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NEWS FROM EDSA MEMBERS

THE DOWN SYNDROME ASSOCIATION OF THE BALEARIC ISLANDS IN SPAIN (ASNIMO) CELEBRATES 40 YEARS (1976-2016)

1. INTRODUCTION

The Down Syndrome Association of the Balearic Islands - ASNIMO was founded in Palma de Mallorca on 20 November 1976, as a non-profit organisation engaged in the care of people with Down Syndrome (D.S.) in the Balearic Islands. It was the first association for Down Syndrome set up in Spain. This year, 2016, therefore, it is celebrating its 40th anniversary.

ASNIMO today provides assistance, through its different services to 460 people with Down Syndrome in the Balearic Islands (including Menorca, Ibiza and Formentera). It is the owner of the Centro Princesa de Asturias in Marratxí, a centre declared as being of preferential social interest (Royal Decree 3260/78. BOE (Official State Gazette) 29 January 79). It has a workforce of 56 professional staff in addition to other collaborating specialists. The Parents' Association (ASPNIMO) is a very active association constantly launching initiatives for assisted individuals and for their families.

Moreover, the Balearic Islands' Down Syndrome Foundation (FSDIB) guides the families and works on the study, planning and execution of actions oriented towards improving quality of life of people with Down Syndrome and to plan for their future in the event of the death of their parents.

ASNIMO collaborates with the Regional Administration through different types of agreements in the provision of specialised services to people with Down Syndrome in the Balearic Islands and voluntarily and annually undergoes an official Accounts audit. The people with Down Syndrome receiving services provided by ASNIMO today represent 85% of the Down Syndrome population of the Balearic Islands.

2. SUPPORT FOR THE DOWN SYNDROME ASSOCIATIONS MOVEMENT

ASNIMO was founded in 1976 and from the start it understood that not all people with intellectual disability could be encompassed by a single group and that it was necessary to consider providing



specialised attention for people with Down Syndrome. For that reason it set up Spain's first ever specific association for Down Syndrome in Mallorca; and from there it worked intensely towards the creation of associations in all the provincial capitals of Spain, and towards the constitution (in 1991) of the Spanish Federation of Institutions for Down Syndrome (today DOWN ESPAÑA) of which it was a promoting and founding member. Today this Federation, of which Dr Juan Perera was President for eight years, is present in all of Spain's Autonomous Communities and represents 83 member associations.

ASNIMO was also a founding member of the European Down Syndrome Association (EDSA) a federation which today is based in Rome. It groups together Down Syndrome associations from 38 countries and the Director of ASNIMO was also its president for eight years. EDSA is a full member of the EUROPEAN DISABILITY FORUM (EDF).



ASNIMO was also a founding member of the worldwide federation Down Syndrome International. (D.S.I) based in London, and has been an active and committed member, its work including organising in Madrid, in October 1997, the 6th World Down Syndrome Congress. This event

brought together for the first time 2,300 congress attendees from 68 countries along with 28 top Down Syndrome specialists from around the world.

3. ASNIMO'S WORK IN THE AREAS OF RESEARCH, TEACHING AND PUBLICATIONS

Singling out, studying and describing the specific aspects of Down Syndrome is the work that ASNIMO's technical team has been carrying out for the last 40 years, in collaboration with scientists from Universities worldwide. This work has been core theme of the most recent world congresses on Down Syndrome, held in Orlando (1994), Madrid (1997), Sydney (2000), Singapore (2003), Vancouver (2006), Dublin (2009), Cape Town (2012), and Chennai (2015).

All these scientific studies have been published in numerous articles in specialised magazines and some of the publications listed later in this document.

ASNIMO has also been concerned with bringing together, over the course of these years, the top worldwide specialists in Down Syndrome, to debate and analyse in depth the "specificity aspects". The result of this collaboration has been the training of numerous professionals (psychologists, doctors, educational psychologists, speech therapists, etc.), who, in the Balearic Islands and other points of Spain and Latin America, provide specialised care for people with Down Syndrome.

4. ASNIMO'S IMMEDIATE FUTURE PLANS

The expansion of the ASNIMO facilities (the current facilities have reached saturation point) through construction of a new building on a plot assigned by Palma City Council.

