

# Editorial

## Parents of Children with Down Syndrome

When a child is born with Down syndrome (DS), parents are swept up in a cascade of reactions, mainly because they focus on DS as a permanent intellectual disability and fear the consequences. Fortunately, public and private institutions now exist that can help them understand, as experience has shown, that «children with DS are likely to grow into pleasant children, no harder to manage and posing no greater behavioral challenges than the rest.» Indeed, with suitable care, people with DS achieve heights of development and independence that would have been unthinkable a few years ago. This message is profusely addressed and taken up with parents, who can then face their task with expectations they hadn't dreamed of at first.

However, once the worries and concerns of the neonatal period are over, parental information about the physical traits and health issues of children with DS is usually inadequate and biased. They are often unaware of the dysmorphic traits caused by the syndrome, nor their prevalence rates and significance. They often persist in the belief that their child will be inexorably exposed to a ceaseless string of disorders that will challenge their development and diseases that will require sophisticated treatments. Currently, the widespread availability of media sources contributes all too often to the spread of myths and beliefs that distort the more accurate picture drawn by present scientific knowledge. While professional journals address these matters very well, parents seldom receive understandable, accurate information written specifically for them.

Aware of these facts, on the occasion of the 21st anniversary of its Down Medical Center (CMD), Fundació Catalana Síndrome de Down (FCSD) has just

published a book for parents, «*Su hijo con síndrome de Down*». De la A a la Z («Your Child With Down Syndrome, from A to Z»). It is intended to provide adequate overall medical information about the health issues of children with DS, undistorted by misguided advice or deliberate misinformation. The first part of this book covers the basic genetic aspects of DS and their practical implications. Part 2, which is longer, describes the manifestations, disorders and diseases that are most likely to occur in children with DS, along with their main screening and diagnostic procedures. The topics, concisely worded and clearly written, are listed in alphabetical order for easy location. Each topic is a brief chapter including a definition, clinical expressions, potential signs alerting to deterioration, and lastly some guidance for prevention and treatment. The third part of the book is an appendix with two of the chief instruments developed and extensively used at the CMD to monitor health in children and teenagers with DS: its Health Program and the DS-specific growth charts for Spain.

This book is largely the work of CMD specialists, in charge of periodically updating the Health Program. Other contributors include prominent pediatric specialists at public and private hospitals in Catalonia and other Catalan-speaking areas, as well as hospital pediatricians from Quito (Ecuador) with whom the Foundation has an ongoing and highly fruitful relationship.

It will mean a lot to the FCSD if this book achieves its intended goal: to help parents grasp the true dimension of DS-related pediatric medical issues, which are not all that different from those faced by all other children.

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