

## **HISTORY OF CHARGE SYNDROME FOUNDATION, INC. and THE MANAGEMENT MANUAL FOR PARENTS (2.1)**

The CHARGE Syndrome Foundation is incorporated in Columbia, Missouri where it has its roots. It began in 1982 with the Deaf-Blind Project in the Division of Genetics, Department of Child Health, University of Missouri, Columbia. The primary participants in the Deaf-Blind Project were Dr. Joyce Mitchell (Medical Informatics), Dr. Sandra Davenport (Genetics and Developmental Pediatrics), Dr. James Thelin (Audiology), and Meg Hefner (Genetics).

### *CHARGE Syndrome: a booklet for parents*

Although the stated aim of the Deaf-Blind Project had to do with diagnosis of CHARGE and description of the features for the benefit of geneticists and other physicians, we quickly recognized that families need information, too. Quota Club of Columbia, a local service organization for business and professional women, had a pot of money and was looking for a project to fund which had something to do with hearing loss. As a result of Jim Thelin's connection with Quota Club, Jim and Meg became the primary authors of *CHARGE Syndrome: A Booklet for Families*, with lots of input from Sandy and Joyce. Quota Club member Marion Norbury volunteered to help send out the booklets. More than 15 years later, Marion has become the Executive Director of the CHARGE Syndrome Foundation and Foundation materials have taken over her house.

In 1988 we printed the first 1,000 Booklets, figuring they would last five years or so (we thought CHARGE was rare!). The typical scenario was as follows: A family would write or call and request one booklet. A week or so later, the same family would request 5-10 booklets so they could be passed out to relatives, doctors, teachers, and others who worked with their child. The booklets were gone in a year, and went through several more printings in the following years. Until the Manual became available, the *Booklet for Families* was the best initial source of information on CHARGE available to families.

After publication and distribution of the booklet, we began to get calls and letters from families asking things like, "Are there any other children with CHARGE in New Jersey?" "Does anyone else have a baby with feeding problems?" "Is my child's heart defect a typical one for CHARGE?" and so on. It was clear we needed a way for families to get more information and to share their information and stories with one another as well as with us.

### *CHARGE Accounts* newsletter

In 1989, Marion, Sandra and Meg published the first edition of the newsletter - *CHARGE Accounts*. The first few years were a bit shaky with issues not always coming out on time, but it was a success with families. Marion has taken primary charge of the newsletter, with editorial assistance from Meg. It is now published four times a year and distributed to all members of the CHARGE Syndrome Foundation.

### International CHARGE Syndrome Conferences

In 1993, we incorporated as the CHARGE Syndrome Foundation, Inc. and held our first International CHARGE Syndrome Conference in St. Louis, Missouri. It was attended by over 250 people, including about 50 children with CHARGE. We continue holding CHARGE conferences every two years with rotating geographic locations.

As of 2001, conferences have been held in St. Louis, Portland (Oregon), Boston, Houston, and Indianapolis. Foundation membership is over 400 and we receive anywhere from 10-20 requests for information every week - by snail mail, e-mail and phone. Our quarterly newsletter *CHARGE Accounts* goes to more than a dozen countries besides the United States. A toll-free number (800-442-7604) and website ([www.chargesyndrome.org](http://www.chargesyndrome.org)) make it easy for families to contact the Foundation for information and support.

#### CHARGE Syndrome Foundation, Inc

The CHARGE Syndrome Foundation has a 12-member elected Board of Directors (primarily parents) who are responsible for publicizing CHARGE, developing additional materials for families and professionals, raising money for conferences and research, planning the conferences and determining the direction of the Foundation. The CHARGE Foundation Professional Advisory Board is made up of more than 30 professionals including a variety of medical and educational specialists, all with a specific interest in people with CHARGE and their families.

#### The Original Team

Although the original team has dispersed geographically, (Marion is still in Columbia, Missouri; Meg is in St. Louis; Jim is in Knoxville, Tennessee; and Sandra is in Bloomington, Minnesota), we remain interested and active in CHARGE (thanks in no small part to e-mail).

#### Listserv on the Internet

In 1997, Casey Fisher established a listserv for CHARGE. Since then, a very active group of families, friends and professionals have been sharing their problems, support and knowledge over the Internet through the listserv (see the CHARGE website for a link). Although not an official part of the Foundation, the list is recognized as one of the most important aspects of our being able to communicate with one another and support each other.

#### The Management Manual

Although the Booklet was really good information in 1988, it quickly became obsolete. Through the conferences, we learned more and more about CHARGE - the features involved, the complexity of the kids, the need of the families to learn as much as possible about CHARGE syndrome. At the Portland conference in 1995, we gathered information on about 50 children and young adults with CHARGE. This information was assimilated with the collective knowledge of the Professional Advisory Board and published in the *Journal of Pediatrics* in 1998. This information and lots more was then assembled and edited into version 1.0 (Medical Aspects of CHARGE) of the Manual, published in 1999. Families said that was great, but what about other aspects of CHARGE such as development, education and behavior? By 2001, we had assembled version 2.0, incorporating a tremendous amount of information about those aspects of CHARGE. We know we are not finished - this is a never-ending project. That's part of why it is in a binder format. Future updates to the Manual will appear in *CHARGE Accounts*. We welcome any feedback you have, as well as suggestions for future updates/additions to the Manual.