Where can I find out more?

If you are concerned about a genetic disorder or disability within your extended family and how it might affect you, please speak to your GP. Take this leaflet with you. He or she may refer you to the Regional Genetics Service, part of Sheffield Children’s Hospital.

Regional Genetics Services offer specialist genetic counseling and advice. They may also be able to offer tests to identify some recessive conditions, and new tests are rapidly becoming available.

The Regional Genetics Service in Sheffield employs a Genetics Outreach Worker who works closely with the Genetic Counseling team and is able to provide information in Urdu and Punjabi. Referral into the Regional Genetics Service is through your GP. If you would like to speak to someone about your family history and a possible referral please contact Noshee Zameer, Genetics Outreach Worker based at Sheffield Children’s Hospital, Tel: 07774828184.

There is also work taking place in the community to raise awareness of genetic risk. If you would like to learn more about this or have general questions about genetic risk and inheritance please contact Saima Ahmed, Community Development Worker, based at the Pakistan Advice and Community Association, Tel: 07450701628.

More information is available at www.geneticsaware.org including:

- This leaflet in Urdu
- Audio/ Video Information

Cousin marriage and genetic risk

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**Why is genetics important for me and my family?**

Have you ever wondered why members of the same family look similar? This is because blood relatives share a large number of their genes. Genes are the code that controls the body. For example, you genes control your eye colour, the size of your feet and hands and much more!

We inherit many things from our parents. In the same way, we can inherit some diseases and disabilities from our parents through unusual, changed genes. These are called genetic disorders.

Families from all communities can be affected by genetic disorders. However, some types of genetic disorders known as recessive disorders are more common among families where couples are blood relatives, for example cousins. Most children born to cousins are healthy, but there can be problems when there is a changed gene in a particular family and both parents happen to have this changed gene.

We have been talking with community members and they tell us that people want better information and services to support families in understanding the issues around cousin marriage and genetic risk. This information aims to answer some common questions based on facts and figures.

**My husband and I are not cousins. In fact we are not even related, but my child has a genetic disorder. If genetic disorders are related to cousin marriage, then why is my child affected?**

Genetic disorders can affect anyone. Every couple, including those who are not related, has a chance of having a baby with a genetic disorder. Children of unrelated parents have on average a 2-3% chance of being born with a genetic disorder of some kind. For most genetic disorders, the risk of having an affected baby is the same whether or not the parents are related to each other.

**I am married to my cousin and my oldest son has a serious genetic disorder. However, my younger child is completely healthy. If cousin marriage is related to genetic disorders then why is one of my kids OK and the other is not?**

Being married to a cousin is not the reason that a child is born with a genetic disorder. Most babies born to cousin couples are healthy. However, the problem arises when there is a changed gene for a recessive disorder in the family and both parents happen to have this unusual changed gene. For such a couple, there is a chance in every pregnancy that the child may inherit the disorder (see Ruby and Adam’s story). In this case, the older son must have inherited an unusual changed gene from both his mother and his father. In the case of the younger son, who appears healthy, there are two possibilities. First, it is possible that he is a carrier of the condition having inherited one usual and one changed gene. Second, he may have inherited two usual genes, one from each parent and therefore is not affected.

Contact information for Muslim scholars who are willing to discuss these issues are listed below:

**Mufti Muhammad Zubair Butt**  
Leeds Teaching Hospitals NHS Trust:  
Tel: 0113 20 64365; Email: zubair.butt@leedsth.nhs.uk

**Imaam Shoeb Desai**  
Yorkshire Muslim Academy  
Tel: 07878663330; Email: shoebdesai@live.co.uk

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*Note: Images of eye, foot, and hand are included for visual representation.*
How are recessive disorders inherited?

Ruby and Adam are a healthy couple. However, as the picture shows they both have an unusual changed gene for the same recessive disorder. Ruby and Adam are called “healthy carriers” because even though they have one changed gene they do not have the disorder themselves. They have both passed on this changed gene to baby Sara, who has the disorder.

