

Welcome to Version 2.1 of the

CHARGE Syndrome Management Manual for Parents

Meg Hefner, M.S.
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Welcome to version 2.1 of the CHARGE Syndrome Management Manual for Parents. Version 1.0 of the Manual (1999) included the *Medical* issues of CHARGE syndrome. These sections (see the Introduction to the Medical Section) should help you and the people working with your child to better understand the medical implications of a diagnosis of CHARGE.

Version 2.0 (2001) added information on the *Developmental* and *Educational* implications of CHARGE syndrome. It was not possible to include even all of the good information we have come across in this version.

Version 2.1 (2002) compiles versions 1.0 and 2.0 into a single format and updates the contact information for the contributors. Additions and updates to the Manual will be done periodically. Updates and additions may be distributed through the CHARGE Syndrome Foundation newsletter, *CHARGE Accounts*, (hint, hint – join the Foundation and get the newsletter). To be sure you get word of all of the updates:

- 1) **Resister your Manual** by mailing or faxing the completed registration page to:
CHARGE Syndrome Foundation, Inc.
409 Vandiver Dr Ste 5-104
Columbia, MO 65202-1563

Fax (573)499-4694
- 2) **Join** the Foundation (membership application can be found behind the registration page or at www.chargesyndrome.org) and receive the newsletter, *CHARGE Accounts*.

How to compile your Manual:

Get a large (2" or greater), sturdy **3-ring binder** to house the Manual. The pages are hole-punched to fit a binder.

Get several sets of 3-ring **dividers with tabs** to divide the sections (Intro, Stories, Medical, Developmental, Glossary, Resources) and sub-sections. Dividers with a pocket can be helpful to keep track of loose papers. All pages are dated.

Many families find it helpful to keep their own medical records in the appropriate section of the Manual



Meg Hefner, Marion Norbury, and Sandra Davenport at Portland Conference, 1995



Marion Norbury, Jim Thelin and Sandra Davenport at Portland Conference, 1995