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Cancer patient hopeful thanks to genome sequencing

Tuesday 8 March 2016: Today, the Minister for Life Sciences, George Freeman MP, launches Genetic Alliance UK's latest report "Genome Sequencing: what do cancer patients think?" The report finds that cancer patients are excited about the potential of genome sequencing in helping to develop targeted treatments, and are keen to be involved in research in this area. The report also makes 10 recommendations for consideration before genome sequencing becomes widely incorporated into NHS services.

Key findings: The report finds that cancer patients are excited about the potential of genome sequencing in helping to develop targeted treatments, and are keen to be involved in research in this area. Cancer patients want to be involved in decision making about their health and about potential treatments – but need to be provided with relevant and appropriate information about genetics and genomics.

Chloe Judd, cancer patient said:

"I am so excited to see what genome testing and tailored cancer treatments can do for patients like me in the future."

Andrew Anderson, cancer patient said:

"Having been misdiagnosed three times, and in desperation paying privately for the necessary ultrasound, I was finally diagnosed with advanced testicular cancer in May 2000. At the time of diagnosis, the best prognosis was that I had less than six weeks to live.

If I've learned anything, I've learned that 'knowledge is power' – the more knowledge available to the oncologists the better the patient's chance of recovery. As with most cancers, the earlier the disease is diagnosed and treated, the easier the whole experience is for the patient, and the cheaper for the NHS."

About whole genome sequencing: Whole genome sequencing is an area of research that is greatly exciting to cancer patients, offering a wide range of possibilities in diagnosis and the development of future treatments. This, coupled with the fact that the speed and cost of sequencing have dropped dramatically, means that for the first time, large-scale, routine genomic medicine could become a reality for NHS healthcare. It is important that, when introduced into clinical care, services are designed with cancer patients' opinions and experiences in mind.

The UK has been a pioneer in many aspects of research and medical genetics, over the last two decades. In 2012, the Prime Minister committed to sequencing 100,000 genomes before the end of 2017 – this is being implemented through the 100,000 Genomes Project. The 100,000 Genomes Project has so far seen people with undiagnosed genetic conditions be given diagnoses, and has recently started recruiting cancer patients to the project.

About the project: The report "Genome Sequencing: what do cancer patients think?" is the product of a project called My Cancer, My DNA. The project aims to understand the needs and expectations of patients, and their families, when it comes to whole genome sequencing in clinical care and research. Over 80 cancer patients took part in online engagement events which were used to share information about genome sequencing with participants, and to hear their experiences and views on issues relating to whole genome sequencing.

Unit 4D, Leroy House, 436 Essex Road, London, N1 3QP
+44 (0) 20 7704 3141
contactus@geneticalliance.org.uk
www.geneticalliance.org.uk

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

Recommendations from the Patient Charter: The report makes 10 recommendations to be taken into consideration before whole genome sequencing is incorporated into NHS services as part of clinical care. These can be grouped into three sections:

- Patients should be given the information to understand the genetic nature of cancer and the relationship between cancer and genomics
- A streamlined pathway should be established to ensure patients receive the necessary dedicated care required based on all findings from genome sequencing
- Research studies can benefit from the willingness of patients to contribute to research through sharing their genetic data

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Notes for Editors

Contact for further Information:

Angela Wipperman, Public Engagement and Project Officer

Email: angela.wipperman@geneticalliance.org.uk

Telephone: 020 7704 3141

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. 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.

Genetic Alliance UK undertakes various projects and programmes that add evidence and knowledge to improve health service provision, research and support for families. These initiatives include:

- Rare Disease UK, a stakeholder coalition brought together to work with Government to develop the UK Strategy for Rare Diseases. www.raredisease.org.uk
- SWAN UK (syndromes without a name), a UK-wide network providing information and support to families of children without a diagnosis. www.undiagnosed.org.uk

Genetic Alliance UK website: www.geneticalliance.org.uk

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