

## European Down Syndrome Association news

### GREECE Down Syndrome Association of Greece



**Founded:** The organisation was founded in 1990, as a non-government organisation, we are a parent group. The association has a council of 9 members. Elections are every 2 years.

**President:** Theodosios Georgiadis

**Members:** Parents are the only members of the Association. At the moment there are 350 family members. Most of these families live in the broader region of Northern Greece, but we have members from all geographical regions of Greece and the number is always growing.

**Finances:** Our association is not supported on an annual basis by the Greek government. Specifically, we raise funds from the following sources:

- Annual subscription fees from the members
- Production and sale of Christmas and Easter cards, bazaars
- We organise various cultural events and the income from these events is donated to our association (so far we have organised concerts, art exhibitions, theatrical performances, and we have more ideas for the future)
- Some occasional funding from government bodies (that means that in a given year we might receive 3,000 or 4,000 Euros, but most of the time we get nothing).
- Our annual budget of expenses reaches the sum of 100,000 Euros. We really face many difficulties in raising this amount every year, and we must admit that it is time and energy consuming.

#### Main goals

Our association is the first, and so far the only organised group in Greece.

Our most important goal is to communicate with parents, to inform and support them in the best possible way. We want to inform society of our existence as an association and that we are determined to secure the acceptance of our children, their social inclusion, their appropriate education, their vocational training and their employment inclusion.

We are trying to play an intervention role in the hope of securing a better present and hopefully an even better future for the children with Down syndrome and their families in our society.

#### Services

I. Presentation of the Association:

- making our objectives known through the mass media
- production of information leaflets for parents and the public



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- participation in conferences and seminars
- on a national level we are members of the Greek Federation for People with Special Needs and the National Greek Confederation of Disabled People, and on an international level we are members of the European Down Syndrome Association
- we are in contact with associations from other countries, who provide us with information material which we translate with their permission.
- we have organised a lending library (with Greek, English and French literature) for the use of our members and anyone else who would like more information

2. Counselling and sustaining a network of parents.

3. Educational programmes for children and adults with Down syndrome.

- speech therapy, special physical training and sports activities. Basketball, gymnastic and Greek folk dances – 65 people with Down syndrome between the ages of 2 to 50 years old participate in these programmes.
  - pre-occupational and occupational training: 15 individuals from 15 to 45 years old take part.
  - music therapy and a theatrical group
4. Entertainment.
- We organise celebrations, parties, sports competitions and special events throughout the year, and at Christmas, Carnival etc.

### Publications

Unfortunately up to now we have not managed to publish a journal, although it is one of our main objectives.

We have published information flyers, posters, informational brochures for parents (most of these are translations from the DSA (U.K.), DSA Victoria (Australia) and from APEM (Belgium).

### Awareness campaign

There is no regular DS awareness day. Usually on the 3rd of December (national day of people with handicaps) we organise various events.

Around World DS Day we organised:

- radio and tv spots, press releases and a press conference
- information letters to all the maternity hospitals/clinics so that they became aware of our existence
- street happenings in the centre of Thessaloniki

### Projects and campaigns

Our main projects in the next years:

- continuing all our educational programmes
- performances with our theatre, folkdance and rhythmic groups (We participated in the Special Olympics with 2 girls from our group and they won gold and silver medals)
- setting up a bowling team for our young people
- organising (on a research level) lessons in teaching mathematics skills to our youngsters and teenagers

All the presentations and performances were very successful due to the publicity - it has helped us to become known and also to change some of the stereotypical thinking about people with Down syndrome.

As a useful project tip for other EDSA members we recommend social awareness campaigns. They are most helpful, especially held in schools because of the target group – the citizens of the future.



*Theodosios Georgiadis, president of the Down Syndrome Association of Greece*



### General information

The three main problems in Greece for persons with Down syndrome are:

- education
- work
- independent living

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Almost everything needs to change, but perhaps the most urgent thing is the way that information is given to parents with a newborn child. We believed that this was a problem of the past, but it remains a problem of the present and most likely of the future as well.

### **Numbers**

There are no formal numbers of how many children are born, due to medical confidentiality. From an informal source we know that about 30 children are born with Down syndrome every year in the northern part of Greece, and if we use deductive reasoning that number must be at least double for the whole of the country.

### **Situation of babies and toddlers**

Medical care is sufficient, although there are only a few specialised paediatric clinics/hospitals which do the Down syndrome checks and follow-ups.

If there is need of physiotherapy usually parents refer to private physiotherapists; there are limited organised physiotherapy centres and only in large cities (Athens, Thessaloniki etc.) The expense, or a part of it, is covered by the health agencies of the parents.

Formal early intervention programmes do not exist, but parents usually seek the help of specialised therapists (speech, physio- or occupational therapists etc.)

As an association we provide services for children from 2 years old, and we work on a counselling basis from 0 to 2 years old.

### **Situation of schoolchildren**

We can only give a picture for the children that are in contact with our association.

- about 75-80% of children up to 6 are in mainstream kindergarten
- about 40 % of elementary school aged children are in mainstream schools
- only a few teenagers are in mainstream high-school
- so most of the children attend special schools or some special educational and occupational units in institutional settings.

### **Situation of adults**

Only a few adults work, mostly in family businesses.

Others are occupied in sheltered work-shops and a vast majority of them remain at home.

The problem of independent living is the same for all people with handicaps in Greece. Usually when they are left with no immediate support from their parents, they are placed in institutions. In the last few years some parents have tried to start initiatives, creating independent living accommodation.

The exact number of persons with Down syndrome over 50 is not known to us, but we have some older people in our association (2% of our members). Some of them participate in our programmes, but there are others who are at home and face very serious problems: mainly depression, and different kinds of health problems. For some of these cases the only word to describe their situation is tragic. These are only the people we know about in our association, how many live and under what conditions we really do not know