



Side Event to the 24th Session of the Committee on the Rights of Persons with Disabilities – World Down Syndrome Day 2021

**#CONNECT – Ensuring all people with Down syndrome can
#CONNECT and participate on an equal basis**

Virtual event

Friday 19th March 2021 – 2:30 PM CET/1:30 PM UTC



**UK Mission
Geneva**



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

Side Event to the 24th Session of the Committee on the Rights of Persons with Disabilities – World Down Syndrome Day 2021

#CONNECT – Ensuring all people with Down syndrome can #CONNECT and participate on an equal basis

This event will enable self-advocates with Down syndrome to reach out to members of the United Nations Committee on the Rights of Persons with Disabilities, government officials, and civil society representatives.

The focus of the event will be ensuring all persons with Down syndrome can #CONNECT and participate on an equal basis with others.

Following remarks from representatives of Permanent Missions to the United Nations in Geneva, our guest speaker Sir Robert Martin, together with self-advocates from around the world, will share their views, knowledge and personal experiences of #CONNECT (connecting) during COVID -19.

They will discuss the importance of connecting, the barriers they have found and the solutions they have developed.

Down Syndrome International is grateful to our sponsors the Permanent Missions of Brazil, Israel and the United Kingdom to the United Nations in Geneva, United Nations Office of the High Commissioner on Human Rights (UN OHCHR) and to the International Disability Alliance.

Participants

Moderator: **Eileen Dunne** - Self-advocate, Chairperson of the National Advisory Council of Down Syndrome Ireland

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

Her Excellency Mrs Meirav Eilon Shahar, Ambassador and Permanent Representative of Israel to the United Nations in Geneva

Speakers: **Sir Robert Martin KNZM** - member of the Committee for the United Nations Convention of the Rights of Persons with Disabilities
'The age of great change'

Claire Mitchell - Down Syndrome Advisory Network, Australia
"My Life through Covid"

My Future - Vietnam

Speakers include: **Nguyen Ha Thanh, Nguyen Quoc Uyen Phuong, Nguyen Trinh Mai Phuong, Nguyen Ngoc Lan Anh**
"Connection" before COVID-19 and now" and "Stay in touch during COVID time"

Yated (Down Syndrome Society of Israel) – the Shiluvim project
Self-advocates talk about connections during COVID-19

Gigo Shiukashvili - Founder of the Georgian Down Syndrome Association, Georgia
Gigo talks about his experiences during COVID-19

Türkiye Down Sendromu Derneği (TDSD), Turkey
Self-advocates talk about *'Stay connected'*

Bryan Russell Mujica and Self-advocates –
Sociedad Peruana de Síndrome Down, Peru
"Staying connected is not only a matter of technology"

Sheri Brynard, Member of DSI National Representatives Group, South Africa
'The importance of the group in connecting during COVID-19'

Speaker Bios

Shéri Brynard, Assistant teacher and national chairperson for the self-advocates of Down Syndrome South Africa

Shéri Brynard is the only person with Down syndrome in South Africa who has a tertiary teacher's diploma without any amendments been made to the course, in South Africa. Sheri has also been chosen by her Down syndrome peers as their official South African spokesperson and she is the South African representative on the Down syndrome international Forum, for adults with Down syndrome.

She truly believes that all people have the responsibility to strive to make the best of their circumstances and she is a living example thereof. The University of the Free State has invited Shéri to assist in a project to motivate learners in schools for disadvantaged learners in the Free State (before Covid-19). She is currently also a full time qualified assistant teacher at a Primary school for learners with special educational needs and she still presents motivational speeches all over the world virtually.

Shéri strives to change negative perceptions about people with Down syndrome and she actively advocates for the rights of all people with any disadvantage to be granted the same opportunities they would have had if they were more privileged. Although she is intellectually disabled and was educated in our Afrikaans language, she succeeded in learning to speak English in order to reach more people with her story of hope. When she grew up there was little or no support in the form of therapy, etc. available in South Africa. Shéri wrote a book about her life and the manuscript was accepted and published. The book has been launched internationally in English and also in Afrikaans locally. Sheri is currently the co-presenter of her own radio show, in Bloemfontein. She invites well known guests to tell the listeners about themselves and the work they do.

Eileen Dunne, Chairperson of the National Advisory Council of Down Syndrome Ireland.

"My achievements are about communication and independence. People with Down syndrome should speak up for themselves. I like my photograph because it shows me talking about all. I am at the moment doing training sessions in bowling. I am happy and proud of representing Ulster in the Special Olympics Ireland in bowling. My dream is I would like to be an ambassador for Down syndrome and would like to be doing films and photography."

