



# INTERNATIONAL MEDICAL REVIEW ON DOWN'S SYNDROME

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## EDITORIAL

### Thirtieth anniversary of the Medical Centre of ‘‘Fundació Catalana Síndrome de Down’’

### Treinta años del Centro Médico de la Fundación Catalana Síndrome de Down

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Available online 22 September 2017

Centro Médico Down, which celebrates its 30th anniversary this year, is the result of the indignation and rebellion that Montserrat Trueta felt, more than three decades ago, as a result of the indifference, if not contempt, with which society at large, including the medical profession, were treating people with Down syndrome, particularly children. All involved were devoted to promoting the development and reintegration of these people, with the empathy and support of Catalan regional public health institutions. The year 1984 saw the creation of the Catalan Down Syndrome Foundation, under the so-called LISMI Social Integration of the Disabled Law (*Ley de Integración Social del Minusválido*), promoted by Montserrat's husband, Ramón Trias Fargas, and inspired by the innovative *Child Development and Mental Retardation Center, Experimental Unit* within the University of Washington, Seattle (USA).

There, he started up the first Early Stimulation Programme in Spain for people with Down syndrome. It was the right moment to give these people visibility, and free them from their ancestral marginalisation, always dependent upon family support.

Shortly afterwards, aware that good health—so often at risk in people with this syndrome—was fundamental for patients to achieve the best possible psychosocial development, he encouraged a group of outstanding professionals from the Barcelona university area to become involved. This was also a first: a specific health programme for those affected by Down syndrome, with no age limits, aimed at

preventing or promptly treating any associated comorbidity that might threaten them. Three years after this premonitory decision, in 1987, this pioneering and still practically unique institution was set up: the Down Medical Centre (CMD in its Spanish acronym), an integrative organisation run by a multidisciplinary medical team, capable of meeting the challenges entailed in providing assistance for sufferers, and with all possible guarantees, and as well as this; research and publicity.

Over these 30 years, the Centre has been working uninterruptedly. The children, their greatest beneficiaries, have gradually grown up, and the progress made in the medicine and surgery within their reach has been providing them with a progressive improvement in their hopes and their quality of life. In addition to this, new specialists have come on board to meet their needs.

An extensive database was developed, currently containing almost 3000 clinical records, and becoming a fundamental tool to reach a consensus on the assistance required and provide a basis for biomedical research work. The development of these foundational objectives has made the Centre a benchmark in its field, not limited to Catalonia but much further beyond, with a far-reaching presence in Latin American countries.

This was further strengthened by its links with prestigious and specialised European and North American institutions, and consolidated through numerous additional activities. These include: organising periodical national and international conferences, and participation in others; training national and foreign scholarship holders; publication and broad circulation of the only existing monographic medical

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<https://doi.org/10.1016/j.sdeng.2017.07.002>

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journal on Down syndrome, with versions in Catalan, Spanish and English. In addition are updates and guides published for professionals and parents; drafting and publishing research projects. This includes the design of essential instruments for monitoring cases, such as the growth charts on Spanish children with Down syndrome, and an adapted schedule of systematic vaccinations. Both of these have been adopted by numerous public and private institutions. Also noteworthy is the compilation of studies and recommendations on specific chapters of paediatric medical papers on vaccinology and preventive medicine, as well as historiographic works, such as the recent book by the Catalan Society of Paediatricians, commemorating its 90 years of history. All this comes with the knock-on effect of prizes and public, national and international awards, both for the Medical Centre and the Foundation.

If this was the original work proposed, the changes that have taken place in recent times have highlighted aspects that were difficult to predict at the outset. In this direction, the Centre's latest plans are its definitive coordination with the Catalanian Comprehensive Healthcare System for Public Use; the strengthening of links with tertiary hospitals, such as Sant Joan de Déu and Sant Pau, through selective agreements; and the creation of the necessary structures to detect, research into and address newly emerging aspects of the syndrome. These include potential psychopathologies in children and adolescents, or, in adults, early propensity towards cognitive disorders. Moreover, the Centre faces these new challenges with their ever-present determination and enthusiasm.