

### SUMMARY

01

21<sup>st</sup> MARCH 2017  
WDSO

04

CONFERENCE ON  
DOWN SYNDROME

05

NEWS FROM EDSA  
MEMBERS

## 21<sup>st</sup> March 2017 WDSO

### EDSA Initiative: World Down Syndrome Day in Brussels



About 20 to 30 young persons with Down Syndrome attend the event in the EU Parliament, that was especially organized for them on the WDSO, 21st March.

Our meeting point was the Parlamentarium where we got to know the team of the WYA (World Youth Alliance) who were the organizers of the first part of this World Down-Syndrome Day event in Brussels.

There were delegates from several EDSA-member associations but also others with Down-Syndrome who participate together with their family or friends, and who came from different groups in Belgium and France.

The Parlamentarium is the visitor center of the EU Parliament with interesting information about the history of Europe. It was quite a job to get all the different groups looked after by a guide speaking their language, but then we all passed the controls and could look around in this very interesting exhibition. Unfortunately we had only short time there, it is definitely a place to come back to and spend more time in.

Then we all went into the EU Parliament. After being checked once again, most of us were able to meet a Member of Parliament from their home country. I got the feeling that the croatian, slovenian, slovakian and italian MEPs were very engaged and showed a real interest in the young people with DS and their families. My daughter and I were welcomed by Dr. Peter

Liese, MEP from Germany. We had the possibility to spend some time with him. The main topic we discussed was the job situation on the open market and the insufficient health care for adults with DS in Germany.

All participants could visit the MEPs offices, asking questions and talking about important topics. Most of us were invited for lunch in one of the Parliaments restaurants, together with the MEP and their assistants.

Before the conference began in the afternoon there was a photo session. Politicians, people with DS and their families, the organizers of this event, the WYA people and other guests gathered for a picture.

The conference was organized by the Lejeune Foundation from France. The theme of the conference was: Are we in Europe doing our best for the health of people with Trisomy 21?

Five scientists explained in short presentations the latest research.

Dr. Clotilde Mircher from the institute Jérôme Lejeune talked about comprehensive care at all stages of life and about therapeutic research, f.i. trials to prevent sleep apneas or improving psychomotor development.

The research for gene inhibitors linked to chromosome 21 and involved in cognition (Dyrk1a) was the topic of Dr. Mara Dierssen from Barcelona, Spain and Dr. Laurent Meijer, Roscoff, France.

And in the last session the overlapping pathologies in Down-Syndrome and Alzheimers disease were focussed by Dr. Yann Héroult, Illkirch, France and Dr. Juan Fortea, from Barcelona who is also a member of Horizont 21, the European consortium on DS and Alzheimer disease.

As a surprise Mr. Antonio Tajani, the President of the European Parliament came personally to give his statement, which was very much appreciated by the audience.

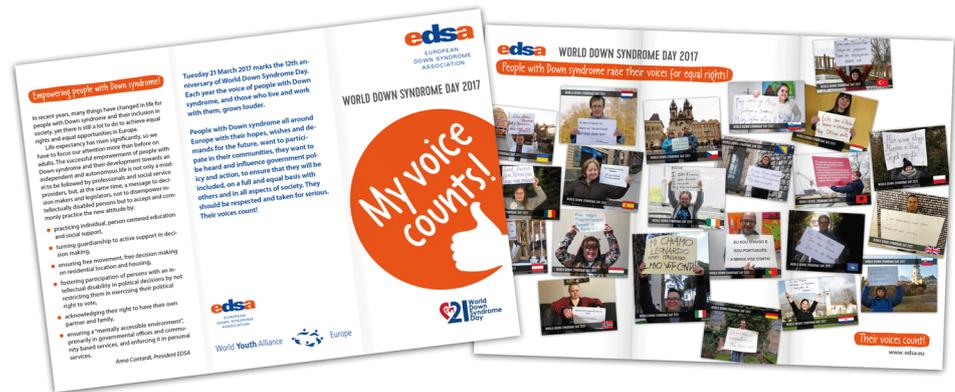
In the last part of the conference young people with DS had the opportunity to ask questions to politicians and speakers, so some of them had prepared their questions. Unfortunately it seemed that only three young ladies from France who were guests of the LJF came up with 3 questions. But no others took the chance.

It was disturbing that at the very end a MEP came up with a long talk about the topic of prenatal testing and asked participants to sign a statement against testing and abortion. He too was stealing precious time from the youngsters with DS!

On the world DS day with the slogan "My voice, my community", where people with DS were supposed to raise their voices, to be heard and be respected for their opinion, we experienced this as embarrassing and disappointing.

All in all, an interesting day, lots of impressions, many good talks and discussions, possibility to meet politicians, high class speakers at the conference BUT not enough voices of people with Down Syndrome themselves!

