



Opportunities for Patients & Families in Wales

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Practical Support

- Organising Patient/ Information Days
- Rare Resources Toolkit -
Information resource to be received at diagnosis when undiagnosed
(feed into the development of the Welsh toolkit at one of today's
workshops)
- Genetic Alliance UK website and membership/ join our Welsh Patient
network

Supporting and enabling patient/family groups

- Annual Rare Disease Day Senedd Reception
- Family Days (*Fragile X syndrome, 16p11.2 syndrome, Tuberous Sclerosis Complex*)
- Rare Inherited Eye Disease Annual Meeting
- Twitter takeovers
- Building Rare Communities Project (*Tuberous Sclerosis Complex; Rare Inherited Eye Diseases*)
- Behçet's in a Day
- Exhibitions (*photography, art*)



Policy and campaigning

- Cross Party Group - due to launch in October 2019
- Campaign for a refresh & review of the UK Strategy for Rare Diseases
- ProtectERNs campaign
- Resetting the Model - evaluating rare disease medicines

Genomics for Precision Medicine Strategy



"Our new Genomics for Precision Medicine Strategy has the potential to revolutionise medicine and public health.

"It's designed to ensure people across Wales have access to quicker, more accurate diagnosis by enabling clinicians to better understand a patient's individual disease by analysing their genes. This will help clinicians develop targeted treatments for individuals."

Vaughan Gething



Llywodraeth Cymru
Welsh Government

llyw.cymru
gov.wales



Genomics for Precision Medicine Strategy

July 2017



Partneriaeth
Genomeg
Cymru
Genomics
Partnership
Wales



Signposting to Research

- Wales Gene Park Research Portal - bringing together rare disease research projects
- Signposting to training and support for research involvement

Rare Disease Research Portal

What?

- A gateway for patients and public to become involved in research
- Highlight research opportunities in Wales; signpost to other organisations and information
- Provide information on training and up-skilling to empower and support participation in research

How?

- Consultation Workshop: RD Network Annual Meeting
- Development
- Usability testing (17 July 2019)
- Launch (10th October 2019)



Education and Engagement



Schools	Public	Health Professionals	Patients & Families
<p>Genetics roadshows</p> <p>Sixth Form Conference</p> <p>Teachers' Genetics Network</p> <p>Careers events</p> <p>Teachers' CPD</p>	<p>Public talks & lectures</p> <p>Community group talks</p> <p>Public Genetics Network</p> <p>Public Genetics Conference</p>	<p>Study days</p> <p>Conferences</p> <p>Workshops</p> <p>Genomics Roadshows</p>	<p>Events: meetings/family days/ information days</p> <p>Support groups</p> <p>Policy work</p> <p>Patient network</p> <p>Campaigns</p>

Other Involvement Opportunities

- Launch of our Genomics Cafe - across Wales
- Volunteer to speak and share your experience at our events/ write a blog for our website
- Join our Rare Disease Patient network, receive updates and information about upcoming events

Educating & Informing

Living with Genetic Conditions sessions (nurses, allied health professionals, schools, public)

Someone with a genetic disorder giving us lectures makes me understand it well

Healthcare student

A fantastic opportunity for trainees to really hear about and understand the experiences of families. This leads to better care, as trainees provide better support to patients and know how to link with genetic services

Genetic Counsellor

Through sharing our personal experiences I have been empowered...sharing my experiences with students and others who will provide care for families like mine is so important; knowledge is key to improve future outcomes for my son and others who live with a rare genetic disorder

Family member

Very informative and great to be give the opportunity to ask questions to find out more about CF from a patient's perspective

Nursing student

Teaching sessions e.g. RD Teaching Week (medical students); MSc Genomic Counselling

Spotlight on Rare Diseases

Teachers' CPD

Wales Gene Park @WalesGenePark · 15 Feb 2016
Hearing a personal account of cystic fibrosis at 'Living with Genetic Conditions' with @CUHealthSci students today.



Networks

Rare Disease Patient Network

- Launched Oct 2015
- Over 150 members
- E-newsletter: information on activities, events and involvement opportunities
- Annual Meeting (October)



Public Genetics Network

- E-newsletter: information about WGP activities; genetics/genomics news
- Public Genetics Champions; involvement opportunities
- Annual Conference (summer - south Wales, autumn - north Wales)





- Rare Disease Research Portal usability testing - 17th July
- Genomics Cafes throughout Wales - ongoing
- Tuberos Sclerosis Association Family Day - September 28th
- Lynch Syndrome Awareness Day - September 18th
- Cross-Party Group - *launching October 2nd*
- Rare Disease Patient Network Annual Meeting - October 10th



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