NHS
West of England
NHS Genomic Medicine Centre

Update from your Genomic Medicine Centre: October 2018

Genetics lead awarded honorary degree

WEGMC partnership board member Eileen Roberts has been awarded an honorary degree by UWE Bristol.

Eileen was presented with the award in August in recognition of her commitment to providing genetics and genomic services to the UK and internationally for delivering the 100,000 genomes project as a partner in our WEGMC and for supporting UWE's genetics and genomics education and research.

Eileen is also head of the Bristol Genetics Laboratory at North Bristol NHS Trust and has been instrumental in the success of the WEGMC, where she is also co-chair of the workforce and development group.

In the article to the right Eileen updates on the future provision of genetic testing.

North Bristol Trust announced as lead of Genomic Laboratory Hub

On 2nd October NHS England announced the seven organisations that will be leading the provision of Genomic Laboratory Hubs as part of the future Genomic Medicine Service

North Bristol Trust was announced as one of the seven Genomic Laboratory Hubs that along with six other organisations will be tasked with developing a new national network to deliver a single national testing service for all genetic and genomic testing in the NHS.

NHS England's announcement confirmed that from October 2018 Genomic testing in the NHS would be provided through a single national testing network aimed at consolidating and enhancing the existing laboratory provision. The aim of the consolidation being to create a world class resource for the NHS and underpin the future Genomic Medicine Service with each of the seven Genomic Laboratory Hubs (GLHs) responsible for coordinating services for a particular part of the country.

Over the next 18 months the Genomic Laboratory Hubs supported by clinical services and the future Genomic Medicine Centres will be working to roll out the national test directory for genomic services and facilitate patient access to genetic and genomic testing across the region.

Eileen Roberts, Head of the Bristol Genetics Laboratory stated, "This means we will be supporting more personalised medicine for patients with cancer and rare diseases in the South West and beyond. Treatments will be more tailored and effective to each individual's own disease profile. Also in some cases patients will be able to avoid aggressive treatments that may be of no benefit.
It is very exciting to be a part of this – we are proud that our long standing expertise in genomics has been recognised."

Eileen Roberts, Head of Bristol Genetics Laboratory
WEGMC Partnership Board member and
co-chair of the centre's Workforce and Development Group

100,000 Genomes Project closes to rare disease patient enrolment having collected over 60,000 samples nationally

Enrolment of patients with rare disease to the 100,000 Genomes Project closed last month. Locally the final eligible patients were consented in clinics across the region and their samples will be managed through the Genetics Laboratory in Bristol before being sent for Whole Genome Sequencing in the national sequencing centre in Cambridge.

Within the West of England region over 2,500 individuals with rare diseases and members of their family will have accepted the invitation to participate in the 100,000 Genomes Project and the core team want to extend a massive thank you to all the staff across the NHS who have helped to facilitate this fantastic achievement. Andrew Mumford, Clinical Director of the West of England commented "This is a great achievement for the West of England Genomic Medicine Centre and it has been a fantastic effort by the team to offer genome sequencing to so many patients across our region."

The closure of the 100,000 Genomes Project marks the start in a new era for genomic medicine as the newly announced Genomic Laboratory Hubs commence building on the work of the project to establish pathways for whole genome closes as part of standard care in the NHS.