Cora Halder  
EDSA secretariat



## Folder “My voice counts” in Brussels.

The folder “My voice counts” was distributed in the EU parliament on World Down Syndrome Day 2017. We brought the voices of young Europeans with Down Syndrome to Brussels and we hope that their voices will be heard by political leaders. For this publication Anna Contardi, EDSA’s president, wrote a statement “Empowering people with Down syndrome”. The folder shows the pictures of the participants with DS from European countries, holding their posters with their statement “My voice counts”.

## People with Down syndrome raise their voices for equal rights!

Tuesday the 21<sup>st</sup> of March 2017 marks the 12th anniversary of World Down Syndrome Day. Each year the voice of people with Down syndrome, and those who live and work with them, grows louder.

People with Down syndrome all around Europe with their hopes, wishes and demands for the future, want to participate in their communities, they want to be heard and influence government policy and action, to ensure that they will be included, on a full and equal basis with others and in all aspects of society. They should be respected and taken for serious. Their voices count!

## Empowering people with Down syndrome

In recent years, many things have changed in life for people with Down syndrome and their inclusion in society, yet there is still a lot to do to achieve equal rights and equal opportunities in Europe. Life expectancy has risen significantly, so we have to focus our attention more than before on adults. The successful empowerment of people with Down syndrome and their development towards an independent and autonomous life is not only a model to be followed by professionals and social service providers, but, at the same time, a message to the decision makers and legislators, not to disempower intellectually disabled persons but to accept and commonly practice the new attitude by:

- practicing individual, person centered education and social support,
- turning guardianship to active support in decision making,
- ensuring free movement, free decision making on residential location and housing,
- fostering participation of persons with an intellectual disability in political decisions by not restricting them in exercising their political right to vote,

- acknowledging their right to have their own partner and family,
- ensuring a “mentally accessible environment”, primarily in governmental offices and community based services, and enforcing it in personal services.

*Anna Contardi, President EDSA*

## **CONFERENCE ON DOWN SYNDROME 31.8.2017 – 1.9.2017, at The National Library of Norway, Oslo**

### **Communication in individuals with Down syndrome – which future does the research predict?**

The University of Oslo, in cooperation with The National Library of Norway, invites you to a conference on Down-syndrome and communication this autumn in Oslo. The conference will be held at The National Library of Norway between August 31st and September 1st, 2017.

The topic of this conference is communication in its broadest sense. This encompasses for example speech, all modalities of language, hearing, understanding, reading and writing, as well as interaction and social functioning.

The purpose of this conference will be to share knowledge, and to present the most recent research on this important topic. We therefore invite researchers and students to submit their proposals. Papers and posters are welcome on all the above mentioned topics. The abstract for poster or oral presentation should not exceed 250 words. Please submit via e-mail to: [k.a.b.nass@uv.uio.no](mailto:k.a.b.nass@uv.uio.no)

Important dates:

- Deadline for abstract submission: June 1st
- Notification of outcome of submission: June 15th
- Deadline for registration: August 10th.

We hope to reach a wide group of professionals, encompassing researchers, practitioners and students. Additionally, the conference will be open to all interested public. We encourage you to forward this information to other who might be interested.

Web page for more information and registration: <http://www.uv.uio.no/isp/om/aktuelt/arrangementer/communicati-on-in-individuals-with-down-syndrome.html>

## NEWS FROM EDSA MEMBERS



### DOWN'S SYNDROME ASSOCIATION UK

#### 5 ways to be a better workplace ally to your colleague with Down's syndrome

The Down's Syndrome Association WorkFit programme gives advice on how employees can better support a work colleague with Down's syndrome.



Over the past decade, societal and workplace attitudes towards individuals with Down's syndrome have made positive strides forwards, but there is still room for improvement. For employers and their workforce, being equipped with the knowledge and understanding of how to better support a colleague with this condition is at the heart of the matter.

In fact, it is key to achieving an inclusive work environment.

Today, many companies' perception of Down's syndrome has advanced significantly and many employers are becoming aware of the numerous advantages of employing individuals with Down's syndrome and the huge contribution they can make to the business.

Like many people with learning disabilities who are striving to achieve their fullest potential in the workplace, people living with Down's syndrome need support from co-workers. Having a work ally or mentor will offer the person with Down's syndrome a first port of call for any queries or concerns.

It is fundamental. In fact, it is the cornerstone to integration.

As is the case with any new starter, it will also help them to form an effective working relationship, encouraging integration and inclusion as one of the team.

But don't just take our word for it. We've taken advice from our colleagues living with this condition to get tips on ways to become a better workplace ally to a colleague with Down's syndrome.

