

## Serious Crime Bill

### Proposed amendment by Fiona Bruce MP on abortion for fetal sex

Briefing from Antenatal Results and Choices (ARC) and Genetic Alliance UK, February 2015

#### Background

The following amendment to the Serious Crime Bill has been tabled by Fiona Bruce MP:

*Termination of pregnancy on the grounds of the sex of the unborn child:*

*Nothing in section 1 of the Abortion Act 1967 is to be interpreted as allowing a pregnancy to be terminated on the grounds of the sex of the unborn child.*

#### Antenatal Results and Choices and Genetic Alliance UK oppose this amendment

ARC provides non-directive information and support to women and couples experiencing antenatal testing and making decisions as a consequence of the detection of a serious fetal anomaly. Genetic Alliance UK is the umbrella organisation for families living with genetic conditions.

On behalf of our constituent groups we oppose this amendment and urge MPs to do so for the following reasons:

##### 1. This amendment will restrict reproductive choice for women at risk of having a child affected by a serious inherited condition

When a genetic fetal anomaly is confirmed following testing during a pregnancy (prenatal diagnosis through chorionic villus sampling (CVS) or amniocentesis), doctors use Ground 'E' of the Abortion Act to enable a woman to terminate the pregnancy if she wishes to do so. However, in order to achieve the prenatal diagnosis we have to know the genetic mutation associated with the condition. In reality, **there are relatively few genetic conditions where a mutation is *always* found.**

This means there are a significant number of families who have children with or have a family history of a condition that is clearly sex-linked, but **prenatal diagnosis is not possible** as the mutation remains unknown. They need the option of ending the pregnancy on the basis of fetal sex which this amendment expressly prohibits. Examples of sex-linked conditions where it is not always possible to offer prenatal diagnosis are **X-linked severe combined immunodeficiency (XSCID – see box), Kabuki syndrome, and X-linked infantile spinal muscular atrophy.**

There is also a large group of families with what is called '**non-specific X-linked mental retardation**', where the diagnosis is established on the basis of the characteristic family tree, but the causative gene is not found. **These would not be detected by antenatal ultrasound** as the problem is with brain function, not structure. So some families will decide to terminate the pregnancy if the baby is found to be the sex usually or more seriously affected by the disorder, in this case boys.

### X-linked severe combined immunodeficiency (XSCID)

XSCID is a severe immunodeficiency syndrome. Babies born with XSCID become ill in the first few months of life. They have recurrent infections which they cannot fight due to their partly absent immune system, these infections are a normal part of life for most babies but are life threatening for babies with XSCID. They have chronic diarrhoea, and generally fail to thrive. Without a prompt bone-marrow transplant (which cannot be arranged for all babies), XSCID babies usually die in their first year of life.

The impact upon parents of having such a severely ill child is devastating. Watching a child suffer repeated infections and not being able to provide any effective medical treatment is profoundly distressing for parents. The plan of care for their new born baby suddenly changes to 24 hour care for a seriously ill child, who requires frequent unplanned hospital visits.

The proposed amendment on abortion for fetal sex would limit reproductive choice for couples who have already been through this experience.

## 2. Defensive medicine

While supporters of the amendment may argue it does not allude to or seek to prevent terminations for fetal anomaly, the foregrounding of fetal sex in this way is likely to have a ‘chilling effect’ on doctors and lead to the practice of what the Royal College of Obstetricians and Gynaecologists call **defensive medicine**. Fearing prosecution, doctors may feel they cannot sanction a termination under ‘Ground E’ when the woman requests it, because although the sex of her fetus makes it more likely that the child if born will be affected by a heritable disorder this cannot be verified by prenatal tests.

This could have **two negative results**. Firstly, women may choose not to disclose the results of fetal sexing tests to their doctors and seek an abortion on other grounds. The lack of disclosure may lead to them **not being offered or accessing emotional support** or genetic counselling that can be helpful after ending a desired pregnancy. Secondly, some women will feel that without having the option of termination they would rather avoid pregnancy altogether and so be **forced to forego parenthood** completely.

## 3. Prioritising the fetus

If passed, this amendment would set a **dangerous precedent** that ARC and Genetic Alliance UK believe could be **to the detriment of the families we represent**. For the first time it would be set on statute that doctors must prioritise a characteristic of the fetus (in this case fetal sex) over the wellbeing of the pregnant woman. It represents a first step to affording the fetus the status of personhood which would afford rights that would be in **conflict with those of the pregnant woman**.

Furthermore, once a prohibition on abortion for a *reason* that is seen as ‘undesirable’ becomes law, it **opens the door for further restrictions** based on *abortion reasons* that are deemed unacceptable, which could include certain fetal anomalies. We feel it is **essential** that the pregnant woman is enabled to decide, **in consultation with her doctors**, whether she can continue the pregnancy when there is a confirmed or substantial risk of fetal anomaly.

## Please oppose this amendment

The consequences of this amendment could be devastating to women and couples at risk of having a child affected by a serious x-linked condition. Given the scarcity of cures and treatments for genetic conditions, reproductive choice remains one of the most powerful options for women at

risk of having a child affected by a genetic condition. In some of the most rare and serious conditions, abortion on the grounds of the sex of the fetus may be the only way women and couples can exercise this choice.

The debate will take place on Monday 23 February, we urge you to oppose this amendment and to vote against it if taken to a vote.

### **About Antenatal Results and Choices (ARC)**

ARC offers non-directive information and support to parents before, during and after antenatal screening; when they are told their baby has an anomaly; when they are making difficult decisions about continuing with or ending a pregnancy, and when they are coping with complex and painful issues after making a decision, including bereavement. We also work closely with health professionals in the field.

In the aftermath of prenatal or genetic testing, expectant parents are best placed to make the decisions concerning their pregnancy that they can best live with and doctors need to be able to help them do this without fear of prosecution.

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### **About Genetic Alliance UK**

Genetic Alliance UK is the national charity working to improve the lives of patients and families affected by all types of genetic conditions. We are an alliance of over 180 patient organisations.

The majority of the conditions cared for by our member groups have neither a cure nor an effective treatment available to patients in the UK. The opportunity to avoid the birth of affected children is a key option for families at risk of having children with a genetic condition.

Sex-linked conditions can run in families, a woman at risk of having an affected pregnancy may have known other families members to have had an affected child, and will be very familiar with the impact of the condition on families. Alternatively genetic conditions can often come to a family with no advance warning. The couple may have discovered their risk for the first time by having an affected pregnancy. This realisation is a shocking event to a couple, which brings stresses and tensions to what is usually a happy event: pregnancy and the birth of a child.

Registered charity numbers: 1114195 and SC039299 Registered company number: 05772999

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