when you need it.
- Don't be afraid to ask for help!

Suggestions made by Elaine Moats, Dawn Torrence, and Denise Richer