10th World Down Syndrome Day Conference

Session 1

Opening and Launch – #CONNECT

Virtual event
Wednesday 17th March 2021 – 10:00 AM EDT/2:00 PM UTC
World Down Syndrome Day (WDSD)

WDSD is a global awareness day recognised since 2012 by the UN, which takes place on 21 March every year. 21 March, or 21:3, signifies the triplication of chromosome 21, unique to persons with Down syndrome. On 19 December 2011, the United Nations General Assembly declared 21 March as World Down Syndrome Day (A/RES/66/149).

Summary of event

10th World Down Syndrome Day Conference – Opening and Launch - #CONNECT

On Wednesday 17th, Thursday 18th and Friday 19th March join DSi online as we host our 10th annual World Down Syndrome Day Conference as a series of virtual events.

Speakers will include people with Down syndrome, supporters and advocates, government and UN officials and NGO representatives. They will share their experiences, knowledge and expertise, bringing perspectives from around the world.

In Session 1, we will look at the importance of #CONNECT (connecting) for people with Down syndrome and intellectual disabilities, in the context of the COVID-19 pandemic and the resulting exacerbation of inequalities.

We will identify barriers and solutions to connecting to inform COVID-19 recovery plans and to build a future where connecting is possible on an equal basis with others.
Participants

**Moderator:** Morgan Maze, National Self-Advocate Representative from Indonesia

**Opening remarks:** Vanessa dos Santos - President of Down Syndrome International and Co-Vice Chair of International Disability Alliance

**Her Excellency Ms Joanna Wronecka** - Ambassador and Permanent Representative of Poland to the United Nations

**His Excellency Mr Kimura Tetsuya** - Ambassador Economic, Social and United Nations Management Affairs Permanent Representative of Japan to the United Nations

**Speakers:**

**Vladimir Cuk** - Executive Director at the International Disability Alliance. ‘The effect of Covid-19 on people with disabilities and what needs to happen now’

**Andrew Boys** - Executive Director of Down Syndrome International ‘The importance of connecting and the issues facing people with Down syndrome’

**Dennis McGuire** - Consultant at the Global Down Syndrome Foundation and international expert in Mental Wellness in the Down syndrome population ‘Mental well-being during COVID-19’

**Representatives from the Down Syndrome Society of Bangladesh DSSB** – Self-advocates and advocates ‘Living with Down Syndrome during COVID-19 - An Amazing Experience’

**Down Syndrome Foundation Nigeria (DSFN)** – Self-advocates ‘Connections during COVID-19’

**Türkiye Down Sendromu Derneği (TDSD)** – Self-advocates ‘Stay connected’
Speaker Bios

Andrew Boys
Executive Director, Down Syndrome International, United Kingdom

Andrew Boys has been the Executive Director of Down Syndrome International since the launch of the DSi secretariat in 2009 in the UK, working with DSi’s Board of Trustees to establish a global membership network in 140 countries, promoting the inherent right of people with Down syndrome to be accepted and included as valued and equal members of their communities.

For the last 9 years, Andrew has led DSi’s World Down Syndrome Day campaign, including the global sharing website [www.worlddownsyndromeday.org](http://www.worlddownsyndromeday.org), WDSD global video event and the successful WDSD Conferences following the UN General Assembly resolution (passed in December 2011) officially recognizing WDSD on 21 March each year.

Andrew established DSi’s “global support” training programs to enable people with Down syndrome facing limited life opportunities, their families and those who live and work with them, to access expert advice, information, support and resources, with successful projects taking place in Tajikistan, Oman, India, Rwanda, Peru, Turkey and Nigeria to date.

In a former life Andrew was a chartered surveyor in London. Andrew’s younger brother Alex is a motivated, independent young man ...he also has Down syndrome.

