

HISTORY OF CHARGE SYNDROME FOUNDATION, INC. AND THE MANAGEMENT MANUAL FOR PARENTS

The CHARGE Syndrome Foundation was founded 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), Dr. James Thelin (Audiology), and Meg Hefner (Genetics).

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 all quickly recognized that families need information, too. Audiologist Dr. James Thelin was at the time working with the Quota Club of Columbia, a local service organization for business and professional women. Quota Club had a pot of money and was looking for a project to fund that had something to do with hearing loss. As a result, 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.

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 several more printings followed.

After publication and distribution of the booklet, we began to get calls and letters from families asking: “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. Until 1999, when the Management Manual was first published, the *Booklet for Families* remained the best initial source of information on CHARGE available to families.

In 1989, Marion, Sandy, and Meg published the first edition of the newsletter: *CHARGEAccounts*. The first few years were a bit shaky, with issues not always coming out on time, but it was a success with families.

In 1993, we incorporated as the CHARGE Syndrome Foundation, Inc. and held our first International CHARGE Syndrome Conference in St. Louis, Missouri. We continue to hold CHARGE conferences every two years, with rotating geographic locations. The Foundation now has a 12-member Board of Directors and a Scientific Advisory Board made up of both medical and research professionals.

As we were completing the Management Manual in 2001 we were also preparing for our 5th International CHARGE Syndrome Conference in Indianapolis, Indiana. Previous conferences were held in St. Louis, Portland, Boston, and Houston. Since Indianapolis we have held conferences in Cleveland, Miami, Costa Mesa (CA), Chicago, Orlando, and

Phoenix. We will be returning to Orlando for our 13th International CHARGE Syndrome Conference, in July 2017.

CHARGEAccounts now goes electronically to more than a dozen countries in addition to the United States. Our website makes it easy for families to access information (<http://www.chargesyndrome.org>) and our toll free number (800-442-7604) and email (info@chargesyndrome.org) give families the option to contact us.

In 1997 an active group of families, friends, and professionals began sharing their problems, support, and knowledge over the Internet through an e-mail listserv managed by one of our parents. In 2011, a CHARGE Syndrome Foundation [Facebook group](#) was created, which now has over 5,000 members from all over the world and has become the primary means for parents to connect with one another.

Version 1.0 (Medical Information on CHARGE) of the Manual was available for the first time at the Houston conference in 1999. Version 2.0 (with Developmental and Educational information) was first available at the Indianapolis conference in 2001. All of the basic information about features seen in CHARGE is accurate, but some of the management and treatment information may be out of date.



CHARGE Syndrome Foundation Founders Marion Norbury, Jim Thelin, and Sandra Davenport (L) and Meg Hefner, Marion Norbury, and Sandra Davenport (R) at the Portland conference in 1995.