

MEDICAL VISIT PAD / RECORD KEEPING

The typical child with CHARGE is followed by an average of 17 different medical specialists and will have more than 20 surgical procedures before he or she is 10 years old. Although the ideal would be to have a Patient Care Coordinator for your child, in reality it is the parents (most often the mother) who take on this role. Organized record keeping will help keep track of what is going on, aid in coordination of appointments, and facilitate communication among all concerned (parents, physicians, and other specialists).

Organization of Medical Records is an important skill for you to learn, if you haven't already. To help with this, we have designed a Medical Visit sheet. Your Manual includes a separate pad containing about 50 of these sheets. Take a moment to look this over. The purpose of the visit pad is to help you keep track of office visits. An example of a completed sheet follows this description.

The top of each sheet has a place for your child's name and date of birth. The date of the appointment, name of the doctor being seen and his or her specialty should be completed, as well as where (name of hospital or clinic) the visit took place. Before each appointment, think about what you hope to get out of it. Jot down any questions you have on the upper section. During the visit, be sure your questions are addressed.

Keep the pad with you during your visit and make notes about what you are told. You may want to ask the doctor to write a short summary on the sheet for you. If any tests are done at the visit, make a note of them and when you should expect to hear any results or findings from the tests. Be sure write down your next appointment and any referrals made by this doctor.

The sheets have holes punched in them so you can keep them in a three-ring binder. You may want to keep your child's records/notes in your Manual or establish a separate binder for records. You may decide to keep all records in chronological order, or establish separate sections for each specialist (see also the Minnesota Developmental Timeline in Development section).

Some parents have found it helpful to keep a master list where they list every visit (and every hospitalization or procedure) in chronological order. You will be amazed at the number of appointments and the variety of specialists you and your child see. Keeping such a list can also help coordinate appointments and even medical procedures. For example, if your child needs an other set of PE tubes in her ears, the ophthalmologist may want to take advantage of her being under anesthesia to get a better look at her retina at the same time. This will take advantage of one general anesthesia to perform multiple tasks.

CHARGE Syndrome Medical Visit**Child****Birth Date**

Date of Visit:	Next Visit:	Time:
Specialist:	Referral to:	
Specialty:	Date/Time:	
Place:	Place:	
Our questions: what we would like to discuss at this visit:		
Information discussed at this visit:		

_____ APPOINTMENTS from ____/____/____ to ____/____/____

Date	MD	Specialty	What was done	RTC

*Return To Clinic, e.g. 3 mo, 6 mo, 1 yr