

SUMMARY

01

WHAT'S NEW IN
EDSA?!

02

EDSA INICIATIVES

04

EDSA
ANNIVERSARY.....

07

NEWS FROM EDSA
MEMBERS

09

NEWS FROM THE
PROJECT WITH
EDSA MEMBERS IN
THE CONSORTIUM

WHAT'S NEW IN EDSA?!

EDSA AGA DUBLIN 2017

From 10 to 12 November 2017 EDSA members met in Dublin for their annual assembly.

During the AGA the elections of the board have also taken place.

[Please find the minutes of the meeting in the restricted area.](#)

After three years, Anna Contardi concluded her Presidency.
Following her letter to all Edsa members.

To the members of Edsa

With the Dublin Assembly, I closed my term of office and passed the baton on to Pat Clarke. I wanted to thank you for the trust you have given me in these years.

I have done my best, within the limits of time and resources, with the help of other board members, to respond to that trust.

We have tried to improve the exchange of experiences and skills between us and to give Edsa greater organizational and communication skills. There is certainly still a great deal to be done and the success of this undertaking is in the hands of all of us.

With some of you we have known each other better, with others less, but this experience has certainly further extended my knowledge of people with Down syndrome and its associations. It was an honour to be President of Edsa, for me, for Italy and for my organisation. Many times I have been moved and I have felt proud to see people with Ds grow and express their opinion, to be heard and recognized as people and citizens.

It is with this image that I want to greet you and leave this Irish blessing that I distributed to those present in Dublin and which is one of the best wishes that I hold for my friends.

**May the road rise to meet you,
may the wind be ever at your back.
May the sun shine warm upon your face,
and the rains fall soft upon your fields.
And until we meet again,
may God hold you in the palm of his hand.**

Buona strada (have a nice path)

Anna Contardi

EDSA INITIATIVES

Conference on Inclusive Education

Survey on School Inclusion in Europe

From 10 to 12 November 2017 EDSA members met in Dublin for their annual assembly. Part of the program was a conference on Inclusive Education. Pat Clarke had organized this conference, which took place in the premises of Down Syndrome Ireland.

The day was opened by **Mr. Finian McGrath**, Minister of State with responsibility for Disability issues, who is also has a daughter with Down Syndrome.

It was a very informative day starting with an overview of school inclusion in Europe by **Anna Contardi**. The data came from a survey EDSA recently carried out among its members. In total 21 questionnaires were answered by 19 countries. (the questionnaire from Denmark came too late, to be included in the results). Main conclusions were:

- > *We go towards school inclusion, but the experience of special schools is still very strong (in 86% of the countries there is still the dual channel)*
- > *Most children with SD are in mainstreaming schools, but in 66.6% of the countries they spend at least part of the day out of the classroom*
- > *Support teacher is the most used form of support*
- > *There is still much to do!*

[The presentation can be found here.](#)

In two very interesting lectures **Rebecca Baxter**, who is a consultant of Down Syndrome Education in the UK shows the benefits of inclusion in education, what the main keys to success are and what the strategies are for accessing the curriculum and the implementation of inclusion in the classroom.

We have learned a lot from her lectures. If people are still not sure that inclusion is the best way for our children with DS, you nearly must be after having listened to Rebecca.

It was very nice to listen to the story of **Patricia Griffin** and her son **Canthal Griffin**. They gave an overview of Canthal's way through life, from early intervention to actually holding a regular job on the first market. The program Latch-On about further education for young adults after having left school, was especially interesting for all participants.

Fidelma Brady, Education Officer of Down Syndrome Ireland presented the new Irish model of allocating supports to children with special educational needs with specific reference to children with Down syndrome. She focused on the allocation of teaching resources for pupils, special needs assistants and current speech & language therapy initiative.

The last contribution was prepared by **Prof. Juan Perera**, from the association Asnimo on Mallorca. Unfortunately Juan, who is also a founder of EDSA could not be with us in Dublin, but his son Juan Perera junior came instead, showed us the

presentation, while Pat read the English translation. This presentation looked in the specifics and recent research in Down Syndrome and how this knowledge is an important criterion for quality education of the pupils with DS.

