

## Genomics and Our Patients

GPW has made great progress in recent months and I would like to thank all of you for your dedication and hard work.

We have seen the completion of Genomics England's 100,000 Genomes Project with 154 families being recruited in Wales. Our ongoing collaboration with NHS England and the other devolved nations for genomics is being developed in a way that will best serve our patients.

Our Patient & Public Sounding Board is now established. They provide a valuable patient voice on the Strategy and topics have included consent to research, website design, clinic and waiting rooms, and new genomics service pathways. Two Sounding Board members have joined our Governance and Programme Boards, so that the discussions and decisions remain patient-focused.

Lots of engagement with staff and the public is taking place. Genomics Cafes are being held across Wales, providing an informal opportunity for people with a rare or genetic condition to meet and find out about new advances in genomics. We are also launching our Genomics Champions initiative – find out more on page 3.

The NovaSeq sequencer is now installed allowing new services to be provided to improve patient care which is central to our Strategy. This issue gives details of an improved service for bowel cancer patients, and we are developing new services for sick children and in pharmacogenetics. Look out for further highlights in future newsletters.

And finally I would like to congratulate our Head of Programme, Catrin, on her Leadership for the Future award – very well deserved as I am sure you will agree!



  
**Len Richards**  
Chief Executive  
Cardiff and Vale UHB  
Senior Responsible Officer  
GPW

## GPW In Focus

### Genomics Ball

Thank you to all who supported and attended the Genomics Ball In July. The event was a fantastic success and the raffle/silent auctions raised nearly £300 for the NHS Wales health charities.

As this inaugural celebration of GPW was such a hit we are pleased to announce that the Ball will be an annual occasion.



Keep an eye out for information over the coming months as preparations get underway for the 2020 Genomics Ball!

### GPW Patient & Public Summer Consultation

In June the GPW Patient & Public Sounding Board met for the second time for their Summer Consultation. They were presented with two topics and there were a variety of opinions expressed and some good suggestions were made.

The first consultation in the morning covered website design and layout for the development of a new AWMGS website, the need for jargon-free content, Welsh language requirements, signposting to information through other organisations and use of social media 'plug ins' such as chat boxes/messenger applications.

The session in the afternoon about aspects of the patient journey through the clinical genetics service highlighted the need for clear and concise communication with patients about the referral pathway (explaining processes and wait times within the service and other NHS departments they may be referred to). Changes to improve physical waiting/clinic areas were suggested. Any information given should be in a clear and accessible format.

AWMGS have taken on board some of the suggestions already and made small, practical changes as a result to improve the environment for patients. Thank you to all the staff involved in making this a productive and useful consultation experience for all parties.

If you would like to use the Sounding Board to consult on subjects relevant to your area please contact the Programme Office who will be more than happy to help arrange this for you. Email consultations with the Sounding Board are also available where appropriate.

## #Journeyto Genomics

*Showcasing just some of the many Genomics Partnership Wales members contributing to the future of Welsh Genomics*

### **What inspired you to pursue a role in the field of genomics?**

Having worked in a few different areas of the lab it became clear to me I wanted to move into a more clinical based role where I could have a bigger impact on patient care. I was already aware of the Scientist Training Programme (STP) and the massive developments in genomics so when the post came up it seemed like the perfect opportunity..

### **What happens during a typical working day?**

As a trainee I am able to rotate around the various sections of the lab in order to complete competency based training. I'm only a few months into my first year so I'm still finding my feet but I have loved it so far (except exams!). My general day can involve observing techniques in the lab, microscopy analysis and helping write reports. I have also been able to attend MDTs and clinics which is great to see how everything comes together.

### **What advice would you give to someone interested in joining the field?**

The STP is a 3 year programme including a part-time MSc. So my advice would be to research, understand the commitments involved and make sure you have suitable work experience. We are very lucky in Cardiff to have such great training and support from the department. I think it's an amazing training programme and great way to get into genomics.



**Amber Pryce**

Trainee Clinical Scientist (Cancer Genomics)

*Institute of Medical Genetics*

After gaining her degree Amber registered with the HCPC and shortly after began working as a Biomedical Scientist. She has gained a wide range of experience in a number of pathology disciplines in different hospitals. Outside of work she also likes to be involved with fundraising and volunteering, ranging from festivals and cake sales to science fairs



**Matthew Howells**

Deputy Directorate Manager  
*All Wales Medical Genomics Service*

Matt has always been a sports fanatic; he graduated from U.W.I.C with a bachelor's degree in Sport and Exercise Science followed by five years working for the Nutrition and Dietetic Service. He volunteers in the community as a football coach, which presented him with an opportunity to start his own business, opening doors into the business world and then into the world of Genomics.

### **What inspired you to pursue a role in the field of genomics?**

Reading into the vision for Genomics in Wales provided me with the excitement to apply for this role to see if I can bring the skills I have developed in the private sector into the public sector to support this. Therefore the opportunity to look back in the years to come and say "I was part of that!"

### **What happens during a typical working day?**

Every day is a School day for me, for 2 reasons, 1. The world of genomics is completely new to me and 2. We are part of a service that is always looking to develop and progress. Working in a standalone position providing business support to the whole service means every day brings new challenges.

