

# **EUROPEAN DOWN SYNDROME ASSOCIATION**

September 2021

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# **EDSA WEBINAR**



Serious illness in children with Down Syndrome

Speaker: **Dr. Elizabeth Herrieven, Consultant in Emergency Medicine and Paediatric Emergency Medicine in Hull** 

Date: Wednesday, 15 September 2021, 17.00 h. CET, per Zoom

Registration

link: https://us02web.zoom.us/webinar/register/WN nptY8WpvRPeTTGGkqRGRyQ

People with Down's syndrome are at increased risk from serious illness.

Dr. Elizabeth Herrieven shall be reviewing some of the reasons for this, discussing what can be done to keep people healthy and explaining some of the warning signs to watch out for.

She shall be including information about COVID-19 and vaccination, but this will not be the main focus of the presentation.

### **BIOGRAPHY**





Dr. Elizabeth Herrieven is a Consultant in Emergency Medicine and Paediatric Emergency Medicine in Hull, East Yorkshire, UK, where she lives with her husband and two children. Her eldest child, Amy, is 15 and has Down's syndrome and autism. Because of her childhood healthcare issues she has developed an interest in health inequalities and access to healthcare for people with a learning disability or autism.

She trained at the University of Sheffield Medical School, graduating in 2001. Her qualifications are MBChB (hons), MRCS Eng (2004), DCH, FRCEM. She is a member of the Steering Group for the Down's Syndrome Medical Interest Group (UK and Ireland), has presented nationally and internationally on serious illness and health inequalities for people with learning disabilities or autism. Dr. Herrieven has written a number of articles for healthcare professionals and parents, along with a guideline for the pre-hospital management of patients with communication difficulties for **JRCALC** UK. She is also a member of the online medical training team behind Don't Forget The Bubbles (for paediatricians) and an editor for RCEM learning (for emergency physicians).



# **WDSC DUBAI 2021**



Dears European Down Syndrome Association,

Best greetings from World Down Syndrome Congress Dubai 2021.

In recognition of your outstanding work and your significant contribution to People with Down syndrome community, we are reaching out to you today to seek your kind cooperation in promoting the 14th World Down Syndrome Congress Dubai 2021 which will take place virtually on 18-20 Nov. 2021, under the patronage of HH Sheikh Hamdan Bin Mohammed bin Rashid Al-Maktoum Crown Prince of Dubai, Chairman of The Executive Council. The congress will discuss the significant developments and quality research in recent years in key areas of global relevance to people with Down syndrome. Topics of interest will include health, education, employment, sports, recreation, and leisure.

I'm pleased to inform you that we have extended the deadline for Abstract submission until the 22nd of Sept. 2021. Attached please find the E-Shot email and social media posts that we use to announce the extension of abstract submission. We would highly appreciate your kind support to endorse the congress and circulating the e-shot among your members and on social media platforms.

You may find further information and details via the congress website: <a href="https://wdsc2021.org.ae/">https://wdsc2021.org.ae/</a>

Thank you very much for partnering with us in promoting this very important event for people with Down syndrome, and looking forward to your valuable participation in the congress.

Please don't hesitate to contact me if you require any further clarification or details.

With much appreciation and gratitude,

Dr. Manal Jaroor

President of WDSC Dubai 2021

Chairperson of Emirates Down Syndrome Association



# 14. World Down Syndrome Congress Dubai 2021

Virtual Congress, 18-20 Nov, 2021



**HH Sheikh Hamdan Bin Mohammed Bin Rashid Al-Maktoum** Crown Prince of Dubai Chairman of The Executive Council

Under the patronage of HH Sheikh Hamdan Bin Mohammed Bin Rashid Al-Maktoum Crown Prince Of Dubai Chairman of The Executive Council, Emirates Down Syndrome Association is hosting the World Down Syndrome Congress (WDSC) 2021, which will be held virtually in November 2021. This is the first event of its kind to be held in the Middle East and North Africa. In a global phenomenon, the WDSC will bring together an anticipated 1500 delegates including people with Down syndrome, their families and advocates, experts, specialists and researchers in the field of Down syndrome.

The congress will discuss significant developments and quality research in recent years in key areas of global relevance to people with Down syndrome. Topics of interest will include health, education, employment, sports, recreation and leisure. Focus will be on human rights based issues (in line with the United Nations Convention on the Rights of People with Disability (UNCRPD)) such as ensuring adequate standard of living, social protection, legal recognition, social and cultural inclusion and the right to live an independent life.

The WDSC is a global event organised by Down Syndrome International (DSi) and hosted by DSi National Representative Organisations in different locations around the world.







**Dr. Manal Jaroor**President of WDSC 2021
Chairperson of Emirates Down Syndrome Association

It gives me a great pleasure to invite you to the World Down Syndrome Congress Dubai 2021, a great event that will bring together experts, parents, professionals, researchers sharing with us the latest trends and issues as well as success stories of people with Down syndrome. Appreciate the great support from our prudent leaders by adopting laws, legislations, National Policies and ambitious initiatives that promote the participation and inclusion in the community and positively engaging for People of Determination in their environments, as capable individuals of society. It is a unique and amazing experience to host this Congress for the first time in the Middle East and North Africa region. We are proud that the choice from DSi was due to recognition of the role played by Emirates Down Syndrome Association (EDSA) and a culmination of its efforts in contribution to the improvement of the quality of lives for people with Down syndrome in the UAE, the most tolerant place on earth whereas more than 200 nationalities living together in peace and harmony. Looking forward to your valuable participation.



