

Wales Gene Park



Dr Karen R Reed
Health and Care Research Wales Conference
Oct 5th 2017



Wales Gene Park Structure and Function

Wales Gene Park support for the Welsh Government's "Genomics for precision medicine" strategy

Research Centres

Centre for Aging and Dementia Research

National Centre for Mental Health

National Centre for Population Health and Wellbeing Research

PRIME Centre Wales

Wales Cancer Research Centre

Research Units

Brain Repair and Intracranial Neurotherapeutics (BRAIN) Unit

Diabetes Research Unit Cymru

Wales Kidney Research Unit

Clinical Trials Units

South East Wales Trials Unit

North Wales Organisation for Randomised Trials in Health

Swansea Trials Unit



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

School for Social
Care Research

Infrastructure Support Groups

Welsh Health Economics support Service

Sail Databank



Support and Delivery

Health and Care Research Wales Support Centre

Health and Care Research Wales Workforce

NHS Research and Development (R&D) Offices

Mission Statement



“To promote and facilitate Welsh medical genetic and genomic research and its application to improve health and wealth in Wales.

Also, to engage the public and health professionals to improve understanding of the opportunities and challenges arising through genetics and genomics.”



Genomics

VS

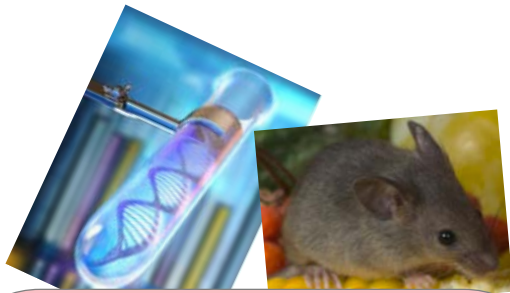


Genetics

- The study of an organism's complete set of genetic information.
 - 'Genome'- the complete genetic information of an organism.
 - The genome includes both genes and non-coding DNA.
- The study of heredity
 - The study of the function and composition of single genes.
 - 'Gene'- specific sequence of DNA which codes for a functional molecule.

Director
Prof Julian Sampson

Operations Manager
Dr Karen Reed



Work package 1
Genomic Editing & Transgenics

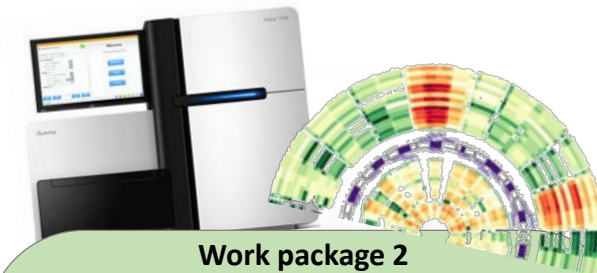
Genome Editing Lead
Prof. Ros John

Transgenic Pre-clinical Trials Lead
Dr Ming Shen

Genome Editing Research Manager
Mrs Bridget Allen

Research Associate
Dr Jian Yang

Research Associate
Dr Kalin Narov



Work package 2
Genomic Facility

NGS Laboratory Lead
Ms Sarah Edkins

Bioinformatics Lead
Dr Kevin Ashelford

Research Manager
Ms Shelley Rundle

Bioinformatician
Dr Marc Naven

Research Technician
Dr Vikki Humphreys

Bioinformatician
Dr Anna Evans

Research Technician
Mrs Jincy Winston

Bioinformatician
Dr Peter Giles
WCRC funded



Work package 3
Education and Engagement

Work-Package Lead
Mrs Angela Burgess

Education and Engagement Officer
Dr Rhian Morgan

Genetic Alliance Policy & Engagement manager Wales
Mrs Emma Hughes

Education assistant
Mrs Nina Lazarou

Technical and research coordination support

Research Technician Julie Maynard

Research Coordinator Dr Hala Jundi

Research Coordinator TBA

Research Associate Dr Anna Derrick



UKCRN project governance
Neurology & Molecular Neuroscience group - Swansea Neurology Biobank



**Researcher
s provide**

The idea!

The samples

Consumable costs

Collaboration

**Wales
Gene Park
provide**

Expertise

Sequencing

Bioinformatics

Training

Research

*All supported by Welsh
Government through
Health and Care*

WGP impact



- Supporting Research across Wales
 - Since April 2015 (current funding period)**
 - 73 research grants supported, and £20,706,837 grants awarded
 - Supported 170 research articles
- Upskilling health professionals and informing the public
 - A total of **7178** people attended WGP Education & Engagement events in 2016
 - **1450** Health professionals across Wales received training
- Informing and implementing Government Policy
 - Welsh Rare Disease Implementation Plan (revised July 2017)**
 - Welsh Government Genomics for Precision Medicine Strategy (launched July 2017)**



Genetic Alliance
Policy & Engagement
manger Wales
Mrs Emma Hughes

Genomics for Precision Medicine Strategy

Last updated 06 July 2017

Share    

Our plan to create a sustainable, competitive environment for genetics and genomics to improve health and healthcare provision for the people of Wales.

