

## European Down Syndrome Association news



### CZECH REPUBLIC Association of Parents and Friends of Children with Down Syndrome



**Founded:** 1996, a statewide Czech non-profit organisation

**President:** Dr. Dagmara Džúrová

**Members:** approx. 600

**Finances:** Member fees and donations. Financial support from state now and then by grant support

#### Main goals

First parental help/support for families; early intervention programmes for children and parents.

Researching new methods and offering support programmes contributing to positive development of children.

Empowering parents to defend their rights and activating society by promoting a positive image of persons with Down syndrome.

Promoting all actions which contribute to the welfare of all individuals with Down syndrome and improve quality of life for them and their families.

#### Services/Activities

1. Counselling
2. Rehabilitation and therapies:
  - Early care programme "Loves in hands" (support by accepting the child in the family)

- Speech therapy, orofacial rehabilitation therapy
- Feuerstein methods – development of cognitive skills is one integral part of our intervention service.

#### 3. Seminars

- For parents. Topics mainly about how to develop cognitive learning skills of their children



*President of the Down syndrome Association in the Czech Republic, Dagmara Džúrová, who is the mother of a young boy with Down syndrome*

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### 3. Seminars

- For parents. Topics mainly about how to develop cognitive learning skills of their children
- For professionals (e.g. teachers), supporting them in the inclusion of children with Down syndrome.

The goal of these seminars is to support the process of inclusion of children with Down syndrome in mainstream schools, clubs etc. We believe that each child is unique in his/her needs and potential. It is not possible to determine beforehand what type of school is best, which goals can be reached, and what can be achieved in life.

### 4. Library

#### 5. Other activities:

Twice a year we organise a 'Children's day' and there are workshops for parents twice a year. We have one winter camp and 2 summer camps in the mountains (for 300 people per year)

### Publications

The journal PLUS 21 is published 3 times per year.

We have published several information flyers and the following brochures and books:

- Jenikova, Dzurova et al.: "Dear mum, dear dad" a book for new parents
- Cora Halder: "Together at school", a brochure for teachers
- Struskova: "Children from the planet DS", family stories

- Two videos: "One chromosome plus" (60 min.) and "Together at school" (60 min.)

### Awareness campaign

There is no regular Down syndrome awareness campaign. For the first World DS Day a big press conference in Prague was organised and three different postcards and other press material was published and distributed.

### Projects and campaigns

The main project for 2006 is the 10th anniversary celebration of our Association.

### General information

The three main problems for persons with Down syndrome here are:

- Poor work opportunities for adults
- Lack of support systems throughout the life span of individuals, and insufficient speech therapy
- Children in institutional care – because of lack of support, some families leave newborns in institutions.

Therefore creating better conditions for families with children who have Down syndrome in our society is one of our main priorities.

### Numbers

There are about 70 babies with Down syndrome born per year. We estimate that there are around 5000 individuals with Down syndrome living in the Czech Republic.

### Situation of babies and toddlers

There is very good medical care available, but other specialist intervention (like physiotherapy, early intervention, speech therapy) is mostly offered by the non-profit organisations.

### Situation of schoolchildren

The following numbers relate only to members of our Association! The situation is very different for families who are not members, who have not had access to special courses, lectures, information etc.

- About 90% of children up to 6 years old are in mainstream kindergarten
- About 60% of children (6-12 years old) are in mainstream schools
- About 10% of teenagers (12-18 years old) are in mainstream schools. Other children attend special schools

### Situation of adults

Adults have a few opportunities to work in special sheltered workshops, but no other alternatives. They live in institutional care or with parents, only very few of them live in special group houses.

We do not have any information about persons with Down syndrome, who are over 50 years.

