# LIFE Submission to UK National Screening Committee Consultation on Screening for cfDNA in pregnancy.

October 30, 2015

We are opposed to the proposal to add cfDNA analysis as a contingent test for those unborn babies in whom screening has shown a 1:150 risk of Trisomys.

We note that NIPT testing from a previous study showed that it is extremely reliable in detecting Trisomy 21, more commonly known as Down Syndrome. Adding cfDNA testing can only mean significantly higher detection rates for Down Syndrome. We are already concerned that 9 out of 10 babies diagnosed with Down Syndrome are aborted. In 2014 the abortion statistics reported that 662 abortions were performed on Down Syndrome babies (an increase of 12%), with Down Syndrome being the most commonly reported (21%) chromosomal abnormality justifying abortion. This is part of a 34% overall increase in such abortions in the last three years. [1]This substantial increase in the number of babies aborted due to trisomy has been attributed to the increased usage of NIPT.

Given that adding cfDNA testing to other screening will increase the detection of babies with Trisomys like Down Syndrome, we wish to object to greater use and funding for it on the basis of the objections below.

1. **Use of the cfDNA detection contravenes the United Nations' Convention on the Rights of Persons with Disabilities (CRPD)**.

On March 30 2007, the United Kingdom became a signatory to the United Nations' Convention on the Rights of Persons with Disabilities(CRPD). The CRPD promotes recognition and respect for the equal human dignity of all human beings without any distinction, the rejection of unjust discrimination and respect for human difference and variation.[2]

The State signatories of the CRPD are therefore required by its provisions:

- To apply the general principles of the CRPD systematically and with analytical rigour to all policies affecting disabled people (including health policies) so that they are consistent with the purpose and principles of the CRPD.

The deliberate targeting and elimination of unborn babies with Down's Syndrome which would increase with greater use of cfDNA detection, is inconsistent with the principle of rejecting unjust discrimination and promoting respect for human difference and variation.

- To observe due process observed in the formulation and review of all policies affecting disabled people (including health policies) in keeping with the principles of participation, inclusion and 'nothing about us without us'. This entails that persons with intellectual disabilities must be afforded the opportunity to participate in decision-making, especially regarding policies which affect them.

We understand that many disability rights campaigners and groups are unaware of this consultation.

Any policy to fund the increased use of cfDNA to screen out disabled people should never be implemented before full and direct discussion and engagement with the disabled community. The absence of such robust consultation is a violation of this article of the convention.

- To undertake awareness raising measures to undo negative social constructions of disability in health policies.

The advocacy of cfDNA and other targeting and detection technology seems to assume that there is something wrong with having a disabled child and parents would want to abort that child. It feeds that negative social construction of disability which this article addresses. Rather than raise awareness of the equal value and dignity of a disabled child it promotes an opposite negative view as candidates for detection and elimination.

- To avoid any prospective demand on public resources offending the principles of the CRPD.

Having already shown how cfDNA testing would contravene the principles of CRPD, we believe the estimated cost of £105M to the NHS should not be borne by the taxpayer. To do so can mean that all members of the public who subscribe to the principle of equality and non-discrimination are being made to pay for a technology which leads to the detection and elimination of disabled children inside the womb.

- To monitor the effects of antenatal screening on base population numbers, including reductions in population.

We have already pointed out the large number of babies aborted for Down Syndrome because of detection techniques. We expect this to result in a decrease in the number of people with Down Syndrome over time. In the United States, where there is greater use of screening technology, it is estimated that there would have been a 34% increase over 16 years in the number of people with Down Syndrome had it not been for prenatal testing for Down Syndrome.[3]

2. **We are concerned about the message sent to people with Down Syndrome who become aware of increased efforts to detect Down Syndrome babies before they are born.**

The medical and broader communities seem to perceive that prenatal testing is an extension of good prenatal care i.e. it helps parents have healthy babies. However, such “care” does not constitute a treatment for Down Syndrome when it is detected. On the contrary, in most cases it means the termination of babies with that condition. Advances in science should be directed at improving their lives, not preventing them.

As a society which gives equal value and respect to all groups, we cannot be seen to be saying that we value disabled people once they are born but we will pursue strategies to ensure others with disabilities are not born again.

Just earlier this month the report of the International Bioethics Committee (IBC) of the United Nations Educational, Social, and Cultural Organisation (UNESCO) pointed out that “the potential ethical disadvantages of NIPT can be summarised as routinisation and

institutionalisation of the choice of not giving birth to an ill or disabled child" . [4] Aside from sending the wrong message to disabled people, it would symbolise a eugenic philosophy in which some people are less valuable than others.[5]

3. **There is a risk that cfDNA testing could one day lead to sex selective abortions.**

One feature of cfDNA is its ability to identify the sex of the foetus. This could one day lead to a large number of abortions on the basis of gender as the sex of the baby could be ascertained much earlier in the pregnancy. The IBC report referred to above made this observation: "Another risk lies in the cultural prejudices of preferring a child of the male sex, the sex of the baby being one of the characteristics that can obviously be discovered by NIPT. As this test can be carried out at a very early stage of the pregnancy it would be difficult, even impossible for doctors to forbid the communicating of sex to the parents, and especially at a time when many countries have liberalised abortion. This could lead to a selection based on sex, which is against ethical values of equality and non-discrimination." [6]

4. **A greater availability of tests such as cfDNA and NIPT could mean that, given the negative stereotyping of disabilities like Down Syndrome, there is an expectation that women will abort their baby if it has the condition.**

That expectation may mean women feel pressured to submit to such screening and maybe even feel stigmatised if they refuse.

5. **We also fear that more prenatal testing could lead to women rushing into abortion before receiving adequate counselling and information about the disability detected.**

This problem was highlighted in the IBC report when it referred to NIPT: "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. Furthermore, there is the risk that pregnant women with a positive result don't await the validation of the result through invasive diagnostics, but immediately choose to abort the embryo or foetus, without adequate counselling about the relevance of the detected abnormality. Also women may feel pressured to submit to such screening. They might be stigmatised if they refuse to take the test." [7]

## Conclusion

Whilst at LIFE we acknowledge the benefit of information to help equip parents to deal with the challenges of bringing up a disabled child, we believe that in the current social context where three babies are aborted every day for Down Syndrome [8], increased detection will only mean greater elimination of babies with Down Syndrome. For all the reasons given above we therefore cannot support any technology which leads to greater rates of detection and elimination of the disabled.

As a society we should be reaching out to help parents with disabled children- as LIFE's daughter charity Zoe's Place does [9]- to deal with the challenges of bringing up a disabled baby. Parents should not be made to feel that they are alone in their experience and that they would be better off if their baby was not here.

[1] Abortion Statistics, England and Wales: 2014 (Summary), section 2.19, pg. 14: http://bit.ly/1Pjey95

[2] http://www.un.org/disabilities/documents/convention/convoptprote.pdf

[3] http://abcnews.go.com/Health/w_ParentingResource/down-syndrome-births-drop-us-women-abort/story?id=8960803

[4] Report of the IBC on Updating Its Reflection on the Human Genome and Human Rights', October 02 nd 2015, section 89: http://unesdoc.unesco.org/images/0023/002332/233258e.pdf

[5] http://www.ncbi.nlm.nih.gov/pubmed/18771038

[6] Op cit., IBC report, 91.

[7] Op cit., IBC report, 89.

[8] http://www.telegraph.co.uk/news/health/news/6440705/Three-babies-aborted-every-day-due-to-Downs-syndrome.html

[9] http://www.zoes-place.org.uk/