Sir Robert Martin KNZM, Whanganui, New Zealand

Sir Robert has spent his life advocating on behalf of disabled people and in particular people with learning disability, both in New Zealand and around the world. Sir Robert spent most of his childhood in institutions. This experience has given him a great interest in ensuring that all disabled people get the opportunity to live in the community from birth.

Working for IHC New Zealand for some years, Sir Robert assisted the organisation to bring self-advocacy and People First to New Zealand. He is now a Life Member of the Disabled People's Organisation, People First New Zealand Ngā Tāngata Tuatahi.

Sir Robert was a long-standing member of the Inclusion International Council and was Chairperson of the Self-Advocacy Taskforce from 1996 to 2008. Through his roles in Inclusion International, he took part in negotiations around the United Nations Convention on the Rights of Persons with Disabilities.

Sir Robert is a recognised role model for people with learning disability and a sought-after international speaker and advisor on self-advocacy. Over the years, Sir Robert has travelled the world speaking to organisations, families, and people with learning disability about many topics, including the right to live in the community, deinstitutionalisation, the right to work, and having the life of your choice.

His words have effected change in policies and practices which have made a positive difference for disabled people around the world.

Sir Robert has had a book written about his life called “Becoming a person”.

Sir Robert was New Zealand’s nominee for the Committee for the United Nations Convention of the Rights of Persons with Disabilities and was successfully elected to this role in June 2016. He has just completed his first four-year term as an Independent Expert and has been reelected for a second term.

Sir Robert received his knighthood in January 2020 for his achievements and it is believed that he is the first person with a learning disability to have received such an award.

Claire Mitchell, Down Syndrome Advisory Network, Australia

Claire Mitchell is an independent director on the Down Syndrome Australia Board, and a member of Down Syndrome Advisory Network. She is passionate about being a voice for people with Down syndrome. Claire believes in having a positive attitude and that the best support outcomes for the Down syndrome community happen when everyone is working together as a team.

The Down Syndrome Advisory Network (DSAN) is the Australian self-advocacy network for people with Down syndrome. It includes representative from each State and Territory. The DSAN provides advice to the Down Syndrome Australia CEO and Board. DSAN makes sure that Down Syndrome Australia receives direct input from Australians with Down syndrome on issues that affect them.

DSAN helps Down Syndrome Australia to:

- understand what is important to people with Down syndrome
- make sure the work of Down Syndrome Australia reflects input from people with Down syndrome
- be a credible representative voice for people with Down syndrome
- develop resources, and
- identify and develop people with Down syndrome as leaders.

Claire’s comments on being part of the DSAN “It means a lot to me being an ambassador for people with Down syndrome. I will keep on trying to the very best of my ability along with the support and training I receive through the network, to support and advocate for people with Down syndrome; this is something that I am very passionate about.”

Bryan Russell Mujica and self-advocates, Sociedad Peruana de Sindrome Down (SPSD), Peru

Bryan Russell Mujica is a Social Communication’s graduate from Universidad San Ignacio de Loyola. He became a self advocate at Sociedad Peruana de sindrome Down and participated in many local and international events defending the right of inclusive education. After that, he traveled to Colombia to promote inclusion in education as part of Fundación Progresia Colombia.

When he got back to Peru, he was interest in political participation. He has participated in a Congressman election being the first candidate with Down syndrome seeking that position. Actually, he is running for the next Congress elections.

My Future, Vietnam

Speakers include Nguyen Ha Thanh, Nguyen Quoc Uyen Phuong, Nguyen Trinh Mai Phuong, Nguyen Ngoc Lan Anh

My Future is a group of young people with Down syndrome and Intellectual Disability, operating under the financial support from parents, established in 2009 by a parent.

Day care services had been provided to persons with Down syndrome and Intellectual Disability from its establishment until 2017.

From 2017 until now: My Future provides programs focusing on the life skills and independent life: cooking, speaking in public, performing dances in public, taking internship in the supermarket.

Cooking competitions developed and organized by My Future actually encouraged persons with Down Syndrome and Intellectual Disability to learn and develop their cooking skills .

At present, there are about 25 young persons with Down syndrome and Intellectual Disability in My Future network, including 3 persons who are members of the group.

Vanessa dos Santos, President of Down Syndrome International 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.

H.E. Mrs Meirav Eilon Shahar, Ambassador and Permanent Representative of Israel to the United Nations and International Organizations in Geneva

Ambassador Meirav Eilon Shahar was appointed Permanent Representative of Israel to the United Nations and International Organizations in Geneva in August 2020. Prior to this mission, she served as Deputy Director-General for Coordination and Policy Planning (2017-2020), and as Israel's Ambassador to Vietnam between 2012 and July 2017.

