

100,000 GENOMES PROJECT

Autumn 2016

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Our Partners

Northern Devon
Healthcare NHS Trust

Plymouth Hospitals NHS
Trust

Royal Cornwall Hospitals
NHS Trust

Royal Devon & Exeter NHS
Foundation Trust

Torbay and South Devon
NHS Foundation Trust

Taunton and Somerset
NHS Foundation Trust

Yeovil District Hospital
NHS Foundation Trust

SUCCESSFUL EXOME Sequencing Day



The South West GMC with the support of the Health Education England Genomic Education Programme were delighted to host a very successful Exome sequencing workshop at the Rougemont Hotel on 19th September. The event brought together a total of 74 delegates including a number of local facilitators and representation from genetics services across the country. Clinical geneticists, bioinformaticians, lab scientists and genomic counsellors came together for this event focussing on the essential requirement of multidisciplinary team (MDT) working when analysing genomic data.

Feedback collected on the day was extremely positive with the vast majority of attendees responding that they had learned significant amounts of new information and would recommend the event to colleagues. In fact the workshop was vastly oversubscribed; such is the demand for such an innovative facilitated learning event. With over 30 people on the waiting list, a new date of March 7th has been set to re-run the workshop.

**Meet our new
Genomic Champions**



Tom Hannah - Plymouth



Oliver Leach - RCHT



Jane Baker - Torbay



Frank McDermott – RD&E

Focus on Cancer

Cancer launch

Senior responsible officers for the project have been appointed in each of our LDP Organisations. These officers will chair and oversee the local operational board and represent the organisation at meetings and update calls. A cancer launch event is being planned to bring together the SRO's from each Trust along with a core membership including surgeons, CNSs, pathology leads and MDT surgeons, CNSs, pathology leads and MDT co-ordinators. The event will be held at Sandy Park and will provide background to the project and start discussions regarding pathway design, eligible patients and consent training.

A number of additional cancer types have been added to the list of eligible cancers; adult glioma, brain tumours, renal cancer, bladder cancer, endometrial cancer, melanoma, upper GI tumours and testicular cancer. There are also plans to allow haematological and childhood cancers

Focus on Rare Disease

As of September 30th, 305 family referrals have been received from clinical genetics, renal medicine, paediatrics, endocrinology, diabetes, neurology, ophthalmology, dermatology, immunology and cardiology. Recruitment is close to target with 558 participants (220 families) recruited. Work continues to engage clinicians outside of Exeter and the Community Paediatrics team at Truro have already made a significant contribution to the project. The GMC will be working with groups of clinicians at each of the LDPs as they come on board so that eligible patients can be referred.

Communications

As the LDPs come on board, their communication teams have been involved in spreading the message and using social media to raise the profile of the project. Support from the centre has been given in the form of video links/leaflets and advice regarding education opportunities for staff. Information has been well received and promotion is on-going through websites and intranets.

Education and Training



Professor Anna Murray – Programme lead for MSc in Genomic Medicine

The last few months have seen lots of activity around genomics education and training. September saw the launch of the MSc in Genomic Medicine with a fantastic number of attendees from a broad range of specialities and a great mix of experience. Each of the first two modules was attended by over 30 people, leading to some great discussions from a very engaged group. The vast majority were funded by the Health Education England funding stream allowing genomics to be embedded directly into NHS practice, although there were a couple of self-funders and international students.

Following the Successful Exome Sequencing Day in September, a new date has been arranged and will include:

- Communicating results to patients
- Exome sequencing strategies
- MAF, transcripts and conservation
- The role of the MDT in interpreting results.

The day will be organised by Professor Sian Ellard and Dr Emma Baple.

