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FRANCE

SUBMISSION BY

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PRESENTATION

The Jérôme Lejeune Foundation, created in 1995 and based in France, has been a government-recognised public interest foundation since 1996. The Foundation has three missions: to seek, to treat and to defend. It seeks treatments for Down syndrome (Trisomy 21) and other inherited intellectual disabilities, it treats persons with Down syndrome and other inherited learning disabilities through a specialist consultation centre, and it defends the life and dignity of every person from their conception to their natural end.

ABSTRACT

Down syndrome, also called Trisomy 21, caused by the presence of a third chromosome 21, results in a genetic intellectual disability. On average, trisomy affects 1 in 700 babies conceived. It is estimated that there are about 8 million people with Down syndrome in the world, including 60,000 in France. Unfortunately, it is an incurable handicap and very easily diagnosed. But even more so, France does not help people with this disability to live better. France is increasing this handicap. Indeed, the law, doctors and society as a whole do not welcome it well.

On one hand (A), people with trisomy 21 do not have easy access to school, to the labour market, to appropriate support. The French state is struggling to solve these problems of access to education and personal development. But where France is most at fault is in the unacceptable restriction of freedom of expression for people with trisomy 21. The video “Dear Future Mom”, showing people with trisomy 21 expressing their joy of life, was banned from broadcast as a "message of general interest" by the French CSA (*Supérior Audiovisual Council*) in 2014.

Despite numerous requests, the CSA has maintained its decision. In doing so, France is still not in conformity with the Convention on the Rights of Persons with Disabilities, by which it has committed itself to raise awareness of the rights of persons with disabilities, to protect their rights and to enhance their visibility.

On the other hand (B), embryo with trisomy 21 are easily diagnosed, because of various markers. However, since it can lead to eugenic abuses against the population carrying this handicap, certain diagnostic methods are still prohibited in France. In 2021, the French Parliament refused to legalise PGD-A, which consists of the diagnosis of aneuploidies (abnormal chromosome numbers) in vitro. Nevertheless, and contrary to the UN recommendations in 2021, (*concluding observations on the initial report of France – Committee on the Rights of Persons with disabilities – October 2021*) today, states agencies authorized both basic research and clinical trials using this diagnosis discriminating people with Down Syndrome and despite French law.

This inexhaustible search for children with Down syndrome results, in 96% of cases, in a termination of pregnancy, proposed if not imposed on the parents. Five years after the last Universal Periodic Review, it is time for France to recognise the dignity of these people with trisomy 21, in accordance to the Convention on the Rights of Persons with Disabilities and the latest recommendations published in the UPR 3rd round, to protect them like any other person and to recognise their rights even before birth.

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This is the purpose of this contribution, which consists in pointing out the progress to be made in France in terms of recognition of people with Down syndrome through several recommendations.

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