## 1. Educate: Learn more about the condition



“The team members are really supportive, kind, helpful and positive. It makes me feel like they really helped me out a lot.” Luke, Wiltshire Police Headquarters

Educating yourself about Down’s syndrome is the best starting point. By understanding the genetic condition and arming yourself with knowledge, you’ll be in a better position to support your colleague.

Ask your employer or HR department to provide learning materials or training. Alternatively, contact an expert organisation for advice, for example The Down’s Syndrome Association (DSA).

The DSA provides resources and bespoke Down’s syndrome awareness training which includes practical advice and information that you can use to support your colleague.

## 2. Include: Make your colleague feel welcome



“When Cedric, the Pastry Chef, made me a birthday cake not long after I had started at the hotel, I felt so happy as it was presented to me and a valued member of the team’. Alex, Hilton Bournemouth

Social inclusion in the workplace is important for all employees, and colleagues living with Down’s syndrome are no exception.

Be their support system in the workplace and offer to mentor them in tasks to ensure they have all the help they need.

Making your colleague feel included will also ensure they feel like a valued member of the team, and will create a positive atmosphere.

This could be as simple as asking the employee with Down’s syndrome to join you for lunch, or letting them know about a workplace event that all staff

are participating in. An inclusive environment is a happy environment.

### 3. Speak up: Empower your colleague

People with learning disabilities can be more vulnerable to workplace bullying. Make it your business to ensure that there's zero tolerance to discrimination or abusive behaviour.

If you see any mistreatment or bullying of any colleagues, including colleagues with Down's syndrome, vocalise it. Report the incident immediately and speak up for your colleague. Stamp out the bullies.

### 4. Explain: The unwritten rules



“By working with Sarah we have learnt a lot, and as a result have adapted our working environment to provide her with the support she needs.” Staff at Thistle Hotel

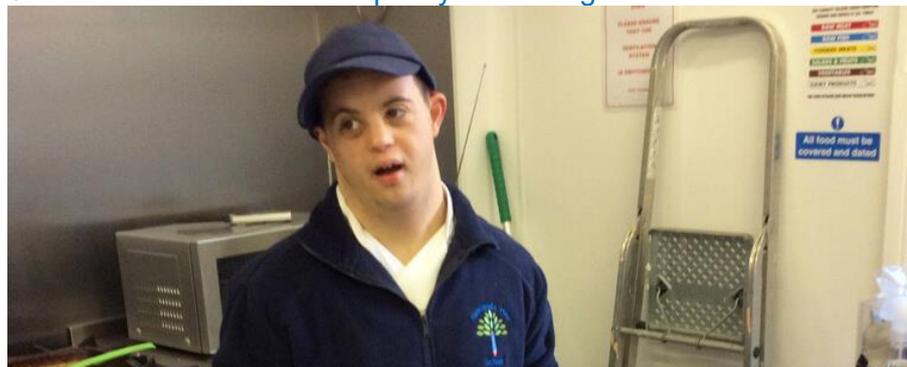
While most employers will dedicate time to inducting new starters in the formal rules and regulations of the workplace, it's often the unwritten rules that make the difference. It is the little things that matter, for example which mug to use, where to make a cup of tea etc.

Acting as a workplace ally/mentor in all informal things will help your new colleague to settle into the workplace. Communication is key.

Communicate with short clear sentences and use open ended questions. Allow time for your colleague with Down's syndrome to provide you with answers and to ask you any questions they might have.

Always ask questions to confirm that they have understood the task or instruction. Provide further explanation if needed in a way that is clear, and visual.

### 5. Don't underestimate: Respect your colleague



“Before I was offered only unpaid work. But I’ve always wanted a job where I can get paid for my work, to help me understand money and budgeting better and to be more independent.” Ben, Newlands Hey School.

Although some adults with Down’s syndrome may need additional training or time to get used to their working environment, do not underestimate their work abilities.

In 2015 Ben Small, 28 years old, faced constant rejections from companies in his search for a job, despite having an NVQ1 in catering. Ben has Down’s syndrome and as a result, many companies underestimated his working potential.

In a bid to help her step-son have the chance to work, Fiona Hodge asked for help on Twitter, creating the hashtag #GetBenAJob. Not only did the hashtag go viral, but as a result Ben was inundated with job offers, eventually opting to choose a job in Wilson’s Kitchen.

By Veronica Mulenga

Veronica Mulenga is the Employment Development Manager at the Down’s Syndrome Association. Since joining the Down’s Syndrome Association in 2011, Veronica has led the development and implementation of one of the charity’s flagship programmes: WorkFit, and has been responsible for its immediate success.

## 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](mailto:internazionale@aipd.it)

### THE STAFF

Carlotta Leonori

Paola Vulterini

Claudia Galieti