All presentations are on the EDSA website in the restricted area for members.
Care of Cora Halder

EDSA ANNIVERSARY.....



EDSA 30th anniversary 1987-2017.

Dr. Juan Perera, director of ASNIMO (Asociacion Síndrome de Down de Baleares) and one of the founders of EDSA, presented this speech on EDSA 30th anniversary at the AGA 2017 in Dublin:

EDSA was founded in 1987 in response to the need to establish a common line for all the European organisations working for DS.

The idea of creating the European association emerged from various professionals in the international sphere who were giving lectures on DS.

Initially the proposal was seconded by the national associations of countries such as France, the UK, Germany, Belgium, Denmark and Spain. Subsequently representations from the rest of the European countries gradually joined us, eventually shaping the association as we know it today.



This is the photograph, at the Town Hall of Verviers, of the founding members who made up the association's first board of management: CARLOS PICCENNA (Italy) was its first President, MARIA VICTORIA TRONCOSO (Spain) was Vice-president and RICHARD BONJEAN (Belgium) General Secretary and Treasurer.

EDSA was created to support people with DS in all countries in EUROPE and especially to care for their health, their education and training, their integration into society and their adaptation to work. The first action taken by EDSA was to try to organise the different initiatives of the member organisations. To do this we called a General Assembly designed to define the bylaws that would govern our activity.

Once the organisational structure was defined, the next process was the dissemination of EDSA's activities with the publication of "THE ANSWER TO A

CHALLENGE" (1990) which we transferred to all the national associations and presented at the different congresses in the European sphere in the year 1991. In that same year, we carried out more dissemination at the congresses organised by the NDSS (National Down Syndrome Society) in San Diego (California).

In 1991 the "EDSA Scientific Council" was created with the following objectives:

- a) To publish a new issue of the "EDSA Newsletter" every 6 months.
- b) To organise a Seminar on specific aspects of DS every 6 months in different countries.
- c) To create a group of scientists who are specialists in different DS issues.

In June 1991 the first issue of the EDSA Newsletter was published, designed to disseminate scientific issues of special interest for the health and education of people with DS.

In 1992 the "EDSA Science Advisory Board" was created. Its members were scientists and experts from many countries in Europe, with the aim of facilitating contact with experts in DS for the Associations.

By the year **1993** EDSA was fully functioning and this was an especially fruitful year for our association: Two Administration Council Meetings were held, the Board of Management of EDSA was renewed with the appointment of a new President, Augusto Bosio (Italy) and the first meeting of the Scientific Council was held in Montpellier (France). Moreover, EDSA organised the "International Symposium on Specificity in Down Syndrome" in Mallorca and participated in the International Congress in Orlando (USA).

In 1994 EDSA requested its incorporation in the EDF (European Disability Forum) with the idea of representing the interests of people with DS in the body for the representation of people with disability before the European authorities. It also organised the "International Conference on Cognitive Development in Down's Syndrome" at Portsmouth University (England) and the "Journées Nationales sur La Trisomie 21. Fait 21 et G.E.I.S.T 21" in Nimes (France).

In 1995 EDSA continued with its scientific and dissemination work by organising the "Third European Down Syndrome Conference" in Dublin (Ireland) and the "3rd International Symposium on Down Syndrome" in Palma de Mallorca with the subject "Psychology of DS."

In 1996 EDSA participated at various meetings held in Vancouver, Dublin and Cancun, represented by R. Bonjean and J. Perera, to form part of the International Committee that subsequently approved the constitution of the IDSF, today called DSI (Down Syndrome International), which is the World Down Syndrome Federation.

In 1997, in Madrid (Spain), EDSA held the "6th World Congress on Down's Syndrome" which was attended by 2,400 people from 63 countries worldwide and which resulted in publication of the book "Down Syndrome: A Review of Current Knowledge", coordinated by Jean Rondal, Juan Perera and Lynn Nadel, and with versions in Spanish, English, French and German.

