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**BREAKING NEWS****EDSA ANNUAL GENERAL ASSEMBLY**

We are pleased to invite you to attend the Annual General Assembly 2016 of the European Down Syndrome Association (EDSA).

**Date:** Thursday, 04 August 2016, 14.00h-18.00h

**Place:** Turkey - Istanbul

**Agenda**

1. Introduction of the President
2. Discussion of the minutes of the meeting of the previous AGA
3. The President's report
4. The Treasurer's report
5. Status – projects, activities
6. New members
7. Proposal for activities for the 2016-2017
8. Miscellaneous

Anna Contardi, President

Dinka Vukovic, Secretary General

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## EDSA TOOK PART IN THE OSLO CONFERENCE ON DOWN SYNDROME

The Congress on Down Syndrome took place in Oslo at the “Hotel Scandic Fornebu”, from Thursday April the 7th to Saturday April the 9th 2016.

EDSA attended the conference, with contributions on Friday April the 8th from Anna Contardi , President of EDSA and National Coordinator of AIPD (IT), and Sue Buckley, Director of Science and Research for Down Syndrome Education International (UK).



Anna Contardi



Sue Buckley

## EDSC 2016 IN ISTANBUL



Planning on attending the European conference in Istanbul this summer?

Subscribe now and benefit from the early bird price until May the 23rd 2016.

<http://www.edsc2016.org/en/REGISTRATION-INFORMATION.html>

Want to meet the keynote speakers? Take a look here and see which internationally recognised Down Syndrome experts are coming to Istanbul!

<http://www.edsc2016.org/en/SPEAKERS.html>



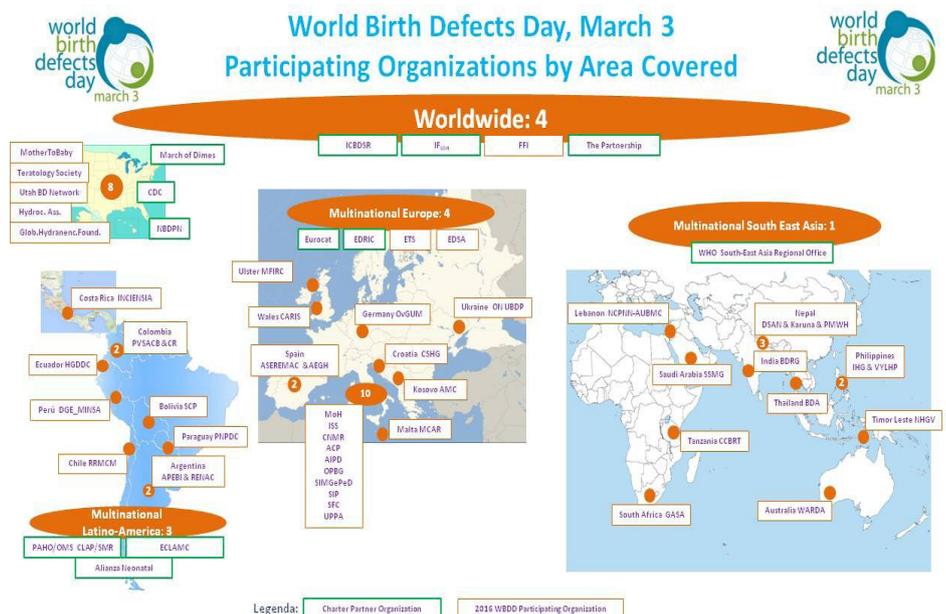
March the 3rd 2016 marks the second annual World Birth Defects Day (WBDD). WBDD provides a platform for increased economic, political, and intellectual support to improve monitoring of birth defects, their prevention, care, and research by global communities and countries.

Recognizing the importance of birth defects, the World Health Assembly passed a resolution in 2010 urging member states to raise awareness about the importance of birth defects, among other steps. All stakeholders, including individuals with birth defects and their families, the public, governments, non-governmental and civilian-run organizations, policymakers, researchers, and health care providers around the world are encouraged to make March the 3rd 2016 a truly inclusive and far-reaching global awareness event.

The preliminary report of the World Birth Defects Day (WBDD) 2016 is available on the ICBDSR website.

Please go to <http://www.icbdsr.org/page.asp?p=21751&l=1> for downloading the summary report and the reports by area/country. To learn more:

<http://www.icbdsr.org/page.asp?n=newsdetails&l=1&i=15947>



## NEWS FROM PROJECTS INVOLVING PARTNERSHIPS WITH EDSA MEMBERS

### ON MY OWN ... AT WORK - ERASMUS PLUS PROJECT

Down Espana joined the OMO consortium in April. Furthermore the OMO's managing group has developed 14 short videos (about 3 minutes each) that describe good and bad practice in the relationship between the trainee with intellectual disabilities and their tutor, as well as with other co-workers.



Click on the image to watch the video

The most frequent tutor questions are addressed:

- What kind of help/support does the trainee need?
- What type of relationship should there be?
- What sort of language should be used?
- What rules and expectations are there for the productivity of the trainee?

