CONGRATULATIONS!
You are an advocate for your child with special health needs!

Parenting a child with special health needs is not easy. The 40,000 members of Family Voices, most of us parents, want you to know that you’re not alone on this challenging journey. And we’ve learned that the sooner we become advocates --- informed, strong voices for our children --- the smoother life becomes. The following tips are based on years of experience from hundreds of families.

First, believe with all your heart that your child, like all children, is wonderful---even when she or he gobbles up so much of your time and energy!

As soon as possible, connect with another family who also has a child with special needs. Talking with a parent who also never sleeps, feels inadequate, and is frightened will change your life. Say hello to the parent sitting next to you at the clinic or school meeting. They’ll be your best teachers in helping you navigate this new, strange world.

Learn everything you can about your child’s diagnosis from your pediatrician, early interventionist, therapist, or other parents. Look up the diagnosis on the internet. If you lack a computer or can’t use one, ask another parent, teacher, or a teenager for help. In every community there is a place with free internet access. Find out about services for your child --- special clinics, pediatric specialists, therapies, equipment, early childhood programs, and state and private agencies. Inquire about financial eligibility, free services, and, most important, where to get the best care.

Become an expert on your child’s health insurance plan. Know the benefits covered. Read everything from your insurance company, managed care plan, or Medicaid. Learn who to call if you get confused.

Keep records of all phone calls, doctor visits, insurance bills, notices, and forms related to your child. Always take notes, including date and person you spoke with. Request copies of everything. Put this paperwork in one place, such as a box, notebook, or drawer.

Develop positive partnerships with the professionals in your child’s life. Find one professional who knows you, your family, and your child very well, and who will advocate with you as a partner.

Know that YOU are your child’s best advocate. No one else can do the job as well. Use all your information, contacts, friends and skills to advocate with kindness and humor. Teach your child to be an advocate, or prepare a sibling or friend to do so, because you won’t be around forever. And please take care of YOU, so that YOU stay healthy.

Then, help another family.

Work with other families and professionals to improve care for all children. Look to the Oregon Family to Family Health information Center or Family Voices for more information on parent leadership opportunities in your community.

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