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EDITORIAL

The origins of the Fundació Catalana Síndrome de Down

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On the 30th of March 1984, a group of parents and professionals met to sign the constitution of the Catalan Down's Syndrome Foundation (*Fundació Catalana Síndrome de Down* [FCSD]).

At that time there were Associations dedicated to individuals with disabilities in general, but with very little information about Down's syndrome (DS). In several countries there was already evidence that showed the need to specialise in this syndrome due to, in many cases, its homogeneous characteristics. The aim was the study, social and medical investigation, and care of individuals with DS and their families. We were immediately ready to listen and adapt to the advice of internationally recognised professionals from countries like Canada, the United States, or the United Kingdom.

One of the most significant projects that influenced the starting of the Foundation was the opening, in 1974, of the Child Development and Mental Retardation Centre - Experimental Unit, of the University of Washington, in Seattle (USA), dedicated to the development of young children with DS. The director, Dr. Valentine Dmitriev, along with Dr. Pat Olwein, gave five seminars from 1978 to 1983 in Barcelona for professionals and parents. With its official recognition, the Foundation was able to become a replica of that centre. Very soon, the Foundation was open to individuals with other intellectual disabilities, growing and creating services depending on the needs of the users and their families.

Another major boost was the passing of the LISMI (Law on the Social Integration of the Disabled) in 1982, promoted by the member of the *Cortes Generales* (Spanish Legislature) and co-founder of the Catalan Down's Syndrome Foundation, Ramón Trias Fargas. This Law provided a legal framework that the Foundation adopted as its mission: to respect the dignity of individuals with a disability, promoting their development and integration into society. With this Law, individuals with a disability changed from being objects to subjects with full rights and obligations, like the rest of the population.

Following this mission, and within the framework of the new scenario, the Early Stimulation Service was created on the 30 March 1984, which very soon became to be called the Early Care Service (SAP, by its initials in Catalan). A group of specialists began to assess and attend to, in a coordinated manner, the needs that arose from the development of children with neuro-psychological disabilities from birth to 6 years old.

But the fulfilling of these expectations would not be possible without enjoying a good state of health, challenged, particularly in DS, by the frequent structural defects and by the tendency to acquire diseases of a worrying course. The need for their prevention and early detection led, in 1985, to the introduction of a specific Health Program for individuals of all age groups with DS, inspired by the Down Syndrome Checklist established in the United States by M. Coleman and P.T. Rogers. The constant diagnostic and therapeutic advances that were continually being made led to, two years later, on 24 July 1987, a pioneering challenge in Spain: the Down's Medical Centre (CMD), by signing an agreement with the Catalan Department of Health and Social Security and the ONCE (National Organisation of Blind Persons in Spain). The Centre was equipped with a multidisciplinary team of medical specialists, particularly attending to children. These children were growing up at the beginning of the new millennium, and required a significant increase in the areas destined for adult care. The CMD always had the support of the Catalan Department of Health, and is currently coordinated into the integral public health system of the Community (SISCAT). It includes 19 medical specialties that cover from paediatrics to geriatrics, and have already attended to more than 2300 individuals from Catalonia and the rest of the Spanish Autonomous Communities.

At international level, since 1993, the CMD forms part of DSMIG (Down Syndrome Medical Interest Group), promoted by Bill Cohen in the United States, and has a close relationship with NDSS (National Down Syndrome Society) of New

York. In Europe, it is co-founder of EDSA (European Down Syndrome Association).

The Foundation, conscious of its bridging role between individuals with an intellectual disability and society, has been creating new services and programmes aimed at achieving good integration in social and work environments, a future with the most freedom possible, or at least a future in which their decisions are of prime importance. These services include school follow-up, adult training, the

introduction of leisure and free time spaces, the incorporation into work and an independent life, as well as therapeutic and family care until old age.

The Foundation has carried out numerous activities on personal care during the last 30 years, running courses, research and publications. And it hopes to increase and improve these, in order to support individuals with DS or with other disabilities who wish to take advantage of our services.