Introduction

1. Genetic Alliance UK is the national charity working to improve the lives of patients and families affected by all types of genetic and rare conditions. We are an alliance of over 200 patient organisations. Our aim is to ensure that high quality services, information and support are provided to all who need them. We actively support research and innovation across the field of genetic medicine.

2. Almost all single-gene disorders are rare. Rare Disease UK is a multi-stakeholder campaign run by Genetic Alliance UK, working towards the delivery and implementation of the UK Strategy for Rare Diseases, signed by all four health departments in the UK and published by the Department of Health in November 2013.

3. Rare diseases affect an estimated 3.5 million people in the UK, 30 million people in the EU and 300 million worldwide. It is possible to identify over 6,000 different rare diseases and the number of diagnosable diseases is increasing on an almost daily basis thanks to research, science and developments in novel technologies.

4. The majority of 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.

What are the views of the general public, women and medical and legal professionals in Northern Ireland about the law on abortion and whether it should be reformed? How have those views changed over time?

5. The Working Group on Fatal Fetal Abnormality which recommended these changes to the legal framework in Northern Ireland took account of the extensive consultation carried out on similar proposals by the Department of Justice in 2014-15 and public opinion polling carried out at that time. They found that all the relevant medical, nursing and midwifery professional bodies, reproductive healthcare groups, human rights organisations and, trade unions, political parties and a wide range of other stakeholder groups were in favour of change, as were the majority of the population. This breadth of opinion in support of change is unlikely to have reduced over the intervening period.

6. Though we welcome changes to allow all women affected by a diagnosis of fatal fetal abnormality to receive their termination lawfully in Northern Ireland, these changes to the law are inadequate, as they are narrow in scope. Women with diagnoses of serious fetal anomalies that are not fatal at or shortly after birth will still need to travel to access terminations available to other UK women. They will continue experiencing the trauma of travel away from home and family at such a difficult time, without the support of their medical team and at significant financial cost.

7. 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. It is important to acknowledge the importance of choice for families in these situations. We support access to a range of reproductive choice options, and for women and couples to be empowered to access information to support their choice. We believe it would be valuable for Northern Ireland to further broaden the scope of review to
access to termination of pregnancy to include women with diagnoses of all serious fetal anomalies.

8. We take no view as to which choice anyone should take in any situation, and would support their decision and their right to make it, whatever it is. Our work to ensure access to reproductive choice is entirely compatible with our work to support patients and families living with a genetic condition which includes campaigning for the implementation of the UK Strategy for Rare Diseases, working to improve diagnostic techniques and pathways, and promoting rare and transparent access to treatments in the NHS.

What are the experiences of women in Northern Ireland who have been affected by the law on abortion?

9. Since most conditions causing fatal fetal abnormality are rare, relatively few women have experienced the distressing circumstances addressed by the proposed changes. Such women also often have very good reasons for not wanting to talk about such a traumatic and difficult time in their lives. Patient groups supporting people affected by rare conditions are often small and informal, and are unlikely to have the capacity to open a Northern Irish office. To ensure a full consideration of the all of the possible future experiences of women in Northern Ireland, we therefore urge the Committee not to ignore the views of women and patient groups with relevant experience and perspectives located outside Northern Ireland.

10. Genetic conditions, such as those which cause many fatal fetal abnormalities, can often come to a woman or couple with no advance warning. If a couple is at risk of having a child with an autosomal recessive condition (a condition which is passed on by both parents, who are unaffected carriers of the condition) then the couple is most likely to have discovered their risk by having an affected pregnancy. This realisation is shocking and potentially overwhelming, bringing trauma and tension to what is usually a happy event: pregnancy and the birth of a child. These are usually rare conditions of which the couple would usually have no knowledge in advance of the affected pregnancy.

11. The couple and ultimately the pregnant woman are put into an urgent situation in which they must assess their options and make a very difficult choice. Termination of a wanted pregnancy is one of the hardest decisions women and couples may have to face. Forcing these women to travel away from home and family at such a difficult time, without the support of their medical team and at significant financial cost, is an unacceptable burden, as is forcing them to continue to carry a fetus that has no chance of being viable. We welcomed the recognition of the majority of UK Supreme Court judges that laws requiring women to choose between these two awful alternatives are incompatible with respect for private and family life.

12. A significant subset of genetic conditions are serious enough to cause death in utero, at birth or shortly after birth. The quality of life of a child which survives long enough to be born with one of these conditions is extremely poor. The impact upon the parents of having a child with one of these conditions is enormous. What is usually a happy event, the birth of a child, is turned into a crisis. Parents must witness their newborn struggling with life without any ability to help. This experience can be so devastating to couples that they may choose not to try to have another child. We emphatically support changes to legislation to permit women in such difficult situations to receive their termination in Northern Ireland, with the support of their family and medical teams.

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