

# Down Syndrome Slovenia

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Weekend seminar for families with children from 7 to 18 years, Moravske Toplice Spa

## Our first steps

Down Syndrome Slovenia began in 1997. It was started by a group of parents of small children with Down's syndrome who met as a self-help group and then decided to found an organisation.

There is a long established and active NGO in Slovenia called "Sožitje" ("Coexistence") that strives for the improvement of both collective and individual care of people with intellectual disabilities and their families, including people with Down's syndrome. The founders therefore decided to set up a "section for Down's syndrome" within Sožitje Ljubljana. Ljubljana is the capital of Slovenia. The Down's syndrome Section existed until 2013, when an independent NGO (non-governmental organization) "Down Syndrome Slovenia" was established.

Since the founding members of the "Section" were parents of small children the first programmes they organized were on early intervention. They were combined with events for families, usually held in hotels over the weekend, and included lectures for parents (while taking care of the children with Down's syndrome and their siblings) and some relaxation activities, like bathing in a spa or at the seaside.

The second issue the "Section" wanted to tackle was securing professional literature on Down's syndrome in Slovenian. Before the establishment of the Section, there were practically no books available in Slovenian on Down's syndrome. Now, at least one book in Slovenian is published every year about different aspects of life with Down's syndrome.

To disseminate information on Down's syndrome, the section started organizing an annual, one day conference on "life with Down's syndrome". Topics covered at these conferences included early intervention, education, early reading skills development, medical aspects and employment.

After two years the "Section" was able to get some funding from the Foundation for Disabled and Humanitarian Organisations, a public foundation securing funds for these organisations. This has become a relatively stable source of funding.



Participants in the program for adults with Down's syndrome, refreshing their academic knowledge, Ljubljana

After a few years of various activities, the following programs have been developed:

## Empowering people with Down's syndrome and their families

- One day workshops for families;

lectures for family members and professionals; programs of learning support and physical skill developments for children and youngsters with Down's syndrome.

- Weekend seminars for families with children with Down's syndrome. Three groups of these seminars have been developed – for families with small children; for those with school age children; for families with grown-up children with Down's syndrome.
- Early intervention programs running the whole school year in different places in Slovenia.

## Dissemination of information on Down's syndrome to the general public and professionals

We work with other NGOs.

- The union of motorcars "Gold Wing" organized a day event for members of the Section during which our members could ride on motorcycles, enjoy a picnic and music performances.
- The Section prepared an exhibition of photos of people with Down's syndrome in one of the galleries in Ljubljana.
- A group of amateur painters contributed to the Section all the pictures from an "ex tempore" they prepared in the countryside.

## Informing and increasing awareness of the general public and publishing

At least one book in Slovenian is published every year about different aspects of life with Down's syndrome.

While we support the publication of works by Slovenian writers it has also been necessary to get books translated from other languages.

We've developed an excellent relationship with an adult learning organization in Ljubljana whose

members, studying German, offered to translate texts from German into Slovenian. They had an expert in special education to take care of the professional terminology as well as another expert who took care of the translation.

With the help of this group we have translated about ten booklets. One of them was a book on early speech development of children with Down's syndrome by Prof. Etta Wilken from Germany. For this work we also got the assistance of researchers from the Department of Education, University of Ljubljana, who reviewed the text. We were also fortunate that the author renounced any royalties.

We've translated other booklets from German published by Deutsches Down-Syndrom InfoCenter who have also very kindly renounced any royalties.

We have also been successful at sharing information on people with Down's syndrome in the media. Newspapers, TV programmes and radio stations have been rather cooperative, especially during World Down Syndrome Day.

### Celebrating World Down Syndrome Day

We have used the opportunity of World Down Syndrome Day to raise awareness about Down's syndrome in Slovenia from the start. The leading daily newspapers published interviews with professionals working with us on different aspects of Down's syndrome; the topic was presented on television; the Section organized local events including lectures, sports days and concerts.

In 2008, the President of the Republic of Slovenia organized a reception for people with Down's syndrome and their families as well as for carers and professionals working with them.

Since we became an independent charity in 2013, the President has hosted such a reception twice. These events are covered by the

media and are great publicity

We worked with other NGOs to arrange three big concerts (in 2014, 2015 and 2017) which were broadcast by TV Slovenia and were very well received by the general public. Every year, local concerts are organized in smaller towns in Slovenia as well. We also take part in most of the EDSA (The European Down Syndrome Association) and DSi (Down Syndrome International) activities on World Down Syndrome Day. We believe that public awareness about Down's syndrome has increased a lot during these years.

### Academic award for diploma papers

Every two years we award outstanding diploma papers on different topics on Down's syndrome, including special education, legal, sociology and medical.

### Becoming an independent NGO – Down Syndrome Slovenia

It seemed a natural development for our group to become an independent organisation in 2013. After this we were able to apply for funds earmarked for an NGO. We could also join EDSA and establish contacts with DSi. We also acquired a new office where we can carry out some of the programs.

Our work broadened and became more diversified. We continued the projects described above while also developing a special program for young adults in the form of a 4 day camp where youngsters take part in everyday activities and learn how to live in nature.

The association established international cooperation with similar organisations in Europe. In this way, we could join a project consortia that applied for (and received) EU funding. Recently we carried out a project on healthy diets, the result of which is an internet program accessible also to persons with Down's syndrome and available in Slovene.

Currently we are involved in two

international projects (Erasmus+) where DS Slovenia is cooperating with related NGOs from Spain, Portugal, the UK and Romania. One is focusing on developing VR (virtual reality) tools that can be used by people with Down's syndrome during occupational training. The other focuses on problems of ageing in people with Down's syndrome.

We are also working on a national program financed with EU funds. It will develop a Ljubljana tourist guide for people with Down' syndrome, will be written in easy language and will be published in both Slovenian and English. We are using the experiences of the SmartGuides program that developed this kind of guide for other European cities.

### Future plans

As the demography of the Down's syndrome population is changing the focus of the association's work will shift and we will offer new programmes: a) ensuring sufficient numbers of adapted work places, b) ensuring suitable residential units for adults with Down's syndrome and other developmental challenges that are integrated into the local community.

Last but not least we aim to develop leisure and recreational activities adapted to the needs of older people with Down's syndrome as they have the right to age with dignity just like every individual.



Weekend seminar for families with children up to 7 years, Radenci Spa