WORLD DOWN SYNDROME DAY 2016



Each year Down Syndrome International selects a theme for WDS Day which can be used by others.

In 2016 the theme is **“My Friends, My Community” – The benefits of inclusive environments for today’s children and tomorrow’s adults”**.

Monday 21 March 2016 marked the 11th anniversary of World Down Syndrome Day. Each year the voice of people with Down syndrome, and those who live and work with them, grows louder.



WHAT about DSI?

GLOBAL VIDEO 2016

Every year, on the occasion of WDS Day, Down Syndrome International presents a Global Video Event, which consists of a series of video clips based on a theme highlighting the need for inclusion in society, featuring people with Down syndrome. The video clips are sent by groups and organisations from many countries around the world. We edit them together and release them by 21st of March.

This year, Down Syndrome International has presented **#MyFriendsMyCommunity**, interviews with children from around the world, talking about their lives, friendships and aspirations.

View the Global video, on YouTube: <https://www.youtube.com/watch?v=B1m2pwqmN5I>

WDS Conference

The World Down Syndrome Conference is an international conference held at United Nations Headquarters on – or, however, as close as possible- to the World Down Syndrome Day. It is organised by Down Syndrome International and sponsored by Permanent Missions of UN Member States, international agencies and non-governmental organisations. The Conference is focused each year on a specific theme, which broadly aims to advance human rights of persons with Down syndrome and disabilities, using the UN Convention on the Rights of Persons with Disabilities (UN CRPD) and other human rights instruments. Speakers comprise a wide cross section from countries around the world and include professionals, advocates and self-advocates.

See more: <https://worlddownsyndromeday.org/wdsd-conference>

In the previous 21 days before the World Down Syndrome Day, EDSA presented short stories about inclusion from different European countries. EDSA members have sent contributions with an example from their respective countries.

See all the 21 stories:

<https://worlddownsyndromeday.org/myfriendsmycommunity>

<http://www.edsa.eu/category/world-down-syndrome-day/>

THE BOOK(S) OF THE MONTH

TWO BOOKS, TWO FATHERS!

Fabien Toulmé – Ce n'est pas toi que j'attendais" and *Gusti Rosemffet - Mallko y Papà*"

Two books, two fathers both expert designers, who express through their art the reaction experienced at the birth of their newborn children with Down Syndrome.

The title of the book by Fabien Toulmé

"Ce n'est pas toi que j'attendais" expresses with total sincerity and crudeness, his anguish, fear and disappointment at the announcement of the birth of a baby girl who immediately appeared to him "different", with the unmistakable features of Down Syndrome. He could not even take up the child in his arms and, when the diagnosis confirmed his fears, Toulmé deeply feels that he will never be able to accept and love this child. Throughout the book, we follow the vicissitudes of life and the together growth of father and child until with mutual knowledge the moment arrives when paternal feelings turn from disappointment, rejection and fear to full acceptance and unconditional love; a love which is equal and even more intense than that for his other child.



Gusti Rosemffet is a famous artist, who won several international awards for his work as an illustrator of children's books.

In his book he uses various graphical techniques associated to a simple and straightforward prose to express the path that he himself followed, starting from non-acceptance at the time of birth and arriving at the full acceptance of this child "different". Gusti, at the beginning feels his soul like an impregnable fortress, with no possibility of letting in this newcomer; yet the "Mallko army" with his strength of

child invades and conquers “the fortress” with grace and innocent charm.

Drawing after drawing we follow the process through which Mallko and his dad build a bond which becomes unconditional love relationship. With the birth of Mallko, Gusti discovers that his life has acquired a new and more interesting scale of values, which will never change back. The secret, he says, is that you have to accept diversity without resistance but simply giving love.

The style of the two stories, very close to a “graphic novel”, is a modern and pleasant reading. In the hope of the two authors, these books may represent a suitable reading for adults and children and help people to follow the same path experienced by Toulmé and Gusti towards acceptance of “diversity”.

Toulmé, F. (2014) – *Ce n’est pas toi que j’attendais*- Editions Delcourt
Rosemffet G. (2014) – *Mallko y Papà* – Oceano Travesia

MAKE THIS NEWSLETTER REALLY YOURS!

Have you got any news that we could publish in EDSA newsletter?
Please send us any information you would like to announce and we shall be happy to disseminate it all over Europe!

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