



## A DOWN SYNDROME-FREE WORLD?

On 20 March 2017, on the eve of World Down Syndrome Day, the Jérôme Lejeune Foundation, DownPride, the permanent mission of the Order of Malta and ADF-International hosted, under the label of Stop Discriminating Down, a side event during the Human Rights Council at the Palais des Nations Unies in Geneva.

This side event focused on the mass elimination of children with Down syndrome before birth, and on the arrival of a new prenatal test.

The new technique is giving rise to legitimate concern. If this test were to be generalized, as it is in several countries today, it could have major implications on the survival of the Down syndrome population.

Already in England, 90% of mothers end their pregnancy following a Down syndrome<sup>1</sup> diagnosis of their child. In France, there is a 96%<sup>2</sup> elimination rate, whilst in Denmark it has reached 98%<sup>3</sup>.

The speakers unanimously underlined the fact that the life of a person with Down syndrome is worth just as much as any other human life.

<sup>1</sup> Alison Gee, "A world without Down's syndrome?", BBC News Magazine (29 September 2016)

<sup>2</sup> State Council's report, 6 May 2009

<sup>3</sup> Renate Lindeman, "Dutch Minister of Health: if National screening program leads to disappearance of people with Down syndrome, society has to accept that", Huffington Post (9 January 2017)



**Clotilde Noel**, Spokesperson for *Stop Discriminating Down* in France, mother of a child with Down syndrome, called upon the public authorities, urging them to take on their part of responsibility in the protection of people with Down syndrome instead of aggravating prenatal selection.



**Kathleen** (UK), 17, **Peter** (The Netherlands), 33, and **Charlotte** (UK), 21, all three with Down syn-

drome, presented their professional and personal projects. They emphasized how unbearable they find the very concept of a prenatal test which leads to the eradication of children with Down syndrome. They publicly stood up against this new test which will progressively be offered to all pregnant women, and reimbursed through public health-care.



**Denise**, the mother of Kathleen, shed light on the modern illusion that consists in believing that a society rid of its children with Down syndrome would be happier. On the contrary, loving and raising

these children helps develop the intangible but essential values which discourage us from reducing life to a simple economical equation.



**Jean-Marie Le Méné**, President of the Jérôme Lejeune Foundation, underlined the current strength of the market, backed by the legal system, which has replaced the notions of good and right with the insatiable ones of progress and profit.



**STOP  
DISCRIMINATING  
DOWN**



**Dr. Teresa Vargas** specialist in the announcement of Down syndrome diagnosis, demonstrated the importance for doctors to provide future parents with balanced information.

**Alexandra Tompson**, in charge of the *Stop Discriminating Down* campaign at the UN, outlined the objec-

tives of the mobilization. She asked States to put an end to the systematic prenatal testing for Down syndrome, as currently implemented into public healthcare programmes. Tompson insisted that genetic testing should be solely used to improve care and wellbeing, and should not result in destruction. Its use must never lead to a violation of human rights.

The first violation of human rights lies in the prevention of children with Down syndrome from being born. The second violation of human rights is that of people with Down syndrome already born. The dignity of people with Down syndrome is being violated by the devaluing messages engendered by the healthcare systems which have already systematised

prenatal screening. The third violation of human rights is that of pregnant women, compelled to go through their pregnancy in a worrying and guilt provoking environment.

Alexandra Tompson concluded her speech by asking States to put an end to any discrimination based on genetic predisposition.



The speakers approached the consequences of Down syndrome prenatal testing from a human rights' perspective. On account of the breadth of testimonies and expertise, the audience was able to fully understand the danger that a widespread system, developed by a State, could set for the future of Down syndrome children in particular, but also on humankind in general.

All presentations are available on:  
[www.stopdiscriminatingdown.com/fr/actualites/](http://www.stopdiscriminatingdown.com/fr/actualites/)  
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