

## **DOWN ESPAÑA's profile**

Internet: [ww.sindromedown.net](http://ww.sindromedown.net)

Founded: 1991

Present Director: Agustín Matía. (President; Fabián Cámara). There are 10 persons on the Board of Directors.

Members: There are 83 Spanish Down syndrome associations integrated in DOWN ESPAÑA.

Finances: Government financial support, private company's financial support, donations, membership fees.

### **Main Goals**

Our mission is to guarantee the excellence of the attention for persons with Down syndrome by means of:

- the impulse to scientific research
- the promotion of the normalization, integration, inclusion and personal autonomy for persons with Down syndrome
- the defense and promotion of the rights of persons with Down syndrome
- the participation and teamwork of our associations

### **Services**

- Early intervention programs
- Health programs
- School integration programs
- Job integration service
- Leisure programs
- Seminars, courses
- Down syndrome Documentation Centre
- Information to new parents
- Training for professionals, families and persons with Down syndrome
- Researches sobre salud y calidad de vida

### **Publications**

DOWN ESPAÑA. I Programa Español de Salud para Personas con Síndrome de Down

DOWN ESPAÑA. II Programa Español de Salud para Personas con Síndrome de Down

DOWN ESPAÑA. Guía de la Convención de Derechos de Personas con Discapacidad vista por sus Protagonistas

DOWN ESPAÑA. DM-ID Manual de Diagnóstico - Discapacidad Intelectual

DOWN ESPAÑA. Evaluación, diagnóstico, tratamiento y servicios de apoyo para personas con discapacidad intelectual y problemas de conducta

DOWN ESPAÑA. Problemas de Conducta en adultos con discapacidad intelectual. Directrices internacionales para el uso de medicamentos.

DOWN ESPAÑA. Guía de Empleo con Apoyo para Familias con Hijos Trabajadores

DOWN ESPAÑA. ¡Estoy en plena forma! Guía para padres y profesionales

DOWN ESPAÑA. Primera Noticia para nuevos padres

DOWN ESPAÑA. Manual de Habilidades Sociales para profesores

DOWN ESPAÑA. Manual de Habilidades Sociales para familias

DOWN ESPAÑA. Manual de Atención Temprana

DOWN ESPAÑA . Guía para padres y madres

DOWN ESPAÑA. El libro del bebé  
DOWN ESPAÑA. El preparador laboral  
DOWN ESPAÑA. 12 claves para la autonomía de las personas con síndrome de Down  
DOWN ESPAÑA. Programa de Formación para Mediadores en Musicoterapia y Discapacidad  
DOWN ESPAÑA. Nuevas tecnologías y aprendizaje matemático en Niños con Síndrome de Down  
DOWN ESPAÑA. Padres que acogen

## **Awareness campaign**

DOWN ESPAÑA has organized the World Down Syndrome Day since 2008. In 2008 and 2009 we organized an event for almost 2000 people to raise awareness on Down syndrome where persons with Down syndrome had the starring role. We invited politicians, non-profit sector and civil society representatives, social activists, persons with Down syndrome, their associations, friends and families.

In 2009 we focused our efforts in a television campaign add “It could be your life, but it’s mine” where we showed that the life of a person with Down syndrome is just the same as the life of a person without this disability. It was shown in 23 spanish television channels more than 2000 times.

We are planning a new campaign for next year to help us raise awareness on Down syndrome

## **Projects and campaigns**

In 2007 we commercialized the first doll with the aspect of a baby with Down syndrome. We obtained a big impact in society and in the media. [www.babydown.es](http://www.babydown.es)

In 2007 we organized the first “Procession of the Three Wise Men for inclusion” with the participation of many persons with Down syndrome.

In 2008 we produced and distributed 20.000 flyers with first information for parents and professionals in private and public hospitals throughout Spain.

In 2009 we produced the campaign “I’m in a perfect shape!” together with a health company to prevent obesity and improve the quality of life of people with Down syndrome. We also organized the first Sports Day “I’m in a perfect shape” to help the inclusion of people with Down syndrome in sport activities.

In 2009, in order to sensitize the medical sector about the importance of a good health for people with Down syndrome, we visited 2.500 gynecologists from all over Spain and handed them our publication “Spanish Health Program for people with Down syndrome”. This program had the goal of informing, give support to parents and unify criteria in the medical sector to treat the health of people with this disability.

In 2010 we organized the first festival Cinema & Down, were we showed a selection of international films which reflect stories of people with Down syndrome.

In 2010 we presented in the United Nations the publication “The United Nations International Convention on the Rights of Persons with Disabilities commented by its Protagonists”, an unprecedented piece of work of 100 young persons with intellectual disabilities regarding their rights. Cristina Rosell and Tonet Ramirez, two young person with Down syndrome spoke in the side event that was held during the 3<sup>rd</sup> Session Conference of State Parties that was held

between the 1<sup>st</sup> and the 3<sup>rd</sup> September. Ana Pelaéz, Vice-President of the UN Committee on the Rights of Persons with Disabilities and the Ambassador, Permanent Representative of Spain to the UN participated also in the side event. This news was followed intensely in the Spanish media.

## **General information**

There are 34.000 people with Down syndrome in Spain. The main problems for people with Down syndrome in Spain are access to secondary education and to employment. We are also concerned about the increase in the development of Alzheimer and similar diseases among this growing population of elderly people with Down syndrome.

### **Numbers:**

In Spain there are approximately 8 children every 10.000 born with the Down syndrome every year. (This shows a great reduction if we take a look at the figures of the previous years. Between 1980 and 1985 there were 14 children every 10.000 born with the Down syndrome every year and in between 1986 and 2006, 10 children every 10.000 born with the Down syndrome)

### **Situation of babies and toddlers under 4 years:**

All children under 4 years in Spain have access to Early Intervention services. Health exams are preserving a good health among the population of this age.

### **Situation of schoolchildren:**

The schoolchildren have access to primary education in ordinary schools but the problem comes when they want to access secondary education. More efforts and supports are needed to let them succeed in this stage. We have great concern because we observe an increasing tendency to segregate them in special schools in the last years.

### **Situation of adults:**

Access to employment is still one of the main problems. We calculate that approximately only a 5% of the people with Down syndrome work in ordinary Companies. They have to empower themselves and reach independence, but programs for adults with Down syndrome are not consolidated in Spain and although there are some pilot experiences in shared houses, these programs are not generalized.

Another problem is that a big part of society is still not aware of the incredible value of people with Down syndrome and therefore they don't give them the chance of being a part of society and be fully integrated.



