



**Progress Educational Trust**

informing debate on assisted conception and genetics

## **PRESS RELEASE**

**Source: Progress Educational Trust**

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### **EVERYTHING YOU EVER WANTED TO KNOW ABOUT GENOMICS BUT WERE AFRAID TO ASK #GenomicsConversation**

Genomics and fertility charity, the Progress Educational Trust (PET), highlights today, at its free-to-attend #GenomicsConversation event, the need for increased understanding about the role of genomics in healthcare and family life now and in the future.

Sarah Norcross, director of PET and co-chair of the event, said: 'Talking about genomics can be difficult – even the word is tricky to pronounce, and that's before you start trying to understand what it means for you and your family. But there is a pressing need for the public, patients and healthcare practitioners to get to grips with genomics because of the enormous influence it is beginning to have on our lives. The time to ask questions is now: about why genomics is so important; how it is affecting healthcare, and what genetic and genomic tests can tell you.'

Dr Anneke Seller, head and scientific director of Health Education England's Genomics Education Programme and co-chair of the event, noted: 'Genomics in healthcare is here: it is already being used to predict disease, aid diagnosis, inform treatment options and give patients more opportunities to participate in research and clinical trials. Advances in technology and our knowledge and understanding of genomics mean that its use in the NHS will grow year on year; soon genomics will be embedded in almost all medical specialities. It's important the public have every opportunity to understand the implications, to ask questions and to be part of the debate, so they can contribute to shaping healthcare in the genomics era.'

The #GenomicsConversation event will hear from Professor Jill Clayton-Smith, consultant clinical geneticist at the Manchester Centre for Genomic Medicine and Dr Simon Ramsden, consultant clinical scientist at the Manchester Centre for Genomic Medicine. Dr Ramsden said: 'Modern technology means that, within the NHS, we can sequence your entire genome. The big question now is: how can this information be used to improve your healthcare.'

The event will also hear from patient Sabine Starr, who is a participant in the 100,000 Genomes Project – Genomics England's project to sequence 100,000 genomes from around 85,000 patients affected by a rare disease or cancer and which created the new NHS Genomic Medicine Service. She said: 'The benefits of being involved in a research project like this for the future are phenomenal. Genomics is changing medicine for the good: it will change lives and it will save lives. I got involved not just to know my own test results; genomics is about the future and how we help future generations.'

Elizabeth Alexander, a genetic counsellor at the Manchester Centre for Genomic Medicine speaking at the free-to-attend event, said: 'The technology we have is very exciting and we've come a long way in the last few years but there's still a lot we don't know; we're only at the start of our understanding. It's important to appreciate that genetic or genomic tests don't always give straightforward, easily interpreted results and answers are not black or white. As well as considering the science and medical management you also have to consider how results can impact that person; how they feel and how they absorb that information into their emotional life and family life, as well as the impact on their health.'

EVERYTHING YOU EVER WANTED TO KNOW ABOUT GENOMICS BUT WERE AFRAID TO ASK is at 18.30 on 4 September 2019 at the Garratt Suite, Science and Industry Museum, Liverpool Road, Manchester M3 4FP. When covering this story, please mention PET and the #GenomicsConversation event, which is produced by PET in partnership with Health Education England and its Genomics Education Programme. Register [here](#).

ENDS

### **Notes for editors**

For interviews with participants and case studies, contact Catherine Hill, PET head of communications on 07305-091466 [chill@progress.org.uk](mailto:chill@progress.org.uk)

1. The Progress Educational Trust (PET) is a UK charity working to advance public understanding of, and engagement with, science, law and ethics in the fields of human genomics, human reproduction, embryology and stem cell research. Funded by grants and public donations, PET aims to improve choices for people affected by infertility or genetic conditions. <https://www.progress.org.uk/>

2. PET organises free-to-attend events debating the responsible application of reproductive and genetic science and publishes BioNews, a free comment and news service. Subscribe to BioNews at <https://www.bionews.org.uk/subscribe>

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