**Vanessa Dos Santos** President of Down Syndrome International



As President of DSi and on behalf of our board, staff and members, it is an honour and a great pleasure to invite you to the 14 th World Down Syndrome Congress Dubai 2021 which will be held virtually. This will be the first time the WDSC has been held in the Middle East and the event promises to inform, inspire and influence everyone who attends for years into the future. It has been really encouraging to see the high level of interest in WDSC 2021 from all over the world, when we were in Glasgow for WDSC 2018 and since then through the DSi membership. We urge all of you to register to attend, submit your abstracts and tell your friends and colleagues about this unique gathering of the global Down syndrome community. DSi would like to say a big thank you to Dr Manal Jaroor, everyone at Emirates Down Syndrome Association and the WDSC 2021 organising team for all the hard work you are putting in to organising this substantial international event. We know that through your efforts, we will all participate in a really successful WDSC, which will ultimately improve lives for people with Down syndrome around the world. We would also like to acknowledge and thank the many partners and sponsors for their support. Thank you to all those concerned. We trust everyone who attends will find WDSC 2021 of great benefit and that you will share your experience with as many people as possible. We look forward to your valuable participation.

More information about registration, abstracts exhibition etc.: <a href="https://wdsc2021.org.ae/">https://wdsc2021.org.ae/</a>



# PRIVATE FOUNDATION



<u>Boustany Foundation</u> Boustany Foundation, a philanthropic organisation founded in 2006 by Nabil Boustany and his son Fadi and based in the Principality of Monaco and Switzerland, is committed to managing scholarships and aid programmes to contribute to the development and well-being of mankind, in particular the younger generation.

With the first edition of the "Sport 4 Children Award", the Foundation intends to:

- promote and encourage children's participation in sporting activities, as well as stimulate new sporting initiatives aimed at children
- improve children's mental well-being and create inclusive relationships and communities with respect to ethnic, cultural and physical differences; and
- to encourage children's engagement in social and educational opportunities by highlighting the value of self-esteem and confidence gained through achievement;
- helping disadvantaged children to live their childhood free from violence by encouraging them to develop as conscientious and responsible adults.

### **CHARACTERISTICS OF PROJECTS**

Projects submitted may involve any sport that stimulates children's engagement in physical activity in line with the objectives of the Award.

The variety of eligible proposals is wide, ranging from the organisation of sports activities/events focusing on the social and educational role of sport to the provision of sports facilities and equipment.

Projects can be implemented in any country in the world.

### **ELIGIBLE APPLICANTS**

Organisations wishing to apply for the award must:

- be legally constituted as governmental or non-governmental organisations, educational, cultural or academic organisations, foundations, non-profit and/or social impact organisations;
- be registered in one of the following countries: any member country of the European Union, United Kingdom, Switzerland, USA or Canada;
- invest economic resources in projects or programmes related to children and sport:
- have at least 3 years' experience in managing this type of project;
- have a track record of achievements through projects or programmes for the improvement of children's lives.



#### **SIZE OF THE AWARD**

The Boustany Foundation offers the winning project a prize of up to 50,000 euros.

The amount awarded to the winner will be determined by the project's cost estimates indicated in its application. Projects exceeding 50,000 euros are eligible, although it will be up to the winner to cover the excess amount.

### **HOW TO PARTICIPATE**

Applications must be submitted according to the procedure indicated on the dedicated page by 22 October 2021.

The foundation will review the entries to identify a shortlist of candidates, who will then be invited to participate in online interviews where they will discuss and evaluate the merits of individual projects to identify the winner.

Link to the award web page



**INCLUSION EUROPE** 



"Employment is a way to inclusion"

a new edition of Europe for us newsletter - Easy to read



Inclusion Europe published a new edition of Europe for us for 2020! Europe for us is their newsletter for self-advocacy. It is written in easy-to-read. The newsletter is available in English, French, German, Hungarian, Italian, Romanian and Spanish.

https://www.inclusion-europe.eu/new-edition-of-europe-for-us-easy-to-read-2/



### **NEWS FROM EDSA MEMBERS**

# **Request from DS Turkey**



As Down Syndrome Association of Turkey we need your contributions to our two activities.

- We want to organize a webinar to promote supported employment programme. In that webinar our target is to invite speakers from compaines and government institutions like municipalities, from all over the world who implement supported employment programme and we want them to share their experineces, how did they start, what they gained, achivements, benefits, weaknesses. Would you please send us the name and contact information of the companies who works with people with intellectual disabilities, Down syndrome, autism and mental health issues, if any. If you want you can be one of the partner of that webinar and contact with that compaines directly on behalf of us. We will arrange simultaneous translation. So there is no language barrier.
- We want to start a work about inlusive education in Turkey. We need to study to learn what are the regulations in classrooms and schools and the materails, what are the qualities of experts, and what are the legal regulations to support it, in different countries. We are planing to make short interviews on zoom ( or if you want you can give your answers in writing) and then decode them and prepare a report about it with our advices for Turkish education system to the Parliament and Ministry of Education .

If you want to help us and share your knowledge please write to me. Fulya Ekmen: fulya@downturkiye.org

Thank you for your contributions and efforts in advance.

I hope you will take part in our works and help us to prepare better conditions for people with Down syndrome.

Best Regards, Fulya Ekmen Secretary General



## 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

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# THE STAFF

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