### **What advice would you give to someone interested in joining the field?**

It is an excitement time, to not only come and be part of but also help shape the future for Genomics in Wales. There are roles for people with various job experiences and skill sets, with lots of opportunity to progress internally. Keep an eye out for the right opportunity for you!!

## A Spotlight On:

*Showcasing just some of the many Genomics Partnership Wales achievements paving the way to the future of Genomics in Wales*

Lynch Syndrome is a condition which can increase the risk of bowel cancer by up to 80%. The chance of it being passed onto children within the same family unit is 50%.

This new commitment by NHS Wales, will pave the way to earlier, targeted interventions improving outcomes for bowel cancer patients in the future. It will achieve this through the pro-active testing of all individuals who are diagnosed with a bowel cancer.

Where a pathogenic gene variant is found, this will enable the NHS to target affected families with regular screening. This will have a huge impact on many lives through earlier surveillance and interventions.

The AWMGS laboratory service support for Lynch syndrome testing in Wales will be launched this September

### *Lynch Syndrome Testing for all Bowel Cancer Patients in Wales*

*In June 2019 Wales became the first nation in the UK to commit to test all bowel cancer patients for Lynch Syndrome. Colorectal MDTs will implement the service for patients in the coming months*

## *Want to be a Genomics Champion?*

*Applications are now open for those who wish to become Genomics Champions. This is a new and exciting role aimed to improve genomic awareness throughout the workforce. The closing date for applications is 31<sup>st</sup> December 2019.*

Genomics Champions will be responsible for raising awareness, disseminating information and supporting the mainstreaming of genomics in their local area. GPW is seeking a diverse group of healthcare professionals across all disciplines, health boards and trusts in Wales, who have a passion to be part of the genomics revolution. We envisage that this will be a fixed term appointment for 12 months in the first instance.

***Are you passionate about the power of genomics to revolutionise personalised treatment for patients in Wales?***

***Are you able to share and communicate your knowledge in a clear and accessible way?***

If yes, then why not become a Genomics Champion! To be a Champion you do not need to be an expert in genomics – all you need to do is express your interest by sending a personal statement (no more than 500 words) and a supporting letter from your line manager as to why you think you would be a good Genomics Champion to Rebecca Hopes, Genomics Training & Education Lead (Rebecca.Hopes@wales.nhs.uk). An informal phone call will then be arranged

*Tell the GPW community about your #JourneyToGenomics or any other good news/opportunities you may have to share  
Email [genomicspartnerhipwales@wales.nhs.uk](mailto:genomicspartnerhipwales@wales.nhs.uk) for more information*

**Want To  
Be Featured?**

## Dates For Your Diary



### PUBLIC GENOMICS CAFÉ'S

2<sup>nd</sup> December 1100 – 1300 *Coffee #1 The Friary, The Friary, Cardiff CF10 2PB*

7<sup>th</sup> December 1100 – 1300 *Coffee #1, St Catherine's Walk, Carmarthen SA31 1GA*

Tickets available from Eventbrite



For more information please visit:

[www.walesdeanery.org/qist/qistmas-2019](http://www.walesdeanery.org/qist/qistmas-2019)



### RAPID Workshop

The Life Sciences Hub, Cardiff Bay,

Date: 13<sup>th</sup> March 2020 at 10:30 till 15:00

A technical workshop on rapid sequencing services

Further details to follow in due course

### Contact GPW

@GenomicsWales

[genomicspartnershipwales@wales.nhs.uk](mailto:genomicspartnershipwales@wales.nhs.uk)

### Programme Updates

- **Ho ho ho! GPW Christmas puddings are coming**

After raising over £250 last year for the C&V Health Charity 'Make it Better' fund, we are pleased to announce that GPW-branded Christmas puddings will be on sale again soon. And this year, we will also be selling the Ultimate Sticky Toffee pudding - so something for everyone! Look out for sales near you or contact the Programme Office directly

- **Patient & Public Sounding Board Two** Sounding Board members have joined the GPW Governance and Programme Boards. Recruitment of additional SB members will take place early in 2020

- **NovaSeq**

The new sequencer is now installed ready for use; the first research run will take place this month with whole genome clinical services starting in 2020

- **Research & Innovation**

Professor Steve Conlan from Swansea University will chair this new group; work is underway with an All-Wales workshop planned for Spring 2020

- **Genomics Showcase**

Preparations are underway for a Genomics Showcase event at City Hall in Cardiff in May. An opportunity for all partners and implementation groups to highlight their areas of Strategy work to healthcare professionals and members of the public. A similar opportunity to engage in North Wales will also be provided. For more information please contact Wales Gene Park

- **Commissioning**

The group has been established with Stuart Davies from WHSSC as chair

- **Estates**

Discussions continue to secure a site for co-location of partners with planning work expected to develop in early 2020

- **Programme Evaluation**

Working with CEDAR to develop and implement evaluation of the Strategy

- **Programme Office Team**

Congratulations to Catrin on the birth of her son Griff! We hope she enjoys her maternity leave