Some typical situations are illustrated:

- Correcting errors.
- Adopting stereotypes.
- How to give reminders of correct professional behaviour: adequate uniform, punctuality.
- Respecting everyone, their time and capabilities.
- Organising and formulating instructions for tasks to be completed.
- Personal relationship between trainee and tutor.

They are available online via the OMO website:

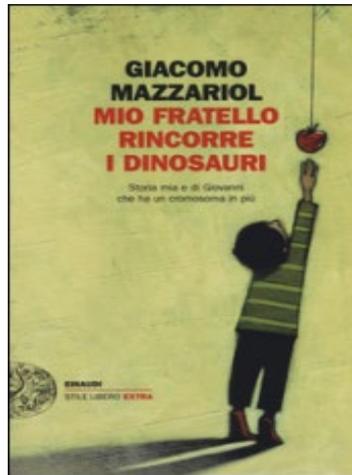
[http://www.on-my-own.eu/en\\_GB/videos/](http://www.on-my-own.eu/en_GB/videos/)

For each video it's possible to choose subtitles with different languages (Italian, English, Spanish and Portuguese) by clicking on the settings button below on the right.

## THE BOOK(S) OF THE MONTH

### MY BROTHER RUNS AFTER DINOSAURUS

My story and of Giovanni that has an extra chromosome.  
Torino, Einaudi, 2016



Giacomo Mazzariol is the boy that the last spring, on the occasion of the World Day of the Down People has imagined a video to tell in a poetic form his little brother born with the Down syndrome.

The title of the clip is “The simple interview” whereby Giovanni imagines to submit his little brother to a very formal job interview. From Giovanni’s answers emerges his original and fanciful personality. Over and above the disability, over and above the Down syndrome, the person comes out.

On the coming out on You Tube, the video met an unpredictable success. Giacomo Mazzariol, following such success, decides to tell in a book the story of his family life.

At the approach of the birth, Giovanni had been introduced to him by his parents as a “special” baby. A word that for him, a 5 years old boy, meant “superhero” with special powers.

But Giovanni is indeed very “different” from what Giacomo expected, and it is difficult to accept him for what he is, to introduce him to the friends and schoolmates.

It took twelve years to Giacomo to learn to actually “see” his brother, the run proved very difficult to him ; from the refusal and shame he comes to feel pride and bondless love for Giovanni. *“It took twelve years to see through the eyes of my brother, and I swear you that the world was not at all so bad”.*

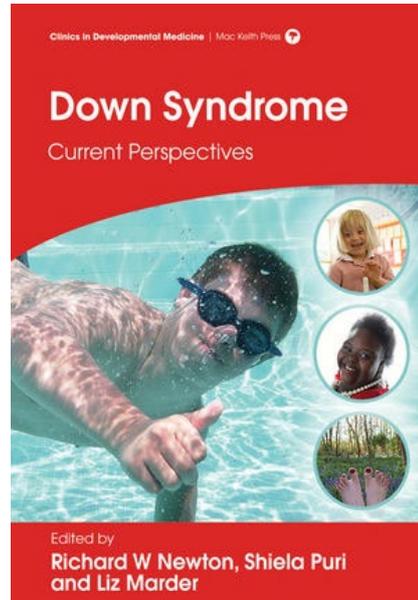
The extra chromosome has made a special person of Giovanni, with a mind rich in imagination and poetry. *“Giovanni with a widest smile than his glasses, that steals the hat from a bum and runs away, that loves dinosaurs and the red colour, that goes to the cinema with a girlfriend, returns home and announces “I have got married”. Giovanni that dances in the middle of the square to the rhythm of the music of a street artist and the people around, one after another, warm up and start to imitate him... Giovanni that knows to be exhausting and wearing out, that every day goes into the garden and brings a flower to his sisters, And if, being winter, he doesn’t find any, hands*

*them dead leaves.”*

After going through adolescence, a series of events and coincidences brought Giacomo to understand who is indeed his brother. He discovers that his initial idea was not so wrong. May be Giovanni really is a superhero ... and at any rate he is his best friend.

### **DOWN SYNDROME Current Perspectives**

Richard W. Newton, Shiela Puri and Liz Marder  
London, Mac Keith Press, 2015



From the foreword:

*Down syndrome is not a medical condition but presents a common recognizable variation of the human form created through a random biological event. Nevertheless, as we will see, people with Down syndrome present with many common medical conditions some that are more specific to the condition. Doctors have an important part to play in the lives of the people concerned. They help parents to readjust to a new set of expectations following the birth of an affected child. They can help with the early identification and treatment of conditions attendant on the syndrome.*

The challenge for doctors today is how to capture the rapidly expanding body of scientific knowledge and devise models of care to meet needs of individuals and their families.

Down Syndrome: Current perspectives has been written by a number of internationally respected clinicians with a special interest in Down syndrome. It provides doctors and other health professionals with the information they need to address the challenge that can present in the management of the syndrome.

Topics covered include:

Comorbidities of Down Syndrome, such as congenital heart disease, gastrointestinal disorders and skin disorders

Molecular genetics, the underlying biology, and antenatal screening

The neuropsychiatry of Down syndrome.

## 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!

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