



CHARGE Syndrome?

Give us a hint

The Honda Foundation are generously funding the production of a new booklet on CHARGE syndrome.

The emphasis is on 'booklet' not 'manual' and it aims to be a practical guide on CHARGE syndrome for individuals, families and professionals. It will contain up-to-date, concise information covering a range of topics from birth to adulthood. But the most important information in this booklet will be contributed by those who are living the experience every day — individuals and families of individuals who have CHARGE syndrome. But we need your help.

We want the hints, tips, ideas and strategies which worked for you—and even those which didn't—from the experiences you have had in managing and living with CHARGE syndrome. Your contribution can be about anything—a hint on dealing with all the medical intervention or therapy; a tip on inclusion or transition; an idea for gastrostomies or hearing aids; a strategy for behaviour management or for supporting the siblings.

It's a good idea if therapists throw away their textbooks, because the developmental stages of children with CHARGE do not follow the 'norm'.

Parent

Once I realised that children with CHARGE syndrome need both a visual and auditory language, it really changed the way I advised parents. I don't pussyfoot around anymore, presenting both languages from as early as possible is the way I think it has to be.

Professional

So, give us a hint. Please send your contribution
and a good quality photograph, to
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