

2014 WORLD DOWN SYNDROME DAY ONFERENCE PROGRAM

1:30pm - 2:10pm

Official Opening and Launch of World Down Syndrome Day “Health and Wellbeing – Access and Equality for All” Conference

With the adoption of United Nations General Assembly Resolution 66/149, the international community agreed to formally recognize World Down Syndrome Day every 21 March, to continue to raise public awareness of Down syndrome. The resolution also calls upon the international community to continue to advocate for the rights of those with Down syndrome, including the right to healthcare, in accordance with Article 25 of the Convention on the Rights of Persons with Disabilities. The speakers on this opening panel will touch on the multiple ways that United Nations Member States and agencies across the UN system are addressing this topic.

Vanessa dos Santos – President, Down Syndrome International – *Welcome & Introductions*

Daniela Bas – UN Department of Economic and Social Affairs, *“Message from the UN Secretary General” and High Level meeting outcome document*

H.E. Mr. Antonio de Aguiar Patriota – Ambassador and Permanent Representative of Brazil to the UN

H.E. Mr. Ryszard Sarkowicz – Ambassador and Permanent Representative of Poland to the UN

Minister Naoto Hisajima – Minister, Permanent Mission of Japan to the UN

Werner Obermeyer – Deputy to the Exec. Director, World Health Organization at UN Headquarters

2:20pm – 3:10pm **Self Advocate Keynote Address – Jaspreet Kaur Sekhon, Singapore**

2:20pm – 3:10pm

Moderator: **Vladimir Cuk** – Acting Executive Director, International Disability Alliance

Panel: **Equal Access – Addressing healthcare without discrimination, bias, or misinformation at the macro & micro level**

Persons with Down syndrome can face many barriers to appropriate healthcare ranging from open discrimination to more subtle practices, with practitioners in some cases not realizing that they are discriminating. This can lead to misdiagnosis and poor health outcomes. Panelists will share challenges seen on a macro, global level as well as specific examples at the country level and recommendations will be presented on how to address these issues.

Drew Boshell – Senior Director, Global Community Health Programs, Special Olympics

Rosica Koleva – Trisomije 21 – Skopje, Macedonia, *“Equal Access to healthcare for people with Down syndrome: a timeline of medical concerns and an outline of good practices”*

Sheila Heslam and Sara Pickard – Service Director and *Self Advocate* (respectively) and presenting together, Down’s Syndrome Association, United Kingdom, *“Health and Well-being – We’re Taking Control”*

3:10pm – 3:20pm **Break**

3:20pm – 4:10pm

Moderator: **Dr. Tom Blumenthal** – Executive Director, Linda Crnic Institute (tentative)

Panel: **Equal Care – Common health concerns faced by persons with Down syndrome and medical best practices**

This panel will share current best practices in different geographical areas and in countries at different developmental levels. A common medical condition, heart defects, will be highlighted and there will be a discussion on how these defects can be potentially life threatening if they are not treated properly. A self-advocate who works in a Down syndrome clinic will also share some personal experiences.

Dr. George Capone – Director, Down Syndrome Clinic, Kennedy Krieger, United States

Dr. S. Suresh – Managing Director, Mediscan Systems, India

Dr. John Mayer – Cardiac Surgeon, Boston Children’s Hospital, Professor of Surgery, Harvard Medical School, and Past President, Society of Thoracic Surgeons, United States

Ben Majewski – *Self Advocate* – Self Advocate Resource Specialist, Massachusetts General Hospital, Down Syndrome Program, United States, *“A Self-Advocate’s Perspective: Medical Issues Affecting People with Down syndrome”*

4:10pm – 5:00pm

Moderator: **Carolyn Cronin** – Executive Director, Down Syndrome Research and Treatment Foundation

Panel: **Equal Research Emphasis – Areas of promise; Latest in Down syndrome research; Down syndrome and Alzheimer’s Disease**

Although there is less funding for Down syndrome on a per capita basis than many other genetic conditions, the research world has made tremendous progress. Relationships now exist between government agencies, NGOs and research scientists. It is an exciting new world - research has shown there are clear links between Down syndrome and Alzheimer’s disease, there are clinical trials for treatments to improve cognition, and more..

Dr. Yvonne Maddox – Deputy Director, *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), National Institutes of Health and Director, NIH Down Syndrome (DS) Consortium, United States, “*Research and Advocacy: Improving the Lives of Those Living with Down Syndrome*”

Dr. William Mobley – Distinguished Professor and Chair of the Department of Neurosciences at University of California San Diego (UCSD), Executive Director of UCSD's Down Syndrome Center for Research and Treatment, and Florence Riford Chair of Alzheimer Disease, United States

Prof. Tony Holland – University of Cambridge, Intellectual and Developmental Disabilities Research Group and Chair in Learning Disabilities, The Health Foundation, United Kingdom, “*Understanding the link between Down syndrome and Alzheimer’s disease: developing preventative treatments*”

Debora Seabra – *Self Advocate* – Brazil, “*Healthcare must be inclusive – Article 25 of UN Convention on the Rights of Persons with Disabilities*”

5:00pm – 5:50pm

Moderator: **Jaroslav Pieniak** – Co-founder, Zespoldowna.info, Poland

Panel: **Equal Prospects – Importance of physical and mental healthcare for total wellbeing and living a full life**

Article 25 of the Convention on the Rights of Persons with Disabilities provides that persons with disabilities, including Down syndrome, are entitled to health. To close the World Down Syndrome Day Conference for 2014, this panel will highlight the importance of this basic human right, not just so a person can stay alive physically, but for him or her to live a meaningful and full life.

Dr. Karen Summar – Healthcare legislative assistant for U.S. Congresswomen Marsha Blackburn, former Joseph P. Kennedy Foundation Public Policy Fellow; and former Director of several Down syndrome clinics, United States, “*Mental wellness and illness in people with Down syndrome*”

Dr. Balbir Singh – Board of Trustees, Down Syndrome International, Singapore, “*Better access for Healthcare for persons with Down syndrome – a Caregiver’s perspective*”

Vera Lucia Mendes – Ministry of Health, Brazil, “*Health guidelines for people with Down syndrome – working with civil society to improve equity and integration for health issues*”

Thanjiwe Ndebele – *Self Advocate* – National Chairperson of the Self Advocacy Movement of South Africa, a programme of Down Syndrome South Africa

5:45pm – 6pm **Conference Close**

Closing Remarks: **Vanessa dos Santos** – Down Syndrome International