In 1998 EDSA prepared a document titled "The EDSA Essentials" which summarised the main lines of the organisation:

1. Identity Document.
2. Healthcare Guidelines for People with Down Syndrome.
3. People with Down Syndrome: Orientation for Families.

In the same year EDSA also published its Ethical Code.

In 1999, EDSA was admitted as a member of the "European Disability Forum" in Brussels (EDF). This meant the official recognition of the "Specificity of Down syndrome" in the international sphere and opened the doors for us to the EU's fifth Directorate General (responsible for people with disability).

In 2000, the EDSA meeting was held in San Marino with the calling of new elections and a new Board of Directors was composed presided over by Dr Juan Perera

(Spain).

In 2001 the organisation's lines of functioning were redefined. The EDSA BOARD MEETING in Luxembourg approved the new "EDSA IDENTITY DOCUMENT" and the EDSA BOARD MEETING held in Palma de Mallorca approved the document "EDSA IS ALIVE". The EDSA MEMBER LIST was also updated (JUNE 2001) and there was continuation of the publication of the EDSA Newsletter.

In 2002, the "2nd International Congress" was organised in San Marino with the theme: "The Adult with DS" and the opportunity was taken to hold the EDSA BOARD MEETING. Also that same year, the "Conference on Medical Issues in DS" was organized in Bielefeld (Germany).

In 2003 the Meeting was held in Luxembourg with the theme: "School integration: a European challenge" and also the EDSA BOARD MEETING was held to approve the New EDSA Bylaws, drawn up by Monique Randel ... and to present the 8th World Down Syndrome Congress which was held in Singapore in November of that same year and presided over by Balbir Singh. From this same year you have very broad and detailed information on the principles, objectives, achievements, meetings and publications of EDSA on the Website "EDSA European Down Syndrome Association", a very well organised page that offers a vision of a solid EUROPEAN ASSOCIATION, with clear objectives and competent parents and professionals.

I wish you all the energy to continue fighting for people with Down Syndrome in Europe, with clear ideas, with perseverance and convinced that every year we are capable of further improving our objectives and ensuring that our children and students enjoy their daily activities and have a healthy and responsible life ahead of them.

NEWS FROM EDSA MEMBERS

Down Turkey



Down Sendromu Derneği

Network of Rights of Children with Disability

We participated on a secretariat member of moderator to the Network of Rights of Children with Disability which is supported by UNICEF. The network is consisted of 30 NGO's for now. The aim of network is to empower NGO's in using tools for working on the rights of children with disability. Also, network aims to make advocacy about it.



I am Independent Because I Work

With the support of Sabanci Foundation Grant Program, we have held the closing meetings of the project which name is "I am Independent Because I Work" for 2 years. Within the scope of the program. We prepared a job coach training program with Anadolu University special education department and published a book about job coaching. Our goal of January is to provide job coaching training to professional career counselors in the employment agency of Turkey.

My Voice My Community Workshop

We started a new project called "My Voice My Community" with partnership of Down Syndrome Int. and the financial support of Sabanci Foundation. We made a workshop with Down Syndrome International's instructors to analyze the current situation of Turkey about self - advocacy. In this workshop we also prepared a draft training program for the support people of people with Down syndrome. Together we took our first steps for the Down Syndrome self-advocacy. The participants of workshop were from the Ministry of Family and Social Policy, Vocational education

schools, the Municipality of Sarıyer, the employees of the private sector, young people with Down Syndrome and their families.

Turkish Parliament Speech

The Vice President of our organization Fulya Ekmen participated as a speaker "Subcommittee on the Problems of Persons with Disabilities in Turkey and Persons with Disabilities and Suggested Solutions" in Turkish Parliament. She made a speech about the problems of women who have child with disability.

5th Down Syndrome Conference



We held the 5th National Down Syndrome Conference on November 25 -26. In conference, we held 15 different experts, talked about the issues from birth to adulthood. The number of participants is 300.

