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# About Health Care Guidelines

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## *Original Interview With William I. Cohen, M.D. on the Significance of Down Syndrome Health Care Guidelines*

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*The late William I. Cohen, M.D., specialized in developmental and behavioral pediatrics in the Child Development Unit of the Children's Hospital of Pittsburgh. He was director of the Down Syndrome Center of Western Pennsylvania and an associate professor of pediatrics and psychiatry at the University of Pittsburgh School of Medicine. Dr. Cohen also co-founded the Down Syndrome Medical Interest Group. He was involved in previous versions of these health care guidelines and was medical editor of Down Syndrome Quarterly.*

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### **WHY ARE SPECIALIZED HEALTH CARE RECOMMENDATIONS FOR INDIVIDUALS WITH DOWN SYNDROME SO IMPORTANT?**

The importance of the document is to support parents in getting the screening tests done that we believe are important to keep children and adults with Down syndrome healthy. Pediatricians may have between three and five children with Down syndrome in their practice, and although they may be knowledgeable about the current recommendations, I don't expect them to be able to keep up in the same way as parents, who really become experts about the needs of their children. And even though we write about and present these issues in a variety of forums - at scientific meetings and continuing medical-education conferences - the issue may not be as compelling for physicians as it is for parents.

Specialized guidelines help define for parents what is needed, so they can communicate with their primary-care physician and say, "This is what is recommended. This is what we need to do." It is a helpful tool for physicians, too, because it defines the medical vulnerabilities and the necessary screenings.

### **WHAT IS THE HISTORY OF THE GUIDELINES? WHY WERE THEY DEVELOPED AND HOW LONG HAVE THEY BEEN IN USE?**

The first person to begin to define the needs of individuals with Down syndrome in terms of health and screening was Dr. Mary Coleman. This goes back to the 1970s, when she began to define the medical vulnerabilities and describe what tests should be done on a regular basis. They were subsequently published in Down Syndrome Papers and Abstracts for Professionals, which was basically a newsletter. They were revised, generally, every couple of years. Dr. Nancy Roizen was editor for a number of revisions. In 1992, together with the Ohio-Western Pennsylvania Down Syndrome Network, we undertook the revision. Subsequently, the Down Syndrome Medical Interest Group, a group of health professionals, took over the editorship in 1996. It's interesting to note that you can go around the world and find that national Down syndrome organizations have very similar documents. The American Academy of Pediatrics, under the auspices of the Committee on Genetics, also issues health-supervision guidelines for Down syndrome and other genetic disorders. In 1999, a version by the Down Syndrome Medical Interest Group was coordinated with the American Academy of Pediatrics. That was a very important step.

In 2011 the American Academy of Pediatrics issued the newest version of the Down Syndrome Health Care Guidelines, which replaces all previous versions.

### **WHAT ADVICE CAN YOU GIVE TO PARENTS ABOUT SELECTING A PEDIATRICIAN AND OTHER HEALTH CARE PROFESSIONALS TO WORK WITH THEIR CHILD WHO HAS DOWN SYNDROME?**

That's a very interesting question, and it comes up very often when we see patients in the Down Syndrome Center. The notion

that many folks would have is that they need to find someone who's very knowledgeable; that it really is going to help them to have somebody who is an expert on Down syndrome. In my experience, some of the people who believe they may be experts on Down syndrome may not be current. They may be enamored of their expertise and fail to listen to parents about what may be different with their child.

A mother once came to me with a new baby and said, "My doctor is a family physician, and he said that he doesn't know anything about Down syndrome." I anticipated that she had reacted to this as if it was a problem, but she went on to say, "And so he told me that any information I could bring him would be so appreciated." He, indeed, is the kind of physician you want-one who is open to partnering with a family. The knowledge that someone has is necessary, but not sufficient. In fact, not having the knowledge is less of a problem than believing you have it.

What we need when we have a child with special health care needs is someone who will collaborate-who is open to listening to parents and seeing them as partners. We need to know how to identify someone with that style. One of the best ways to find a pediatrician is to ask families of other children with Down syndrome in the area. Going to parent support groups can be very helpful.

But I will tell you that the most effective thing is for parents to be the educator of the physician.

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## **NDSS RESOURCES**

- [Webinar: An Evening with William Cohen](#)