

***NAVIGATING the INTERNET and
the BENEFITS of SURFING***

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One of the many challenges that parents of children with craniofacial differences face is the lack of readily accessible information. This is especially true in respect to the various syndromes and treatments. If you are like me, you feel out of control when you lack information.

Most medical professionals do not have the time to devote to guiding parents to a better understanding of the condition that relates to their child and the treatments available. Moreover, most parents are not properly armed to ask the appropriate questions at a craniofacial team conference.

If you've gone to the public library and looked up the words: Goldenhar, hemifacial microsomia or craniosynostosis, you can appreciate the challenges and frustration looking for information by traditional research methods. Fortunately for us, the Internet helps enormously to reduce these frustrations. Whatever you are looking up, chances are you're going to find it on the World Wide Web.

Before I get into some of the websites that can help you in researching your child's condition, a few words of caution:

- Anyone can put anything on the World Wide Web. ALWAYS, ALWAYS, ALWAYS proceed with caution whenever you research anything on the Internet.
- Articles and web pages stay on the Internet *forever*. Watch out for dated material. Refine your search or you will be overwhelmed with data! For example, type in "birth defects" and you will receive hordes of data; type in "Goldenhar Syndrome" and see what happens!
- Back up anything you find on the Internet, with research at your nearest medical society library (more on that later!)

In addition to searching for information, there are a number of message and bulletin boards where you can

exchange information with other parents. A couple of words of caution with respect to these boards:

- As with websites, anyone can say or suggest anything. Be very skeptical when reading and integrating the information gleaned off these message boards.
- Everyone feels they are taking their child to the best plastic surgeon / ENT / Craniofacial team in the country. Don't undermine yourself by questioning whether or not you are seeing the best doctor based upon what you read on these boards.

Why would you want to read and participate on these bulletin boards?

First, it is worth realizing that you are not alone. Second, a topic may come up that may apply to your child that you did not give any consideration to before. For example, I wanted to know the type of diagnostic tests that should be considered for my daughter before considering a pharyngeal flap. Sometimes you find some helpful tips from parents in similar circumstances.

One night, I was reviewing the messages on Cleft-Talk. Some parents were discussing what to keep in the portable suction bag when leaving the house with a child with a tracheotomy. The ENTs that my daughter was involved with were very complete in their training and guidance concerning trach care, but this was one area that you needed a parent with similar experiences.

Before I mention some of the best websites, a word of caution. Use the Internet to gather information in order to become better informed in regard your child's medical care. Remember, anyone can put anything on the Internet. There is a good chance what you are reading is inaccurate, and needs to be discussed with your doctor.