



Celebrating **two years** of bringing the 100,000 Genomes Project to NHS patients - the Yorkshire and Humber Genomic Medicine Centre

# Genomes Update

Information for our partners, patients and staff



Recruited **OVER 3,000** people into the national **100,000** Genomes Project

**Established** ACTIVE PUBLIC PATIENT INVOLVEMENT GROUP with members involved in every aspect of the project.

NEARLY **400** cancer patients recruited from **20** different cancer types

**OVER 2,600** RARE Disease Samples Collected

Hosted a number of educational events including the...



**WON** Best Example of Adoption and Diffusion category at The Yorkshire & Humber Academic Health Science Network's Innovation, Improvement and Impact Conference 2017



Numerous awareness-raising activities such as during Healthcare Science Week and

**National Pathology Week**

**257** Twitter Followers

**OVER 2,500** visitors to Yorkshire and Humber Genomic Medicine website during 2017

One of 13 national centres, serving a population of **5.3 million People** THE **5TH** LARGEST IN THE PROJECT

MULTIPROFESSIONAL GENOMICS AMBASSADOR PROGRAMME

**launched Sept 2017**

**A JOINT COLLABORATION**

between Sheffield Teaching, Sheffield Children's and Leeds Teaching Hospital's Trusts, **11** local delivery partners, comprising **20** other regional hospitals.



**NHS** Yorkshire and Humber NHS Genomic Medicine Centre

## Over 3,000 people now part of Genomes project

A father-of-three who suffers with a rare complication of the heart has become the 3,000th person to take part in the pioneering '100,000 Genomes Project' in the Yorkshire and Humber region.

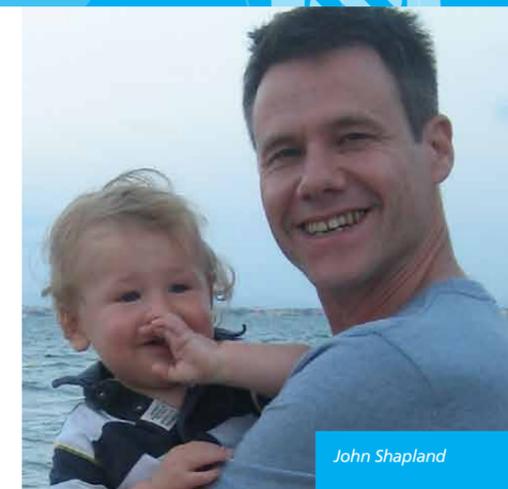
John Shapland, a 45-year-old, hopes that the programme will enable him to uncover vital clues which may lead him to better understand why he might be genetically predisposed to suffering with an aortic root aneurysm.

"I've got three young boys, so my primary focus is on understanding my condition as well as I possibly can so that it could benefit them in the future," said John, whose potentially life-threatening aneurysm was found purely by chance last November.

"They've looked at all the common syndromes for the condition but no link can be found, so at the moment there's no known reason why I might be predisposed to the condition."

Aortic root aneurysms occur when an abnormal bulge prevents the large vessel in the heart known as the aorta from carrying blood from the heart to the rest of the body. If left untreated, the aneurysm can expand and rupture, causing life-threatening internal bleeding.

"It's great that the 100,000 Genomes project is happening as the more people who subscribe and get involved, the more valuable the data becomes and the more chance we'll have of helping future generations," added the mechanical design engineer. "In time it could be the best indicator of a person's likelihood of developing conditions and as a genetic route offers me the most hope and may be useful for my children."



John Shapland

*By unlocking vital genetic information the '100,000 Genomes Project' could help bring new treatments and quicker diagnosis to millions*

## Genomes goes live

Did you know patients being cared for in hospitals managed by 11 NHS Trusts can now take part in the '100,000 Genomes Project'?

- Airedale NHS Foundation Trust
- Calderdale and Huddersfield NHS Foundation Trust
- Chesterfield Royal Hospital NHS Foundation Trust
- Doncaster and Bassetlaw Hospitals NHS Foundation Trust
- Harrogate & District NHS Foundation Trust
- Hull and East Yorkshire Hospitals NHS Trust
- Leeds Teaching Hospitals NHS Trust
- Mid Yorkshire Hospitals NHS Trust
- Sheffield Children's Hospital NHS Foundation Trust
- Sheffield Teaching Hospitals NHS Foundation Trust
- York Teaching Hospital NHS Foundation Trust

*"Nearly 400 cancer patients from 20 different cancer types have been recruited to the Yorkshire and Humber NHS Genomic Medicine Programme"*

# Genomics showcased at leading cancer conference



Debbie Bernie and the Y&H Genomics Medicine Centre stand

People affected by cancer who are living with or beyond a diagnosis of cancer heard how the '100,000 Genomes Project' could pave the way for the development of personalised cancer treatments and speed up diagnosis.

Debbie Bernie, Patient and Involvement Lead from the Yorkshire and Humber NHS Genomic Medicine Centre, delivered a key presentation about the '100,000 Genomes Project' to a 300-strong audience at the Yorkshire Cancer Research's Life with Cancer 2017 conference which was held at Harrogate Convention Centre at the end of last year.

