

# ***CHARGE Syndrome Foundation, Inc.***

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[www.chargesyndrome.org](http://www.chargesyndrome.org)



## ***Introduction to the Professional Packet***

Welcome to the world of CHARGE! As you have already determined, CHARGE syndrome is a very complex condition. Every child is different. Over the years, we have received inquiries from professionals who are, or soon will be, working with an individual with CHARGE syndrome. These professionals are looking for information about CHARGE that is helpful to them. There now exists a large body of information on CHARGE available to physicians caring for the medical issues in individuals with CHARGE syndrome. A gene for CHARGE (CHD7) was identified in 2004. If you are interested in more detailed medical information, see the comprehensive summary at [www.genetests.org](http://www.genetests.org) [choose the "CHARGE syndrome" article in the GeneReviews section]. The CHARGE Syndrome Foundation also publishes the **Management Manual for Parents**, which covers medical information and some developmental information on CHARGE which we have brought together. The Manual is available in .pdf format at the Foundation website ([www.chargesyndrome.org](http://www.chargesyndrome.org) at the "Resources" link) and in print from the Foundation. All of the articles from the American Journal of Medical Genetics special issue on CHARGE are also available through the Foundation website.

Although medical information is plentiful, we are only beginning to bring together the accumulating knowledge for educational and other specialists who work with individuals with CHARGE. This packet is an attempt to provide you with a brief introduction to CHARGE, its complexities, and some strategies to consider in educational and therapeutic settings. Start with the reprint of the article from **ASHA Leader**, which includes an overview of genetics, clinical diagnosis, ears and hearing, feeding, behavior and education. Then read David Brown's article on **Behavior** in CHARGE. Finally, move on to other sections in this packet, which include tips on how to think about the child with CHARGE and the classroom.

This is a work in progress. We know there are more resources out there that we don't know about. And there are lots of gaps in the knowledge that we are working to fill. Please send us feedback: let us know what parts of this were particularly useful, let us know what you would like to have available, let us know if you have come across other helpful materials. Send your feedback to the Foundation ([marion@chargesyndrome.org](mailto:marion@chargesyndrome.org)) or directly to me ([meg@chargesyndrome.org](mailto:meg@chargesyndrome.org)).

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