Editorial

Twenty-One: A Key Figure For Down Syndrome

It is almost 50 years since the discovery that the origin of Down syndrome (DS) is the presence of three copies of chromosome 21 instead of a pair. Today, however, we are not referring to chromosome 21 or to World Down Syndrome Day, which is March 21st – or even to the fact that the problems linked to this syndrome will probably be solved in the twenty-first century. On this occasion, the number 21 is something far simpler, far closer to home. This November issue completes the twenty-first year of uninterrupted publication of the present journal, devised by the Fundació Catalana Síndrome de Down (FCSD) from the very start to serve people with Down syndrome, their families, and other people linked to them.

The past 21 years have seen many changes in our society – both social and technological. Our lives and those of people with DS have been transformed in many ways, and this journal has been no exception. It was over two decades ago that the FCSD took on yet another landmark project for people with DS. The very first issue was published in November 1986 under a masthead that read, «*Síndrome de Down: Articles i Resums Científics*» (Down Syndrome: Science Articles and Synopses/Abstracts). And the very first editorial reminded us that «The scientific study of Down syndrome is generating a constant and growing flow of information that calls for appropriate resources to make it available to all those for whom it is potentially of interest.» Ten years later, that journal took on its present identity: *SD-DS International Medical Journal on Down Syndrome*, with updated objectives.

Considering the needs of people with DS, from the outset the FCSD bravely undertook to cover and disseminate medical information. First, it founded the journal, and then it set up the Down Medical Center (CMD), just 20 years ago, to specialize in medical care for children and adults with DS. The aim of both was to encourage preventive health care for the issues that can arise as a result of this genetic anomaly. Since physicians were the main target audience, the journal laid out clearly from the very start that DS is not a disease, but that people with it tend to develop other conditions independent of the associated congenital malformations, all of which require treatment.

The CMD outlined three basic areas of work.

First, health issues needed to be addressed, so health care was a priority. Over the years we have managed to develop a unique model of specialized health care for DS.

Second, medical knowledge had to be disseminated among parents, professionals, and society at large. This is where the four-monthly publication of SD-DS fits in – a journal published both digitally and in print in Catalan, Spanish, and English, with the ensuing international projection. Eleven years into its second phase, the journal currently focuses on international interdisciplinary research with innovative content, including research undertaken by the CMD itself and other research teams in our community. To commemorate the twentieth anniversary of the CMD, the present issue includes abstracts of all the scientific papers presented at the 9th International Symposium on Down Syndrome under the heading «Into Old Age: Challenges and Hopes», a conference held for parents and professionals with many guest speakers of world renown such as Professor Pueschel and Jan Nisbet.

The third aim of the CMD is to encourage medical research. This journal has published many research papers, including the ones that have earned the Ramon Trias Fargas biennial award organized by the FCSD, and other high-profile projects.

The FCSD has a well-earned reputation in biomedical and health care research for people with Down syndrome. CMD staff are acknowledged both for their work and for their publications, and projects are often undertaken together with other institutions and universities in this country.

While we are unable to list all of the contributions made by the journal, we would like to highlight the difference it has made for over twenty years, together with the CMD, for people with DS. Quality of life and health standards have been attained that would have been unthinkable in the not too distant past. Our better knowledge of the pathogenesis of the health issues involved means that effective early treatment interventions can be put into place. Parents now display higher hopes for the future of their children with DS. Ultimately, society itself is gradually coming to embrace people with DS as citizens enjoying full rights. All this is thanks to many years of work by professionals such as the staff at the FCSD and the CMD, as well as others who regularly contribute to these pages. Nevertheless, the road ahead for the twenty-first century remains long.

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