

Stop Discriminating Down

1. The Jérôme Lejeune Foundation (France) and Downpride (Netherlands and Canada) would like to alert on a new prenatal genetic screening primarily aimed at Down syndrome. The institutional dissemination of this test in the national healthcare system in the Netherlands consists in a noiseless violation of Human Rights.

2. The Jérôme Lejeune Foundation is a French NGO dedicated to Research to identify targeted treatments for patients with genetic intellectual disabilities, to Care to provide specialized medical consultations for patients with genetic intellectual disabilities, and to Advocacy for the fundamental human rights of individuals from conception to natural death.

Downpride¹ is a Dutch grassroots social justice group of families with Down syndrome.

Downpride and the Jérôme Lejeune Foundation have launched together the mobilization Stop Discriminating Down².

Background

3. The NIPT (Non Invasive Prenatal Test) is a new type of genetic test that can potentially detect a range of genetic (chromosomal) conditions, microdeletions and duplications in an unborn child by analyzing the blood of the mother.

4. The Netherlands will integrate NIPT as a first-tier screening offered to all pregnant women in 2017.

5. In April 2014, the Dutch government granted a special permit to carry out a study where NIPT is offered in order to detect a fetus with Trisomy 21 (Down syndrome), Trisomy 18 (Edwards syndrome) or Trisomy 13 (Patau syndrome) based on the assumption that these serious foetal abnormalities cause suffering, which justifies 'reproductive choice'. In the Netherlands, a small group of experts determines the scope of the NIPT. The choice is limited: a woman can choose to screen exclusively for Down syndrome, but not exclusively for Trisomy 13 and 18.

6. Down syndrome is a variable condition and the prognosis during pregnancy remains unclear. One child may graduate from college while another may have difficulty expressing himself/herself verbally. This means that the NIPT can detect, with reasonable accuracy, *if* a fetus has Down syndrome but not *how* this will impact life.

There is scientific consensus that environmental factors (education, lifestyle, a loving and supporting environment, etc.) greatly influence an individual's health and well-being.

I. Lifelong violation of Human Rights of persons with Down syndrome

Emancipation of disabled people

7. Years ago, people with Down syndrome were often housed in institutions. Many were in poor health, had limited self-care and social skills, couldn't read, and died young. It was thought that their problems were unavoidable. Actually, they were mostly limited by segregation, low expectations and poor medical care.

8. *"Life expectancy for people with Down syndrome has increased dramatically in recent decades – from 25 in 1983 to 60 today. People with Down syndrome attend school, work, participate in*

1 www.downpride.com

2 www.stopdiscriminatingdown.com

decisions that affect them, have meaningful relationships, vote and contribute to society in many wonderful ways.”³

9. Decades ago society relied on institutionalization to segregate people with disabilities from society. Today we rely on prenatal genetic testing to make our selections in private, but the effect on society is the same.

Screening requires health gain

10. The Oviedo Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine is the first legally-binding international text designed to preserve human dignity, rights and freedoms, through a series of principles and prohibitions against the misuse of biological and medical advances. Article 12 of the aforementioned Convention on predictive genetic tests specifies that *“Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health purposes or for scientific research linked to health purposes, and subject to appropriate genetic counselling.”⁴* In the Netherlands, the Population Screening Act requires treatment and/or health benefits from screening.

11. The purpose of prenatal testing for Down syndrome is not health gain but to decide whether to carry a pregnancy to term, as may be the case with 'serious foetal abnormalities'. Many pregnant women and couples feel it is important to be given the choice to 'prevent' a life of serious suffering for the child and their family. The Dutch government granted a special permit to carry out the NIPT-study based on the assumptions that Down syndrome is a serious foetal abnormality causing suffering which justifies 'reproductive choice'.

What constitutes 'serious suffering'

12. According to conventional medical definitions, 'serious' means an abnormality that is life threatening and/or severely limits quality of life. For example, Trisomy 13 and 18 are considered 'serious' chromosomal conditions because they severely limit life expectations, which the Dutch Health council justifies as a ground for prenatal screening.

13. Nowadays, medicine knows how to treat symptoms associated with Down syndrome: cardiac and digestive disorders, orthopaedic and visual malformations, etc.

