

Finding Trustworthy Information and Support

frequently-asked questions from families of children with special health needs

What should I look for when searching the internet for information about my child's condition? Look for sites that are current, and that are not trying to sell you anything. Government, education, and nonprofit organizations are a good place to start. Web addresses ending with ".edu" come from educational institutions. Those ending in ".gov" come from the government agencies. Web addresses ending in ".org" come from nonprofit organizations.

What about blogs? Blogs can be an excellent source of information and inspiration. Reading about someone's personal experience parenting a child with special health needs can give you hope and ideas. You might even choose to share your own story this way. However, personal blogs should not be mistaken for professional medical advice.

There are organizations that want us to participate in research. Are they trustworthy? Enrolling your child in a research study is a personal decision. Some children have benefited from participating in studies. Consult with your child's doctors before participating in a study.

How do I know if support groups I find on the internet are trustworthy? Support groups can help. Members may have good information they are happy to share with you, but trust your instincts. What works for someone else is not necessarily right for your family, and vice versa. Avoid people who judge you, try to sell you something, or who push you to see things their way.

Is it safe to talk about my child in on on-line support group? Follow internet safety guidelines for your child with special needs, as you would for any child. Do not reveal his or her identity or whereabouts. Don't post anything (including videos or photos) that could embarrass your child.

Besides the internet, where else should I go for information? Other parents are likely your best source for non-medical resources. Don't be shy about introducing yourself and asking for their input. Also ask your child's health care providers, teachers, therapists, or social workers for advice and information. These professionals are paid to help, and they often have the latest information and resources.

Why is it so hard to find the help and information I need? It takes time (sometimes months, or even years) to figure out what works best for your child and family. It is frustrating, but don't despair! Over time, you will gain more confidence and knowledge and become an expert yourself.



Questions? Contact us.
We're here to help.
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