Precision Medicine is an emerging approach for disease treatment and prevention that takes into account an individuals variability in genes, environment, lifestyles etc.

Rare diseases implementation plan

Last updated 31 July 2017

Share    

A rare disease is defined as a life-threatening or chronically debilitating disease that affects five people or less per 10,000.

There are around 150,000 people affected by these diseases in Wales, most are genetic.

Rare Disease UK & the Welsh Rare Disease Patient network: Empowering patients to take part in the policy process



Genetic Alliance Policy & Engagement manager Wales
Mrs Emma Hughes



Welsh Twitter takeover by Marie James, carer, patient advocate, and Tuberosus Sclerosis Association Ambassador



In collaboration with the Wales Gene Park, RDUK established the Welsh Rare Disease Patient Network to engage patients, families and patient organisations to ensure the patient voice is properly informed of, and effectively represented in the discussion and development of the implementation of the UK Strategy for Rare Diseases. The network was launched in October 2015. Over 80 people attended the launch and signed up to the network. Contact is maintained with network members through email and a twice yearly newsletter keeping them informed of latest news, advances and initiatives. Patient involvement in events such as Rare Disease Day, Patient Pledge Campaign & a Twitter Takeover has been enhanced by using network contacts. The network continues to grow with over 140 members at present.

'Working collaboratively with other groups as part of the rare disease patient network provides a united voice for campaigning to improve rare disease provision for patients and families across Wales'.

Kayleigh Old, Public Affairs Officer, Cystic Fibrosis Trust

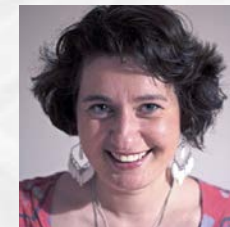


WGP supporting policy implementation



Genetic Alliance
Policy & Engagement
manger Wales
Mrs Emma Hughes

- Ensuring patient voice is heard and acted upon
 - Co-ordinate the Welsh Rare Disease Patient Network
- Facilitating patient recruitment into Research
 - A Welsh Genomic Medicine Centre is to be developed initiated through public participation in 100K genomes project in Wales



100,000 Genomes
Project in Wales
manager
Dr Iris Egner

WGP supporting policy implementation



Work-Package Lead
Mrs Angela Burgess

E&E Officer
Dr Rhian Morgan

Education assistant
Mrs Nina Lazarou



- Committed to support AWMGS to develop model of **informed patient consent** to allow routine research access to surplus clinical genetics samples and data for medicine and genomics research
- Training Health and Social Care Professional
 - Ensuring better identification of rare diseases to deliver faster diagnosis and access to treatments &/or support for patients.
 - Mainstreaming genomics into the wider NHS
- Continue to promote genetic literacy and raise awareness of genomics within the public in Wales

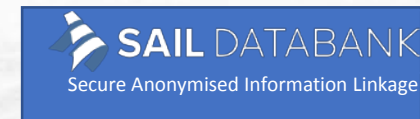
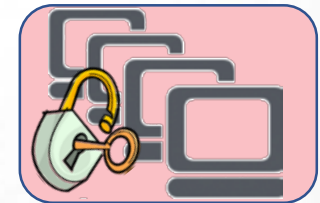


WGP supporting policy implementation



Bioinformatics Lead
Dr Kevin Ashelford

- Development of IT infrastructure, networking capabilities and data governance for NHS in Wales.
 - Establishing a two-way secure network between NHS and CU
 - Working with the SAIL databank to link genomic data with other routinely collected health/social data
 - ISO accreditation within CU data centre
- Knowledge transfer into the NHS for the benefit of service delivery
 - NHS representation within the College research data strategy
 - CU representation within the NHS IT implementation group



Specialist clinic for patients with tuberous sclerosis complex (TSC)

TSC gives rise to non-cancerous growths in various organs, that can lead to severe complications. Patients affected by TSC often require expertise from a number of specialties.

Provide a multi-disciplinary and coordinated approach to management and treatment for patients with this rare condition.

Offers opportunities for patients to contribute to research.

Translation of pre-clinical research into using mTOR inhibitor treatment (Everolimus), is now being prescribed for patients with TSC tumours in the specialist TSC clinic.

Lesley Roberts was extremely positive about the holistic package of care that was offered by the multi-disciplinary team at Cardiff - offering clinical expertise, research opportunities and provision of information and support through coordination with an advisor from the Tuberous Sclerosis Association based at the clinic.





Contacts



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