14. 'Serious' can also refer to development or IQ: children with IQ scores lower than 50 are considered to be 'severely' intellectually delayed. Children with Down syndrome have on average an IQ between 50 and 60 which is usually referred to as 'mildly delayed'.⁵

15. While the variability of Down syndrome can lead to ambiguous views, the average life-span, IQ and other possible life-limiting factors do not qualify to be defined as 'serious'.

3 <http://www.ndss.org/Down-Syndrome/Down-Syndrome-Facts/>

4 Convention on Human Rights and Biomedicine, Council of Europe, 1997.

5 <http://www.nationaalkompas.nl/gezondheid-en-ziekte/ziekten-en-aandoeningen/psychische-stoornissen/verstandelijke-beperking/beschrijving/>
<http://mens-en-gezondheid.infonu.nl/aandoeningen/78742-syndroom-van-down-kenmerken-gedrag-erfelijkheid.html>

16. People with Down syndrome themselves refute the assumption that their condition constitutes suffering further: research among a large population shows that persons with Down syndrome and their families have an above average appreciation for life, not depending on their individual functional skills⁶. The majority of persons with Down syndrome (according to some American research⁷ 99%) report to be content with their lives. Other research⁸ shows that 88% of siblings and parents experience Down syndrome positively in their family. Dutch Research Organization TNO⁹, reports that 8 out of 10 parents, and 9 out of 10 siblings in the Netherlands say Down syndrome has enriched family life.

Prenatal exclusion affects those living with Down syndrome negatively

17. The UNESCO International Bioethics Committee reported: “A widespread use of NIPT, namely as general screening in order to detect abnormalities, followed by an abortion, is perceived by some people as an evidence of the will to avoid permanent pain in a lifetime, by others as a sign of a situation of the exclusion society gives to people affected by this illness, meaning indirectly that certain lives are worth living, and others less.”¹⁰

18. On one hand, healthcare, housing, education and equality in society are ongoing matters of serious concern. On the other hand, the State pours hundreds of millions of Euros into screening programs. By investing in prenatal selection, the State encourages in society the mentality of not investing in the lives of persons with Down syndrome.

19. In 2011 the NIPT was introduced. At the same time, funding for research into Down syndrome has been shrinking¹¹. Despite Down syndrome being one of the most common genetic variation in the population, it is also the most underfunded. A sign that society has found the ‘solution’ in the prenatal exclusion of people with Down syndrome.

20. A policy of routine prenatal screening and targeted abortion against persons with Down syndrome necessarily has negative consequences in terms of stigmatization, welcome, inclusion and care for children with Down syndrome who grow up in our societies.

II. Violation of Human Rights of unborn babies with Down syndrome

Public and medical opinions do not reflect the positive reality of life with Down syndrome

6 Brian G. Skotko, Susan P. Levine, and Richard Goldstein, *Having a Son or Daughter with Down Syndrome: Perspectives from Mothers and Fathers*, American Journal of Medical Genetics, 2011.

7 Brian G. Skotko, Susan P. Levine, and Richard Goldstein, *Self-Perceptions From People With Down Syndrome*, American Journal of Medical Genetics, 2011.

8 Brian G. Skotko, Susan P. Levine, and Richard Goldstein, *Having a Brother or Sister With Down Syndrome: Perspectives From Siblings*, American Journal of Medical Genetics, 2011.

9 TNO Brochure, een kind met Downsyndroom: Hoe ervaren ouders, broers en zussen een kind met Downsyndroom. https://www.tno.nl/downloads/folder_downsyndroom_voor_zwangeren.pdf

10 *Report of the IBC on Updating Its Reflection on the Human Genome and Human Rights*, UNESCO, October 2015. <http://unesdoc.unesco.org/images/0023/002332/233258E.pdf>.

11 <https://www.disabilitycoop.com/2012/02/24/funding-down-syndrome-shrinks/15058/>

21. Making screening widely available for Down syndrome and pushing for abortion implies that babies don't have the same value. This is particularly reflected in the high number of abortions around the world if Down syndrome is diagnosed.

10 out of 18 European countries are reported to have an average abortion rate of 88% after a diagnosis of Down syndrome¹².

22. In the Netherlands, the abortion rate during the past 23 years was between 74 and 94% after Down syndrome was diagnosed.¹³

23. According to a 2013 study, one in four participants said they had been encouraged by a medical professional to abort, and many received inadequate information and little compassion¹⁴. Similar findings are confirmed in other studies.¹⁵

24. Blackbook Downsyndrome¹⁶ gathered testimonies of parents receiving inadequate support or feeling pressured to proceed to screening or abortion. They talk of their initial fears and worries not reflecting the reality and joy they experience parenting a child with Down syndrome. Blackbook Downsyndrome was presented to the Dutch Minister of Health in February 2016.

