

## SUMMARY

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## NEWS FROM EDSA

### EDSA founder Montserrat Trueta died

Montserrat Trueta i Llacuna died peacefully in Barcelona on May 4, 2018.



She was one of the founders of EDSA in 1987. Since all these years she has been fighting for a better life quality for persons with Down Syndrome.

Montserrat Trueta i Llacuna was the patron founder of the Catalan Private Down Syndrome Foundation, a reference point for families and professionals, in both medical, educational, social and professional aspects. The Foundation offers its services to over a thousand families in both psycho-educational and social aspects, and boasts the first preventive medical centre in the world.

Her legacy has improved the lives of many families. We have attached this obituary, should you wish to contribute to disseminate her memory.

### Portrait of Montserrat Trueta i Llacuna

Montserrat Trueta i Llacuna was the second of the three daughters of the famous Catalan surgeon Dr. Josep Trueta, and his wife Amèlia Llacuna. She spent her early years in Barcelona, at a boarding school in Italy (from 1936) and, from 1939, in England. She began a BA in Biology at the University of Oxford, but broke off her studies after marrying Ramon Trias Fargas – whom she accompanied in his outstanding academic and political career until his sudden death during an election rally in October de 1989 – and settling back in Barcelona.

She had four children who all survive her: Toni, Katy, Mireia and Andy. She also leaves behind her beloved companion, the US academic Lowell Lewis.

## **Son with Down Syndrome**

One of the turning-points in her life was the birth of her youngest son, Andy in 1972. He was born with Down's syndrome, and Montserrat "accepted the diagnosis but not the daunting prognosis that accompanied it". Not giving in to local medical advice she visited specialist Val Dmitriev from the University of Washington and began to apply early stimulation techniques. She took up her university studies again and completed a degree in Clinical Psychology at the University of Barcelona in 1986. A board and AGA decided to have a similar website campaign like in the years before. This is the information about what we plan to do and how you can participate.

## **Foundation of the Catalan Down Syndrome Foundation**

In the absence of a well organized system for supporting families, she founded in Barcelona the Catalan Down Syndrome Foundation in 1984 with her husband, and at the time of her decease she was still the chairperson of its Board of Trustees.

The Foundation has become a reference point for families and professionals, in both medical, educational, social and professional aspects, and continues to improve the quality of life of persons with Down Syndrome. It offers its services to over a thousand families in both psycho-educational and social aspects, and boasts the first preventive medical centre in the world. Montserrat was a "brave, determined" woman in her pioneering crusade to give her son Andy and others like him "as autonomous a life as possible" and developed a close relationship with leading scientific figures throughout the world.

She was proud her son Andy has been living an independent life, with his wife, for fifteen years, and is a full-time employee of the foundation of a bank.

## **Awards**

In 1992 she received the Creu de Sant Jordi from the Catalan Government (Cross of Saint George) «for her great contribution to the social integration of people with disabilities» and in 2004 the Gold Medal of Honour of the Parliament of Catalonia "for her work in improving the quality of life of people with Down syndrome and for their contribution to the social integration of people with intellectual disabilities". In 2008 she was awarded the Cruz de Oro de la Orden Civil de la Solidaridad Social. These awards were a public recognition of her social and political commitment to human rights and justice.

The baton she leaves in her aim for the "total inclusion in society" of people with syndrome Down and other intellectual disabilities will be enthusiastically taken up. Nevertheless, she will be sorely missed by all who had the good fortune to meet, admire and love her.

## NEWS FROM EDSA MEMBERS

### DOWN SENDROMU DERNEGI (Turkey)



#### DOWN TO EARTH ROAD

Adem Çolak, nicknamed as Iron-horsed Nomad, was on a journey from Istanbul to Nordkapp on 30'th August 2017 with the aim of creating awareness for his brother and all the people with Down syndrome. Now he is ready to make a new route from Turkey to Japan. Would you like to participate this international awareness campaign created by the collaboration of Adem Çolak, himself and Down Syndrome Association?