**For further information and to register interest, please email:
Rde-tr.swgmc@nhs.net**

Patient and Public Involvement



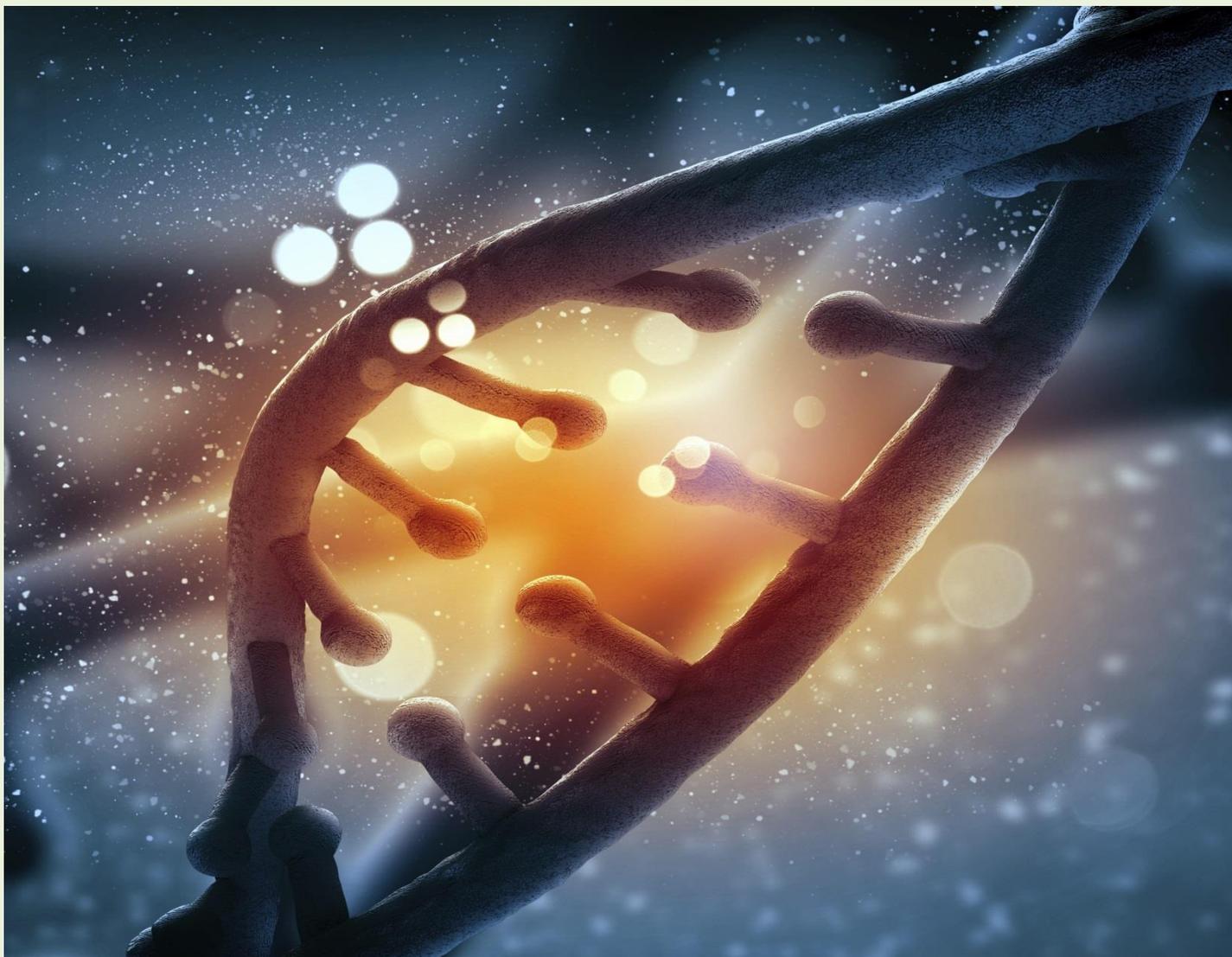
Patient Public Involvement is an important part of the development of any project which aims to improve the diagnosis and treatment for the people in our community. I was delighted and excited to be given the opportunity to help facilitate this and have recently taken up this role along side my position as deputy project manager for 100,000 Genome project in the southwest.

Patient involvement in the south west has already helped make changes which will improve how the project works through a series of meetings and workshops. Participants in the south west have also joined the National Patient Participation team. Amongst the national group's achievements is an informative and accessible animation on how results are managed <https://www.genomicsengland.co.uk/>

All participants who join the project in the southwest can have an opportunity to help us create the best approach to supporting, understanding and delivery the 100,000 Genome Project in the South West.

For more information please contact me..... I look forward to hearing from you.

Email: ana.juett@nhs.net



**Check out our website for more information about the SW
100,000 Genomes Project and contact details at www.swgmc.org**

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