

28th September 2020

Position statement on the implementation of non-invasive prenatal testing in Scotland

Down's Syndrome Scotland has an absolute responsibility and privileged role to defend the rights and promote the value and contribution that people with Down's syndrome make to so many aspects of Scottish life, each and every day.

We offer support to all parents who want to find out more about Down's syndrome and the growing number of positive opportunities for people with Down's syndrome to achieve their fullest potential and to live a great life. We have access to a whole community of experts including people living with Down's syndrome, their parents, siblings, wider family members and friends who all know best about the joy and fulfilment that their loved ones with Down's syndrome bring to their lives.

We understand the arguments that non-invasive prenatal testing is a more accurate screening test and that it can be helpful for parents to know in advance that their child may have Down's syndrome; we want to ensure that expectant couples who opt to have the test are given accurate, informed and balanced information about Down's syndrome, on each and every occasion.

We remain concerned that the introduction of a further screening test for Down's syndrome, unless clearly explained and understood, could lead to an increase in the number of terminations. This may, in turn, lead to a reduction in the number of babies born with Down's syndrome.

We are equally concerned that the approach being taken brings together three very different conditions in one test. It is vital that Down's syndrome is not confused with the two other conditions which have serious, life-limiting outcomes.

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When it became apparent that the decision to implement non-invasive testing had been taken at a UK level and that Scotland decided to join the other home countries in making the screening test available here through the NHS, Down's Syndrome Scotland partnered with other members of the Down's syndrome community across the UK to ensure the approach proposed was informed, accurate and balanced. At times, this meant we were often the minority voice in these discussions, but on a good number of occasions, our views were respected, and changes were made to the implementation approach.

The timing of the introduction of NIPT is particularly unhelpful when all our energy and focus is currently targeted at dealing with the COVID-19 pandemic and the very challenging impact it is having on people with Down's syndrome and their families.

We believe, however, that we have left no stone unturned in our efforts to remove unconscious bias to ensure that expectant parents get the best possible advice, information and counselling from the best prepared and trained health professionals. We are aware that non-invasive prenatal testing is entirely optional and that it is a screening test to indicate whether your baby may have a chance of having Down's syndrome; it is not a certain diagnosis and we would want all parents to understand that.

Down's Syndrome Scotland has identified seven standards that it wishes to see upheld in relation to the implementation of non-invasive prenatal testing in Scotland:

1. That all information and resources prepared to support the implementation of non-invasive prenatal testing, whether printed, online or verbal, must be accurate, informed and balanced.
2. That all health professionals involved at all stages of the screening pathway and supporting expectant parents must have completed the training developed to support the implementation of non-invasive prenatal testing before implementation

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and before they can become involved in any discussions with expectant couples.

3. That a comprehensive and inclusive evaluation to assess the impact of non-invasive prenatal testing is carried out transparently and that the views of people with Down's syndrome and their families are actively sought in any such evaluation.
4. That a full Equality Impact Assessment is completed on the implementation of non-invasive prenatal testing within its first year of operation.
5. That Down's Syndrome Scotland is signposted as a trusted and valued source of support and advice for all parents who opt to take a screening test to find out if their baby may have a chance of having Down's syndrome.
6. That data on the number of babies born with Down's syndrome each year in Scotland and the number of non-invasive prenatal tests carried out annually, together with full data on pregnancy pathway outcomes, is routinely gathered and published and that this data becomes a credible and reliable baseline going forward.
7. That Down's syndrome is properly and always understood and communicated as a unique condition and never communicated as a problem, and that people with Down's syndrome and their families continue to feel valued for the significant contributions they make to Scottish life.

On behalf of its members and the Down's syndrome community in Scotland, Down's Syndrome Scotland will seek to hold to account all of the authorities responsible for the pregnancy screening programme in Scotland, against each of these seven standards.

People with Down's syndrome enrich the lives of everyone they come into contact with and they enhance the communities in which they live. It is our belief that Scotland would be a poorer place without their visible and valued contribution.

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Further information about Down's Syndrome in Scotland:

- Down's Syndrome Scotland (DSS) has over 1,200 members and was established in 1982.
- A baby is born with Down's syndrome once in every 1,000 births.
- In Scotland, it is estimated that there are 70 babies born with Down's syndrome each year and the total number of people living with Down's syndrome in Scotland is estimated to be 4,500.
- DSS provides free parent information packs to all maternity and midwifery units across Scotland.
- The charity provides free teaching and information sessions to student midwives, midwifery professionals, health visitors and other health professionals across Scotland.
- Down's Syndrome Scotland provides "all through life" support throughout Scotland and has a confidential helpline for parents and families which can be reached on 0300 030 2121.
- We also work to influence government policy and change attitudes to ensure that the society in which we all live reflects the needs of and embraces people with Down's syndrome to reach their fullest potential.

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