



Press release

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PET highlights the need for increased understanding around the use of genomic data in assisted reproduction
#PETtestingtimes

Campaigning charity PET highlights today the need for increased understanding of the opportunities and pitfalls presented by the use of genomic data in assisted reproduction, in particular expanded carrier screening where multiple gene variants are screened for simultaneously.

Sarah Norcross, director of PET, said: 'The use of genomic data in assisted reproduction raises challenging questions. Expanded carrier screening is increasingly available via the private sector for prospective parents, either using their own gametes or donated sperm or eggs, but what is the cost to patients – financially and otherwise – of embracing this technology? Will expanded carrier screening be included as an "add-on" to IVF, and is there a role for its routine use within public healthcare?'

Ms Norcross added: 'PET campaigns to improve reproductive choices, but it is important to consider whether these new technologies will reassure prospective parents or create anxiety. How reliable is the latest screening technology? Is adequate genetic counselling available? Professional bodies and regulators need to be considering these questions.'

PET's 'TESTING TIMES: HOW SHOULD WE USE GENOMIC DATA IN ASSISTED REPRODUCTION MEETING' will hear from an international panel of experts, which includes Dr Jess Buxton, senior lecturer in medical genetics at Kingston University London and PET trustee. Dr Buxton will address how genomic data may be used and the limitations of expanded carrier screening and polygenic scoring.

César Díaz García, medical director of IVI London, will provide the clinician's/researcher's perspective, outlining how expanded carrier screening, and other genomic information is used now in the clinic and how it could be used in the future. Dr García noted: 'Healthy live birth should be the only valid outcome of IVF treatments. Genomic information could become a key tool to achieve such an outcome. The implications for the different parties involved in fertility treatments should be carefully evaluated when advising patients and donors.'

Karen Sage, genetic counsellor and leader of the genetic service at CARE Fertility, will discuss the issues around genetic counselling, including the implications of expanded carrier screening for other members of an individual's family, and highlight the lack of guidelines from professional bodies and regulators.

Véronique Berman, scientific adviser at Jewish fertility charity Chana will highlight the impact of expanded carrier screening within the Jewish community, where two radically different approaches to genomic screening exist.

The event will be chaired by Jane Fisher, director of Antenatal Results and Choices.

When covering this story, please mention PET and the Testing times event.

Testing times: how should we use genomic data in assisted reproduction is on 16 May 2018 at 18.30 at Amnesty International, 17-25 New Inn Yard, London EC2A 3EA. The free-to-attend event is sponsored by Igenomix. Register for the event at <https://sforce.co/2U1IEHL>

ENDS

Notes for editors

For media interviews and case studies, contact Catherine Hill head of communications on 020 7278 7870 or chill@progress.org.uk

1. Expanded carrier screening – testing individuals to see whether they carry gene variants that could lead to disease in future children – was previously offered to people based on their family history or ethnicity, but is increasingly available via the private sector for any prospective parent, and sperm or egg donors.

2. Polygenic scoring, a statistical approach different to a conventional genetic test, can be used to give a numerical likelihood to whether a person or embryo will develop a given disease or characteristic. Controversially, a US firm is offering polygenic scores for IVF embryos, so patients can avoid implanting embryos with very low intelligence scores.

3. 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 genetics, human reproduction, embryology and stem cell research. Funded by grants and public donations, PET aims to improve the choices for people affected by infertility or genetic conditions. <https://www.progress.org.uk/>

4. 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>