Joining the Ministry of Foreign Affairs in 1995, Meirav Eilon Shahar has represented Israel in a number of different capacities. Until summer 2012, she directed the Department for United Nations Political Affairs in Jerusalem after returning from New York, where she served as Counsellor at the Permanent Mission of Israel to the United Nations. Previously, Ms. Eilon Shahar served as Consul for Communications and Public Affairs at the Consulate General of Israel in Los Angeles from 2000 to 2002. There, she directed public, media and academic affairs in the southwestern United States. She also served as Second Secretary and Deputy Head of Mission at the Embassy of Israel in Nairobi, Kenya, between 1997 and 2020. In this capacity, she oversaw all aspects of bilateral relations between Israel and six East African countries.

Born in Ramat Gan, Israel, on 12 September 1969, she served in the Israel Defense Forces for two years, after which she earned a dual degree in Political Science and Cinema & Communications from the Tel Aviv University. In the following years, Ms. Eilon Shahar completed her Master's in Public Policy and Administration from the Tel Aviv University.

Ms. Eilon Shahar is married with three children.

Gigo Shiukashvili, Founder of the Georgian Down Syndrome Association, Georgia

I was born on the 25th day of the fifth month of 1995, on Thursday. I love my birthday and looking forward to it year after year. It turns out that my birth caused a great deal of excitement, but how could my coming to earth have been so quiet? I have 1 different thing, which fits only one in 700 people in the world: +1 chromosome! And it's me, Gigo Shiukashvili, boy with Down syndrome.

Life turned out to be very colorful, joyful and interesting. I was born in Moscow, I went to the British Foundation "Down Side Up" Early Development Center. My family moved to Tbilisi when I was 2 years old, I grew up as a Georgian and started walking in the kindergarten. I liked to interact with a lot of people and it did not bother me to limit myself to a few words and non-verbal speech until I was 5 years old. Do you know how easy nonverbal speech is? People of all nationalities are contacted equally. I started walking in the day

center at the age of 7, because at that time there were no inclusive approaches in schools, I only went to the 21st public school at the age of 14. I was admitted to VI grade. I made lots of friends. It's interesting to live with your peers, it was a very cool thing, I love my classmates and school.

When I was 10 years old, one day a genius idea came to the mind of the day center Aisi's staff - They brought us a director who would stage a play with us. Something new, wonderful and beautiful started there. You know how much fun it is to adapt to someone else's role, to portray the mystics presented in the fantasy in etudes, to see actions and emotions from a different angle, that you are and that you are not at this time... Theater has become my life, without it everything would be very colorless. I work in the integrated theater "Azdaki Garden", but I have not been able to get an education in this field yet. This is a problem and my friends and me have to overcome this in my country.

When I was in XI grade, I was hired as a co-host of Mega show X Factor, I have been working successfully on this project for the fourth year and I like my job, my team. As far as I remember myself, I love the scene and being the center of attention.

After graduating from school, I enrolled in college to learn bartending and after graduation I started working at Holiday Inn Tbilisi.

I will not tell you about participating in many other projects and activities, but I have to tell you the main thing. I was able to live a full life and feel all levels of life as much as possible. I have a lot of plans and I know for sure that I will achieve everything.

What is the secret of success?

In my mother's unwavering support and struggle for change, other mothers like her, full of energy, who know exactly what their children need.

Yes, that's right, we are a strong force together today to drive change for the better in the lives of people with Down Syndrome.

Association is our strength. This is a community organization where people with Down Syndrome and their families come together, we can do everything together

Türkiye Down Sendromu Derneği (TSDS), Turkey

Speakers: Self-advocate representatives

TSDS is DSI's National Representative Organisation Member in Turkey. TSDS 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 TSDS's dance club. He is also a self-advocate. Last year he worked in a project for poverty and social exclusion.

Hilal Hamurcuer, 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.

Yated (Down Syndrome Society of Israel) - the Shiluvim project

The project was initiated by Yated 8 years ago in a youth village named Amit. It's in a central city in Israel - Petach Tikva.

In the village we have developed a program for Continuing Education after school years, skills development for work and team work as well as independence skills development. We have teachers and instructors for leisure activities - such as art, theatre training and music.

English, Mathematics, Jewish subjects and Nature and Geography are taught.

The group arrives everyday to a little house near the village, and they have their herbal and plants garden where they work and prepare various products, which are sold from time to time to earn a little bit of money. We raise donations for this project, and we receive some of the budget from the Ministry of Welfare.

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.

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