

European Down Syndrome Association news

Netherlands Stichting Downsyndroom



Internet: www.downsyndroom.nl

Founded: 1988. Foundation, non profit organisation

President: Marja Hodes

Members: 4000

Finances: membership fees, financial support from state, country, town, donations, sponsoring, selling material/books

Main goals

Our main goals are based on the goals of EDSA.

Services

We offer all the following services, partly in cooperation with professionals in the field:

- counselling
- rehabilitation
- seminars, courses
- library
- family days, leisure activities, weekends with special programmes for parents and children

Publications

- journal: *Down + Up*, 4 issues a year
- other information flyers, brochures, books
- videos, films, DVD
- poster
- intervention and therapy material

Awareness campaign

Our first awareness campaign was held on World DS Day 2006. We plan to celebrate this day regularly in future.

Projects and campaigns

Main projects in the near future:

- film project: *"To Settle Down"*, about living independently
- awareness campaign on 21 March 2007
- the next World DS Awareness Day
- developing new medical guidelines together with our own medical worker Roel Borstlap.

Successful campaigns or projects over recent years:

- Project *"Uploading Down"*, where we collected 21 short films about persons with Down syndrome from 21 different countries for an internet presentation
- 21.03.2006 – The launching of this film project by Princess Maxima!

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DVD "Kleine Stapjes Grote Sprong" (about early intervention)

A useful project-tip for other EDSA members:

Organising syndrome-specific weekends for parents, with workshops on early intervention; syndrome-specific learning problems; or teenage issues, with a separate programme for children.

General information

The main problems in the Netherlands for persons with Down syndrome:

- finding inclusive schools and suitable work settings for integrated jobs
- people with Down syndrome don't have any rights
- low expectation is our biggest problem. This means that raising expectations is an important issue.

Numbers

Number of children in the Netherlands born with Down syndrome is approximately 200 per year.

The number of persons with Down syndrome living in the Netherlands is approximately 10,000.

Situation of babies and toddlers under 4 years

Parents have to find our organisation themselves because they do not automatically receive this information from the hospitals.

One of our issues is, informing hospitals and birth clinics about our existence so we make beautiful flyers for those professionals.

Medical care is good. We initiate and support establishing Downteams (specialists in Down syndrome medical clinics) and every paediatrician has access to the medical guidelines.

Physiotherapy is good.

Early intervention: we offer parents an early intervention programme and motivate professionals to use the programme in syndrome-specific play-groups.

Other therapies: We initiate a lot of research in all kinds of fields.

We hope that in the future this will result in better and more therapies.

Situation of schoolchildren

For those children who are developing well, and who have parents who are good advocates for their kids, there are a lot of opportunities in kindergarten and in mainstream schools (but mainly for the younger children).

About 50% of children up to 6 years old are in mainstream kindergarten.

About 30% of children (6-12 years old) go to mainstream primary schools.

About 2% of 12-18 year old pupils are in mainstream secondary schools.

Other children attend special schools.



Situation of adults

Only a few have paid jobs in the normal workplace. It is hard to find such jobs.

Most adults go to day-care centres, sometimes those centres help to find paid employment or volunteer places.

A lot of adults live at home with their parents. Sometimes there are housing projects for small groups in a regular neighbourhood. Many older people still live in institutions.

Because there is no registration we haven't got any idea about the number of persons with Down syndrome over 50 years of age, nor do we know a lot about their living situation.



Marja Hodes, the new president



Erik and Marian de Graaf, founders of SDS and the spirit of the movement for 20 years, are internationally well-known. They have a 22 year old son, David, who has Down syndrome.