Vladimir Cuk
Executive Director of the International Disability Alliance, New York

Mr. Vladimir Cuk has 19 years of a progressive and diverse career in implementing the rights of persons with disabilities and international development as well as personal experience of disability. He started his career in war-torn Yugoslavia by establishing a grassroots organization of young people with disabilities, continued at the University of Illinois at Chicago as a researcher, and finally as the Executive Director of the International Disability Alliance (IDA) - a network of 14 global and regional organizations of persons with disabilities and their families, bringing together over 1100 organizations from 182 countries of the world.

Vladimir is responsible for managing the IDA Secretariat, IDA advocacy towards the UN System as well as for cochairing the Global Action on Disability (GLAD) – the donor coordination mechanism which promotes disability inclusive development. He has an extensive experience in managing multi-stakeholder partnerships and networks (serving at the UNPRPD policy board, UNIASG, UNIASC), external relations, coordination of the Global Disability Summit, resource mobilization and management at the global and national level. He has managed relationships with more than 80 UN missions across all pillars of the UN’s work, and engagement with UNCTs, as well as managed disability related programs for results at global and country level and increased IDA’s resources by 250% in 4 years.

Mr. Cuk received his PhD from the University of Illinois at Chicago in Disability Studies, together with seven awards in recognition for his academic achievements. Vladimir published a book, several articles and encyclopedia entries. Vladimir lives in New York with his wife and daughter.

Down Syndrome Society of Bangladesh
Speakers include self-advocates: Fahim Hasan, Shahadat Akbar Otanu and Sultana Moshfeka Phool. Advocate: Shahanaj Parven Chowdhury and Chairman: Sarder Razzak

DSSB works towards creating an inclusive society in Bangladesh through their development initiatives in health education and employment.
It provides a platform for people with Down syndrome in Bangladesh and their families. It educates and creates awareness about the condition, offers support for the down syndrome community in the country.

Following negotiation by DSSB, in 2016 the government of Bangladesh declared the 11th World Down Syndrome Day should be observed at national level for the first time in Bangladesh.

DSSB is a representative organisation member of Down Syndrome International and an active member of Asia Pacific Down Syndrome Federation (APDSF).

**Down Syndrome Foundation Nigeria (DSFN)**

**Speakers from the DSFN self-advocacy group**

The DSFN self-advocacy group was founded in December 2018. It has about 13 facilitators & 22 self-advocates in our group.

The DSFN advocacy group meets twice in a month to discuss, interact, educate, and also share ideas about the advocacy group. The self-advocates are always fully involved and ready to participate and contribute in every task given.

With every task and event attending the self-advocates confidence is growing.

Some of the greatest achievement of DSFN were:

- when the advocates expressed their right to vote during the last elections in Nigeria in the year 2019.
- during the course of our group advocacy the advocates led a team to the Local Government chairman to sign the Protocol of the African Charter on Human and Peoples’ Rights on the Right of Persons with Disabilities in Africa in 2019.
- in 2021 the advocates visited the Nigeria Institute of Medical Research (NIMR) to advocate for free COVID-19 tests and vaccines, visited the Lagos state office of Disability Affairs (LASODA).
- for Also their confidence is increasing with the number of outings/visits they attend.

**Morgan Maze**

**National Self- Advocate Representative from Indonesia**

Morgan Maze is 22 years of age, and speaks French, Indonesian and English. Morgan is currently working as a Class Assistant on a weekly online class for a Peer Group of young adults with Down syndrome. Morgan is also the co-author of 2 books on Covid-19 in Indonesian easy language. Morgan’s narrative as a self-advocate has been written together with 28 other social activists from all over the works in a book titled ‘Narrative Power & Collective Action’ by Isabel Crabtree- Condor in 3 languages, including English, Spanish and French. Morgan is the only individual with a disability within the collaborators.
Dennis McGuire
Senior Consultant at Global Down Syndrome Foundation, United States

Dennis has had two periods of practice. From 1992 - 2013 he specialised on the behavioural health of persons with Down Syndrome at the Down Syndrome Center at the Lutheran General Hospital. Despite a narrower focus this was a continuation of his earlier focus on families, relationships and behavioural issues, and his emphasis continued to be on strengths and resources rather than deficits.