SAVE THE DATE

WEGMC Annual Conference

29 October - 2pm onwards

Education Centre, UHBristol

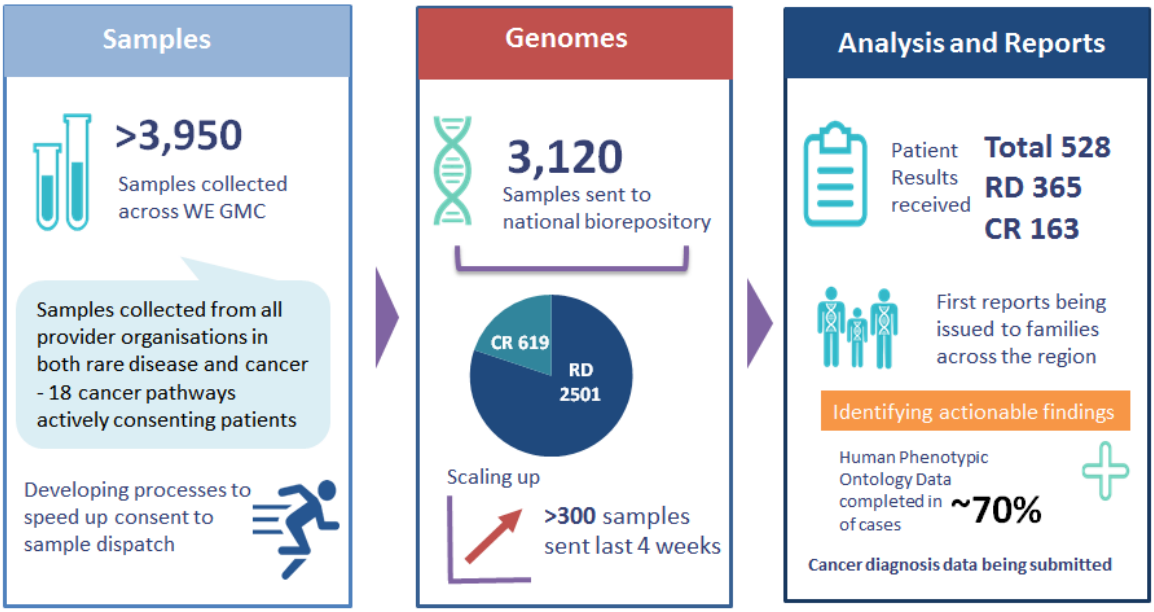
Sessions will include:

- Return of results from the 100,000 Genomes Project
- National Genomics Informatics System
- Considerations for consent to genomic testing consent
- Future Genomic Medicine Service

To register please visit
www.wegmc.org

More news overleaf on page 2

WEGMC Project Summary (update end of September 2018)



"We are so lucky to have this opportunity to be a part of the genome project."

Patient Patricia Gaskin signed up to the project through Gloucestershire Hospitals NHS Foundation Trust, which is part of the WEGMC.

Patricia said: "I was diagnosed with ovarian type cancer in April 2017. When I came for an appointment my consultant introduced me to a research nurse and asked me if I would be interested in taking part in the genomes project.

"[The nurse said] how I could help in the future with research from my tumour samples and that I could also benefit because they could tell me lots of things from my DNA, so I felt I had nothing to lose and that was how it all started.

"I had to sign a lot of paperwork, answer lots of questions and, when I had my surgery, they took samples. When I started getting better I phoned the project lead nurse to find out if they had had any results.

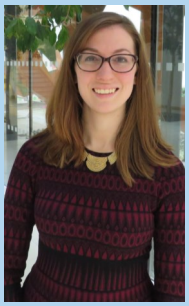
"One week later I had a phone call to say the results were in, so Mr James Bristol told me that whilst the blood tests I had taken previously came back negative for the inherited BRCA ovarian and breast cancer gene, as part of the tests for the genomes project, my tumour was also tested and that came back with a positive result for the BRCA gene in the tumour. Because they found it there in the additional testing as part of the project, I could be treated for it and that has made a huge difference in my treatment, because this would not have happened otherwise.

"I am stage 4 so being offered and finding the BRCA gene is even more crucial for people like me because we can now be treated for it, whereas without the genome testing on our tumour we would not be aware we had it. I think we are so lucky to have this opportunity to be a part of the genome project and although people like me cannot take control of our diagnosis, we can take control in the future about what we do about it."

WEGMC teams celebrate awards across the region

As the 100,000 Genomes Project comes to a close members of the WEGMC team across the region are celebrating receipt of local awards that acknowledge their hard work and dedication to the project:

- In September the Royal United Hospitals (RUH) Bath NHS Foundation Trust's consenting team received the RUH 'Team of the Month' award and have been nominated for the Trust's annual awards ceremony.
- Amanda Pichini, lead genomic practitioner for the WEGMC, whose formal secondment to the project ends this month has received a Divisional Spotlight Award within University Hospitals Bristol NHS Foundation Trust in acknowledgement of her role in supporting delivery of the project both at UHBristol and across the region. Amanda is pictured right.



National 100,000 Genomes Project Update

The 100,000 Genomes Project has reached a landmark for enrolment with over 90,000 patients consented to the project. Rare diseases consenting ended lasts month after its nationally agreed target was successfully delivered. Enrolment of cancer patients will continue until the end of 2018.

The next national GMCs meeting is scheduled for 11 December. For further information contact the WEGMC programme manager Catherine Carpenter-Clawson by emailing **ubh-tr.wegmc@nhs.net**