The conference was attended by cancer patients, carers and members of the public from across the region.

"Around 190,000 people in Yorkshire are living with or beyond a diagnosis of cancer, so it was great to be able to present in front of such a large audience and to help raise awareness of how genomics research could help us better understand and catalogue the

connections and processes that cause cancer as a result of genetic faults in a person's DNA," said Debbie.

Nearly 400 cancer patients from 20 different cancer types have been recruited to the Yorkshire and Humber NHS Genomic Medicine Programme, and 8,000 cancer genomes sequenced in the national programme.

# Spreading the word about genomics

The Yorkshire and Humber NHS Genomic Medicine Centre team has been busy showcasing their work across the region.

The past few months have been busy and provided an opportunity for a number of collaborative events with museums and hospitals around the region. The team went out and about raising awareness and talking to NHS staff and the public about the 100,000 Genomes Project. Genomics Week was incorporated into the @STEM Leeds as part of the Leeds Festival of Science and the team delivered a number of science sessions to students at schools around the region.

The Yorkshire and Humber NHS Genomic Medicine Centre is currently working closely with the York Art Gallery to deliver informal creative art sessions as part of the York Community Engagement programme. This is a fun and exciting opportunity to explore genomics through art. Some of the artwork is currently on display at York Art Gallery.



# Genomics theatre production collaboration

The Yorkshire and Humber NHS Genomic Medicine Centre has been working collaboratively with the members and representatives of the Black and Minority Ethnic communities to explore the most effective way to raise awareness of genomics and the relevance to diagnosis and treatment, now and in the future, in a way that is culturally sensitive.

One example is work we are undertaking with Space2, an arts production company, to strengthen the concept of genomics by communicating key messages and learning outcomes about genomics and the impact it is having on healthcare through the creation of a theatre production.

If you are interested in finding out more contact our PPI lead, Debbie Beirne on [deborah.beirne@nhs.net](mailto:deborah.beirne@nhs.net)

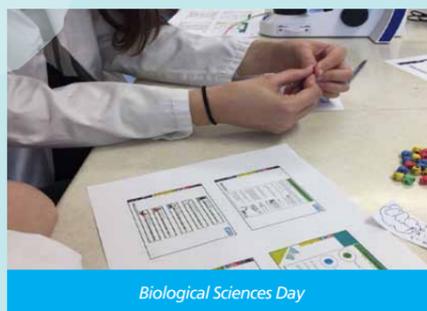
# New ambassadors programme

A team of genomic ambassadors have been appointed to promote understanding of the genomics programme across the Yorkshire and Humber region.

Supported by Health Education England, the team are a multi-professional group consisting of nurses, laboratory staff from genetics and histopathology, pharmacists and clinical geneticists.

As well as disseminating best practice, the team have supported the Yorkshire and Humber NHS Genomic Medicine Centre at a wide range of educational and engagement events.

During Genomics Week the Genomic Ambassadors from Sheffield and Leeds hosted various events at museums, hospitals and universities around the region, delivering science sessions at a number of schools in Yorkshire on 'How do we use DNA?' to key stage 4 and key



Biological Sciences Day

stage 5 students as part of the Leeds Festival of Science.

Genomic Ambassadors Martin Harris and John Filby also attended the Discovery Zone at

the University of Leeds' Science Fair, a popular highlight of the event for schoolchildren between the ages of 8-14 years old to try hands-on science. "It was a fun, hands-on, opportunity to get children engaged with genetics and allow them to see a small part of what being a clinical scientist is about," said Martin.

In spring genomics ambassadors John Filby from the Leeds Genetics Laboratory and Glenda Fozzard from Leeds NHS Digital presented the Genomic Revolution in Healthcare as part of the Leeds Café Scientifique programme. This was a hugely successful event, with an audience of almost 90 people turning up to find out more about genomics and participate in a lively debate.



John and Martin, from the genomic ambassadors team, at the Discovery Zone at the University of Leeds' Science Fair

# National Education Programme launched for NHS Staff

The National Genomics Education Programme has been set up to ensure staff in the health and care system have the knowledge, skills and experience to keep this country a world leader in genomic and precision medicine.

There is now a comprehensive range of resources available for NHS staff to access for free ranging from basic, introductory videos and factsheets to an MSc in Genomic Medicine.

If you are work in the NHS, and would like an introduction to genomics and the 100K project, or an update on how the project is progressing please contact [Julie.Atkey@nhs.net](mailto:Julie.Atkey@nhs.net) or [Denise.Hancock3@nhs.net](mailto:Denise.Hancock3@nhs.net).

**Online courses** eg. Introductory course to genomics, Whole Genome Sequencing MOOC (runs regularly)

**Taught courses** eg. MSc in Genomic Medicine

**Other resources;** Video library including patient stories and Genomics in Medical Specialities series, image library and genetic conditions factsheets.

**For a full summary of resources and to sign up for the newsletter please visit the GEP website at <https://www.genomicseducation.hee.nhs.uk>**