25. A widely offered NIPT leads to the disproportionate stigmatization of children with Down syndrome compared to the reality of their disability. States promoting 'reproductive choice' are at least partly responsible for individual choices leading to the disappearance of people with Down syndrome.

Economical aspects of screening negatively affect solidarity

26. The UNESCO recalled in 2015: *“Prevention as a social objective, focused, for example, on reducing care costs for people with congenital conditions or disabilities, cannot be the goal of such screening. That would imply a discriminatory practice that sends the message that these people are unwelcome in society.”*¹⁷

27. According to the Dutch Health council, *“Prevention in terms of a societal objective, like saving costs in caring for people with congenital conditions or handicaps, is not the aim of this screening. If this were true, those who claim prenatal screening for fetal conditions is a discriminating practice which message is that people with handicaps or genetic conditions are not welcome in society, would be right.”*

12 <http://www.ncbi.nlm.nih.gov/pubmed/18410651>

13 <https://www.nrc.nl/nieuws/2015/06/18/diagnose-van-downsyndroom-leidt-in-meer-dan-90-pr-1504942-a1005981>

14 <http://www.ncbi.nlm.nih.gov/pubmed/24447016>

15 <http://www.ncbi.nlm.nih.gov/pubmed/15746657>
<http://www.nature.com/gim/journal/v13/n8/full/gim2011117a.html>

16 The Dutch Blackbook online: <http://online.fliphtml5.com/bzvo/gskb/#p=1>

17 *Report of the IBC on Updating Its Reflection on the Human Genome and Human Rights*, UNESCO, October 2015.

<http://unesdoc.unesco.org/images/0023/002332/233258E.pdf>

28. One recent tweet a disability blogger received read: *“Should we read in the posts about how much money your (disabled) daughter has cost the tax-payer already?”* Such comments are increasingly common on social media and follow Dutch media attention focusing on financial aspects of disability.

29. Here's one example. A pediatrician and CEO of a Belgian lab offering NIPT to Dutch women, said: *“If the births of 50 children (with Down syndrome) are prevented, the NIPT will pay for itself”*.¹⁸

Persons with Down syndrome have the same right to exist as others

30. In comparison, people who have albinism, another genetic variation, are rightfully protected by several international texts asking States to prevent discrimination and eradication on the basis of strong prejudices.

31. A policy of routine prenatal screening leads to higher number of abortions, which in turn negatively affects acceptance, participation, care and solidarity for 'expensive' and 'preventable' conditions.

32. The Preamble of the Convention on the Rights of the Child states that *“the child, by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, before as well as after birth.”* Article 1 of the CRC defines a child as *“every human being below the age of eighteen years.”*

33. The Netherlands should review its policies and adequate them to its international obligations. The Netherlands should protect the life of all children, including those diagnosed with Down syndrome.

III. Violation of Human Rights of pregnant women and couples

Collective solidarity becomes woman's responsibility

34. A woman's reproductive freedom is strongly valued in Western countries. This freedom is at stake in a time of increasing medicalization and screening.

35. Screening is formally offered as a 'free choice' but expectations, inclusion, education, support, etc. influence choices. In fact, cultural and societal attitudes may be the most important factor in a woman's decision.

36. Equality is required to guarantee freedom of choice to women. However society becomes less accepting of 'preventable conditions' *because* choice exists. Therefore women's decisions are not equally supported.

The system of routine screening now places disability on women's individual shoulders instead of carrying 'the weight' in solidarity.

The initial good intention of liberating women has become a decision-trap: the woman who knowingly gives birth to a child with a disability is perceived to be responsible for the disability, precisely *because* this 'choice' exists. Whatever she chooses, a woman is always 'guilty': either of giving birth to a child with a known disability, or terminating the life of an unborn child.

18 <http://jababy.nl/zwangerschap/gezondheid/bloedtest-belgie-populairder-dan-ooit/>

37. For example, this woman 'lost' her boyfriend when she refused to terminate her pregnancy¹⁹; this woman said terminating her pregnancy was the blackest decision she had to make in her life²⁰.