#### What did Iron-horsed Nomad do so far?

Mounting on his iron horse, he started his journey from Istanbul and traveled up to the Norddkapp which is the northernmost point of Continental Europe. He visited totally 25 countries including Greece, Albania, Macedonia, Kosovo, Montenegro, Bosnia and Herzegovina, Croatia, Slovenia, Italy, Austria, Switzerland, Germany, Denmark, Sweden, Norway, Finland, Estonia, Latvia, Lithuania, Poland, The Czech Republic, Slovakia, Hungary, Romania, and Bulgaria.

#### What did he do in these countries?

He contacted with Down syndrome associations in these countries, met with people with Down syndrome, he listened to their stories, learnt their targets, dreams, their wishes from the people who run the country they live in, he recorded all these, took photos and shared them in the social media. He left a mark of people with Down syndrome in Europe by sticking Down to Earth stickers. And also he had surprises for some of the countries he visited.

#### Why?

All this effort bears solely one target which is to create awareness about Down syndrome: Iron-horsed Nomad spent 80 days on the road to create a synergy between Down syndrome associations on an international level, to have an adventure, to know more about people with Down syndrome, to know oneself, to know ourselves, to live and let live, and to understand that

everyone, regardless of what syndrome they may have, must live a life having the same rights...

### What is next?

LET's meet on route to Japan and spread the spirit....

*Our route is from Georgia to Japan. (Georgia, Azerbaijan, Kazakhstan, Uzbekistan, Tajikistan, Kirghizistan, Russia, Mongolia, Japan)*

## NEWS FROM PROJECT WITH EDSA MEMBER IN THE CONSORTIUM

The ValueAble Network (logo Valueable)

On the 21<sup>st</sup> of April 2018, the Registered Trademark Valueable Handing Opportunities has been registered at the European Union Intellectual Property Office [EUIPO](#) !!!



The Valueable network has been created within the Erasmus + On my own...at work project, financed by the European Commission in 2014-2017. During those years, a group of disability associations, universities, hotels and one foundation for equal opportunities designed, developed and tested the three tools, which are now promoted by the network: an app for the trainees/workers with intellectual disabilities, videos for a proper relationship between people with id and their work -mates and a set of instruments aimed at certifying the efforts of the company towards work inclusion.

Read more: [www.valueablenetwork.eu](http://www.valueablenetwork.eu)



## NEWS FROM EU PROGRAMME

### Commission adopts proposal for the next Erasmus programme 2021-2027



On 30 May, the Commission adopted its proposal for the next Erasmus programme, with a doubling of the budget to 30 billion euros for the period 2021-2027.

Building on the success of Erasmus+, the next programme will provide learning and mobility opportunities to 12 million people, in comparison to 4 million people in the current programme. Its focus on “evolution, not revolution” means that the 'Erasmus' programme will continue to cover schools, vocational education and training, higher education and adult learning - youth and sport, but in a more streamlined manner. Building on the mid-term evaluation and stakeholder consultations, the next programme will be substantially strengthened, extended and more inclusive. It will further promote activities which foster knowledge and awareness of the EU, opportunities in forward-looking knowledge fields e.g. climate change, robotics etc. and better outreach and inclusion of people with fewer opportunities. The international dimension of the programme will also be boosted. Investing in people, their skills, and their knowledge will help respond to global challenges, maintain social fairness and drive Europe's competitiveness.

Tibor Navracsics, Commissioner for Education, Culture, Youth and Sport said:

“I am very proud that this Commission has proposed to double the budget for Erasmus – this is by far the biggest increase for any programme in the EU budget we have tabled. And we need to be bold: this programme will support the big ambitions we have for empowering young people, building a European Education Area and strengthening European identity. I call on Member States and the European Parliament to support us and make sure we invest in our most precious resource: people”.

Read more: [https://ec.europa.eu/commission/publications/investing-people\\_en](https://ec.europa.eu/commission/publications/investing-people_en)

## 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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