

CHARGE SYNDROME MANAGEMENT MANUAL FOR PARENTS

Introduction to the Developmental Sections

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Every individual with CHARGE is unique. Each has his or her own unique collection of medical problems. Each individual has his or her own personality and learning style. On top of that, each individual is in a different family setting and different medical and educational environments. We would love to be able to provide every family with a complete set of resources tailored to their needs. Obviously we cannot do that. As a consequence, every family will find different parts of this Manual helpful to them. Sometimes we have presented the same or similar information in a couple of different formats. Look it all over and choose the parts that are helpful for you. Use the loose-leaf format to reorganize, add, and delete information that is appropriate for your situation.

GET SOME TABS. There is a lot of information here. It will be much easier for you to find what you are looking for if you break the information up in to sections with tab dividers.

A note on “**DeafBlindness**.” We recognize that not all individuals with CHARGE have both hearing loss and vision loss. Nevertheless, much of the information is labeled “deafblind” or aimed mostly at that population. We did this for two reasons. First, families dealing with individuals who DO have dual sensory loss will have the most difficulty with development and communication and will have the hardest time finding appropriate resources. Second, many of these resources are just plain good resources regardless of the title.

Please don't skip a section just because it is labeled “DeafBlind” – take a look and see if it has something to offer you as well.