In his first 15 years I worked as both a practitioner of Family therapy and trained other therapists in this approach at the Institute for Juvenile Research (University of Illinois Medical campus). He developed expertise with couples with marital problems, families of children with behavioural concerns, attention deficit issues, depression, loss issues and a host of other issues.

In 2013 he took up his position as Senior Consultant at the Global Down Syndrome Foundation in Colorado.

Vanessa dos Santos
President of DSi and Co-Vice Chair of International Disability Alliance, South Africa

Vanessa Dos Santos is the mother of 3 boys of which the youngest has both Down syndrome and Cerebral Palsy.

Vanessa is President of DSi and Co-Vice Chair of International Disability Alliance. She has been working in the disability field since 1996, focusing on intellectual disability in poverty-stricken areas in Africa.

His Excellency Ambassador Mr Kimura Tetsuya
Ambassador Economic, Social and United Nations Management Affairs Permanent Representative of Japan to the United Nations

In 1989 Ambassador Kimura graduated from the Faculty of Law, University of Tokyo then obtained a Magister Artium (M.A.) from the Faculty of Philosophy, Ludwig Maximilians University of Munich.

In 1986 he joined the ministry of foreign affairs and then took up various positions in the UN and in Japanese Embassies in Austria, Indonesia and Germany.


In June 2020 he was appointed the Ambassador Permanent Mission of Japan to the United Nations in New York.

Türkiye Down Sendromu Derneği (TDSD)
Speakers: Self-advocate representatives

TDSD is DSi’s National Representative Organisation Member in Turkey. TDSD has a very a very active self-advocacy group.

The representatives of this group involved in the presentation in this session are:

Büşra Gonca Uyanık, 33 years old, she works in a baby clothing store. She is interested in music and painting. She is a self-advocate. She was one of self-advocates who visited the Turkish parliament and made
a campaign for establishment of Down Syndrome Commission. Last year she worked in a project for poverty and social exclusion.

**Halis Güney**, 26 years old. He works as a waiter in a hotel’s lobby bar. He is interested in handcrafts and dance. He is dancing for 3 years in TDSD’s dance club. He is also a self-advocate. Last year he worked in a project for poverty and social exclusion.

**Hilal Hamurcu**er, 32 years old. She works in a baby clothing shop. She loves going to the movies and her hobby is painting. She was one of the self-advocates who visited the Turkish parliament and made a campaign for establishment of Down Syndrome Commission. Last year she worked in a project for poverty and social exclusion.

**Her Excellency Ambassador Joanna Wronecka**  
**Permanent Representative of Poland to the United Nations.**  

Prior to her latest appointment, Ms. Wronecka was Undersecretary of State for Development Cooperation in Poland’s Ministry of Foreign Affairs beginning in 2015, responsible for Africa, the Middle East and Human Rights. From 2011 to 2015, she was Ambassador and Head of the European Union delegation to Jordan. She was Ambassador to Morocco from 2005 to 2010. Between 2003 and 2005, Ms. Wronecka served as Director and Ambassador in the Secretariat of the Foreign Ministry, having been Ambassador to Egypt from 1999 to 2003. She was previously Director of the Foreign Ministry’s Africa and Middle East Department, from 1998 to 1999. From 1994 to 1998, she held a number of positions in the United Nations System Department within the Ministry, which she joined after having held different positions in academia.

Ms. Wronecka earned a doctorate in humanities from the University of Warsaw’s Institute of Oriental Studies, and holds a master’s degree in Arabic studies.

**Thank You**

Down Syndrome International would like to thank all those who took part in this event, at a time when the COVID-19 pandemic is causing disruption and uncertainty in everyone’s lives. It is testimony to the value and importance of the issues discussed in this event that we have made this happen.

We are extremely grateful to our sponsors, the Permanent Missions of Australia, Brazil, Japan, Mexico, and Poland to the United Nations in New York and also to UNICEF and International Disability Alliance.