In each pregnancy, their child inherits one gene from Ruby and one from Adam. So in every pregnancy the child has a chance of inheriting an unusual, changed gene or a usual gene. There are four possibilities every time Ruby becomes pregnant.

1. If the child receives a usual gene from both Ruby and Adam, then the child will not have the disorder.

2. If the child receives an unusual, changed gene from Ruby but a usual gene from Adam, then the child be a healthy carrier and could pass the changed gene on to the next generation.

3. Similarly, if the child receives a usual gene from Ruby but an unusual, changed gene from Adam, then the child be a healthy carrier and could pass the changed gene on to the next generation.

4. If the child receives the unusual, changed gene from both Ruby and Adam, then the child will be affected by the disorder.

The chance of an affected child is the same each time Ruby and Adam have a baby. Their next child could have a genetic disorder like Sara or be a healthy carrier or be completely free of the disorder. The same chances are there each time Ruby is pregnant.
Common questions

I hear a lot about this issue in the Pakistani community. Is this relevant to other communities as well?
Genetic disorders are found in every community. However, all communities that practice cousin marriage have higher numbers of children with recessive disorders. Health services are responding to the needs of these communities around the world. In the UK, the Pakistani origin community has the highest level of cousin marriage, so there is a higher proportion of children with recessive disorders in this community.

I know people who are married to cousins and have healthy kids. Is it really true that marrying a cousin results in disabled children?
Being married to a cousin is not the reason that a child is born with a disability. Most babies born to cousin couples are healthy. However, the problem arises when there is a changed gene for a recessive disorder in the family and both parents happen to have this unusual, changed gene. For such a couple, there is a chance in every pregnancy that the child may inherit the disorder. This happens if the child inherits the changed gene from both the father and the mother (see Ruby and Adam’s story). When a cousin couple has a healthy child this may be because they do not have an unusual, changed gene in common, or because the child in question did not happen to inherit the unusual, changed gene that the parents share.

I don’t see why this issue is relevant to me. I am already married to my cousin. Is there any point in learning more about this?
Whatever the stage of your life, genetic information may be valuable to you and your family. People who are well informed are in a better position to make the right choices for themselves. Genetics services can be useful for anyone who has a genetic disorder in their family or people who are concerned about such conditions.

I am interested to know more about this important issue but I want to understand the religious and moral aspects not just the scientific evidence. Thinking about marriage and childbearing raises religious and moral questions in many people’s minds and you may want to discuss this information with family, friends and other people you trust.

How do recessive disorders affect different communities?
Genetic disorders affect all communities and can cause children to die or have lifelong disability. There are thousands of different genetic disorders.

Communities that marry cousins or other close blood relatives have a higher number of one particular group of genetic disorders. These are called recessive disorders, and examples include cystic fibrosis, sickle cell anaemia, thalassemia and Tay-Sachs disease. Because genes get passed on in families and genetic disorders are rare, if a person marries a blood relative there is a greater chance that both will have a gene for the same recessive disorder and be a ‘carrier couple’. This means that there are more carrier couples, and therefore more children with recessive disorders, in communities that practice cousin or other close blood relative marriage. Of the UK communities that have cousin couples, the Pakistani origin community is the largest with the highest level of cousin marriage.

Research shows that for every 100 babies born to the unrelated couples fewer than 3 have a birth disorder, whereas for every 100 babies born to closely related couples 5 to 6 have a disorder*. This extra risk is mainly because recessive genetic disorders are more common among the blood related couples. National statistics show that for every 1,000 babies born to Pakistani origin mothers around 5 die before their first birthday due to birth disorders**. This rate is higher than other ethnic groups. Some of these extra deaths are caused by recessive disorders.

![Graph showing birth disorder rates](image)

* Sheridan E. et al. 2013 The Lancet  http://dx.doi.org/10.1016/S0140-6736(13)61132-0
** National Perinatal Epidemiology Unit, www.npeu.ox.ac.uk