

Centre for Appearance Research

Information on genetics and support services

Understanding Genetics and Genetic Testing

These resources provide foundational knowledge about genetics and the types of genetic testing available.

- 1. Genomics England
- Learn about Whole Genome Sequencing (WGS) and how it can help diagnose conditions.
- Use their patient guides to understand the process and benefits of genomic research.
- 2. Genomics Education Programme
- Find information about NHS genetic education programme.
- Check how genetic testing can support the diagnosis of rare diseases or inherited conditions.
- 3. Genetic Alliance UK
- Explore their family-friendly guides and resources about genetic conditions.
- Join their advocacy groups or access their advice for navigating healthcare services.
- 4. Wellcome Connecting Science Your Genome
- Use this resource to learn about genetics and genomics in a simple and engaging way.
- Explore their animations and infographics for a clearer understanding of complex topics.

Support for Families Affected by Genetic Conditions

These sites provide emotional and practical support for families living with genetic conditions.

- 5. <u>Unique Rare Chromosome Disorder Support Group</u>
- Download detailed guides about specific chromosome or genetic disorders. Connect with other families for peer support.
- 6. Gene People
- Access their comprehensive library of resources for families living with genetic conditions.
- Find support groups or learn about available services.
- Speak with a registered genetic counsellor
- 7. Contact



- Discover their advice on accessing genetic testing and related support for children with disabilities.
- Join their parent networks for emotional and practical guidance.

Prenatal and Fertility-Related Genetic Testing

These resources focus on genetic testing during pregnancy or fertility treatments like IVF and PGT.

- 8. HFEA (Human Fertilisation and Embryology Authority)
- Learn about fertility treatments and preimplantation genetic testing (PGT).
- Use their clinic search tool to find regulated fertility clinics in the UK.
- 9. Fertility Network UK
- Access support for navigating fertility treatments, including genetic testing options.
- Join forums and support groups for those going through IVF or PGT.

10. ARC (Antenatal Results and Choices)

- Understand your options for prenatal testing, including genetic screening during pregnancy.
- Get advice and emotional support tailored to your situation.

11. <u>Tommy's</u>

- Learn about how genetics and IVF can help if you're struggling with fertility or pregnancy loss.
- Access resources and stories from other families.
- 12. Progress Educational Trust (PET)
- Stay informed about ethical and legal issues surrounding genetic testing in IVF and pregnancy.
- Read their in-depth articles about preimplantation genetic diagnosis (PGD) and PGT.

Mental Health Support

13. <u>RareMinds</u>

• Rareminds offers online counselling and wellbeing services for people living with rare conditions and their families.



Professional Support and Genetic Counselling

These resources can help individuals find professional guidance through the genetic testing process.

14. Genetic Counselling UK

- Find qualified genetic counsellors who can explain testing options and results.
- Book an appointment to get personalised advice.

15. British Fertility Society (BFS)

- Learn about the role of genetics in fertility treatments from trusted experts.
- Use this resource to find information specific to healthcare providers.

Information About Genetic Screening Programs

These sites focus on national screening programs and how they support families.

- 16. UK National Screening Committee
- Find out what genetic screening tests are available in the UK during pregnancy and for newborns.
- Access easy-to-read information about how screening can detect genetic conditions.
- 17. ARC Antenatal Screening Explained
- Use their simple guides to understand the screening and testing options offered during pregnancy.

Learning About Rare and Genetic Conditions

These resources provide specialist knowledge about rare diseases and genetic disorders.

18. Rare Disease UK

- Learn how genetic testing can help diagnose rare conditions.
- Join their campaigns to raise awareness about rare diseases.

19. Unique – Rare Chromosome Disorder Support Group

• Access expert-curated information about rare chromosomal and genetic conditions.