3 youngester with down syndrome who started working this month:

With Job Coach Supported Employment Program, Ridvan İrdem started to work in Petzmondo. We wish the continuation of success.

With Job Work Coach Supported Employment Program, Yasir Saka started to work in Pirelli. We wish the continuation of success.

With Job Work Coach Supported Employment Program, Burcu Doğan started to work in E- Bebek. We wish the continuation of success.

NEWS FROM THE PROJECT WITH EDSA MEMBERS IN THE CONSORTIUM



DS LEISURE PROJECT



Erasmus+

THE EUROPEAN PROJECT DS LEISURE WILL SHARE KNOWLEDGE IN ENJOYING DS LEISURE

**The European DS-LEISURE Consortium announces the launch of
The Project TRAINING PROGRAM FOR IMPROVING QUALITY OF LIFE OF PERSONS
WITH
DOWN SYNDROME THROUGH INCLUSIVE LEISURE (DS LEISURE)**

DS LEISURE aims to increase the competences in terms of attitudes, skills and knowledge of people with Down Syndrome (PDS), of the collective around PDS: persons, families, professionals and volunteers about how to implement inclusive leisure, through an innovative training program.

During the Project, to be executed from October 2017 to September 2019, the European Consortium will develop training materials, practical experiences and an online platform for implementing the training methodology. About 120 persons with Syndrome, families, support professionals and 40 professionals of Leisure Sector will be trained and will participate in the validation of the project results, creating a first direct impact.

The European Consortium is formed by six entities:

- four NGOs working in the field of Down Syndrome as follows: ASOCIATIA LANGDON DOWN OLTENIA CENTRUL EDUCATIONAL TEODORA, Bailesti, Romania as the coordinating entity, Associazione Italiana Persone Down Onlus, Roma, Italy, Stichting Downkidsinternational, the Netherlands, Down Sendromu Dernegi, Istanbul, Turkey.
- two universities as follows: The University of Craiova, Romania is participating as leisure expert as well as Aristotelio Panepistimio Thessalonikis, Greece as expert in the development of ICT Tools adapted to persons with disabilities.

DS LEISURE is a project funded by the European Commission within the ERASMUS+ 2017 Programme, Key Action 2 - **Strategic Partnerships for Adult Education**, with a total cost of the project for the contractual period referred to by the Agreement number 2017-1-RO01-KA204-037465, all financing combined, estimated at **219782.00 EUR**.

PARTICIPANTS OF EUROPEAN PROJECT DS LEISURE HAVE MET IN ROMANIA

*During the 29th and 30th of last October, the Kick-Off Meeting of the European Project DS LEISURE took place in Romania, aiming to launch and to promote **inclusive leisure for persons with Down Syndrome**.*

Two representatives of each member of the Consortium have participated in this meeting.

The meeting took place in Craiova (Romania), where the European Consortium have dealt with issues as the development of the training program adapted, aspects of the structure to follow, theoretical contents, practical activities, the virtual training platform, all to ensure the validity of the material and the imminent launch.

On October 30, the European Consortium have visited the ALDO-CET center which is based in Bailesti, where partners from different countries received a warm welcome and could participate with the users of the center and its professionals, a day of leisure activities such as “The Magical Circle of Relaxation” and “Active in Leisure” interacting through body language, imagination, instruments and multi-language anniversary songs. Later, the European Consortium enjoyed a healthy and traditional Romanian menu made by the parents of ALDOCET. It was a great experience and a good start for teamwork.

For centers or people interested in this program, stay tuned because soon more information will be opened, for carrying out the training program in question.



LET'S SHARING KNOWLEDGE IN ENJOYING DS LEISURE



Romania – Italy – Greece – Nederland – Turkey

MAKE THIS NEWSLETTER REALLY YOURS!

Have you got any news that we could publish in EDSA newsletter?
Please send us any information you would like to announce and we shall be happy to disseminate it all over Europe!

CONTACTS

phone: 0039 06 3723909

e-mail: internazionale@aipd.it

THE STAFF

Carlotta Leonori

Paola Vulterini

Claudia Galieti