Danish case shows how 'choice' becomes 'responsibility'

38. The other factor affecting 'choice' is, as UNESCO International Bioethics Committee highlights, that a widely offered NIPT would have the disadvantage of a participation considered as self-evident and presented as such by care providers. *"This may lead to pregnant women (and their partners) not fully realising that the test results may leave them with a major and possibly extremely difficult decision. Ironically, the introduction of a test that may bring informed choice to more pregnant women may undermine this goal in practice, if NIPT is used without thinking enough about the impact."*

39. In Denmark, Down-screening was widely implemented in 2004 as part of their National screening program. Formally offered as a choice, screening has become so accepted, that practically all expectant parents undergo screening. Last year, 98% of pregnant women who were revealed to be carrying an unborn child with Down syndrome chose to have an abortion. A recent documentary entitled *Dead over Downs* highlights the reality of 'choice' in Denmark: parents are routinely misinformed, intimidated and have to strongly defend their decision towards medical staff and society. The freedom to choose has become a duty to abort.

40. In the Netherlands, the uptake of screening was traditionally low (around 27%) due to the relative risk of invasive screening. The Dutch Health council expects that women will increasingly choose the NIPT and refers to this increase as a 'moral advantage' in its report *Nipt, dynamics and ethics of prenatal screening*.

IV. Chromosomal racism and extinction of the community of persons with Down syndrome

41. Routine Down syndrome screening and selection is against the Charter of Fundamental Rights of the European Union which condemns *"Any discrimination based on any ground such as (...) genetic features, (...) disability"*²¹, and forbids *"eugenic practices, in particular those aiming at the selection of persons"*²².

42. If we let genetic tests contribute to erase people with Down syndrome, nothing will stop the *chromosomal racism*²³ currently decimating the Down syndrome community. Other groups and genetic variations will suffer the same fate.

43. Article 11 of the Oviedo Convention on non-discrimination specifies that *"Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited."* In 1997, UNESCO adopted an Universal Declaration on the Human Genome and Human Rights claiming that *"the human genome is the heritage of humanity"*²⁴; *the dignity and human rights of every individual should be respected, regardless of his or her genetic characteristics, that dignity makes it imperative*

19 http://www.kekmama.nl/article/gespot/in_het_magazine/portretten_ouders_met_een_downkind

20 <http://www.trouw.nl/tr/nl/4516/Gezondheid/article/detail/3770827/2014/10/17/Wie-kiest-er-voor-een-kind-met-Down.dhtml>

21 Charter of fundamental rights of the European Union, Article 21 (Non-discrimination).

22 Charter of fundamental rights of the European Union, Article 3 (Right to the integrity of the person).

23 Pr Jérôme Lejeune: *"Chromosomal racism, like any other kind of racism, is terrible."*

not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity²⁵; and that the human genome, subject to mutations, contains potentialities that are expressed differently according to each individual's natural and social environment.”²⁶

44. *The Copenhagen Post* reported in October 2015²⁷ that Down syndrome is “*heading for extinction*”. This wording does not adequately describe the systematic measures (prenatal screening to select) taken to impede the birth of a targeted group of persons with similar genetic features, leading to the deliberate destruction of the group itself.

45. In this context, we hereby call for recommendations to the Netherlands to:

- Stop systematic prenatal screening programs that target Down syndrome and deliberately encourage abortion as part of public health programs.
- To consider the decrease of the number of abortions for Down syndrome as a state priority.
- Regulate the introduction of prenatal genetic testing, based on the principles defined in the Universal Declaration of Human Rights, in the Oviedo Convention (articles 11 and 12), in the EU Charter of Fundamental Rights (articles 2, 3, 21 and 26), in the UN Convention on the Rights of the Child (Preamble and article 1), and in the UN Convention on the Rights of Persons With Disabilities (articles 5, 10, 14, 15, 23, 25).
- Allow the use of genetic testing solely to enhance human care and well-being, and not to discriminate against people on the basis of their genetic predisposition.
- Provide to citizens through State campaigns positive information on persons with Down syndrome: their beauty, their capabilities, their joy, their smile, their empathy and everything they offer to their environment which is invaluable.

24 Universal Declaration on the Human Genome and Human Rights, Article 1, UNESCO.

25 Universal Declaration on the Human Genome and Human Rights, Article 2, UNESCO.

26 Universal Declaration on the Human Genome and Human Rights, Article 3, UNESCO.

27 <http://cphpost.dk/news/down-syndrome-heading-for-extinction-in-denmark.html>