Wales Gene Park Education & Engagement

Established in 2002, the Wales Gene Park continues to operate in a field of fast developing technologies and rapidly emerging opportunities for their application. Going forward into the second decade since the first release of the human genome sequence, we want to ensure that researchers in Wales are in a position to meet the challenges and opportunities presented by human genetics and genomics and that our health practitioners can use new genetic and genomic knowledge to prevent, better diagnose and better treat human illness. To do this the Wales Gene Park provides technology and expertise, trains and supports researchers and engages with and educates professionals and the public. This broad portfolio of activity is undertaken by an able and enthusiastic team without which the high standard of genetic research and education in Wales would be unsustainable.

Education & Engagement Programme

The Wales Gene Park delivers an innovative and continually developing annual programme of Education & Engagement events.

Continuing professional development is provided for health care professionals through a range of conferences, seminars and workshops on all aspects of genetics. These events provide information about the latest advances in genetics to further the education and training of these professionals and keep them up to date with this rapidly changing field.

For teachers, we provide continuing professional development on the social and ethical issues surrounding gene technology and research-based topics. We also have a Teachers’ Genetics Network with over 400 members who receive a termly newsletter containing genetics-related news and information. For students we hold a 6th Form Conference and a Genetics Roadshow on alternate years as well as organising one offf events such the interactive dramas ‘Boy Genius’ and ‘Meet the Mighty Gene Machine’ and also consultation sessions and discussions throughout the year.

One of our key objectives is to raise public awareness of genetics and this is being achieved through a range of innovative projects, often in partnership with Techniquest. Past projects include a Citizens’ Jury for young people on the issue of ‘Designer Babies’, a mock trial about the National DNA Database, a hands-on exhibition called ‘Diversity, History and Inheritance in Cardiff Bay’. Regular public discussion events on topical genetics issues and illuminating public lectures on subjects such as The Angelina Jolie Effect and Genomic Medicine and the 100,000 Genomes Project, are also organised.

By funding a Development Officer for Wales, first with the Genetic Interest Group and then with its successor organisation, Genetic Alliance UK, the Wales Gene Park has supported patients and families affected by genetic disorders and over 180 patient organisations and groups that represent them. The Wales Gene Park has brought benefits to people with genetic and rare conditions by increasing knowledge through research and its translation into NHS services. The patient and family perspective is at the centre of policy and decision-making. The Wales Gene Park ensures that this view is core to all activities undertaken within research, NHS and policy settings and inputs this to health and social policy work in Wales. This has been achieved by the development of reports and submission of oral and written evidence to the Welsh Government.
Highlights of 2016

The Wales Gene Park continues to run a full programme of Education & Engagement Events. Over the past year there were numerous highlights.

Health Professionals

These events bring renowned world experts and delegates to Wales and also give Welsh Health Professionals the chance to network and promote their work on an international stage.

UK-Dutch Clinical Genetics Societies & Cancer Genetics Groups Joint Meeting
7-8 March 2016, City Hall, Cardiff

This was the 4th Joint Spring Conference of the UK and Dutch Clinical Genetics Societies and Cancer Genetics Groups. It provided academics & clinicians from the UK & the Netherlands with the opportunity to catch up on the latest developments in genetics and an excellent chance to network.

The meeting was attended by 249 delegates, mainly from the UK & Netherlands

Snippets from feedback forms included:

“Excellent conference, venue and speakers. Only problem is I wanted to attend everything!”
“Good balance between clinical/scientific application of current issues in clinical genetics”
“Not too big - ability to talk to speakers & varied programme were excellent”
“Excellent range of speakers, especially international perspective”
“Hearing recent developments and networking were the best aspects for me”

Dysmorphology Day
9 March 2017, University Hospital of Wales, Cardiff

Following on from the UK-Dutch event was a meeting dedicated to Dysmorphology. The meeting gave the delegates a chance to present their latest work, seek advice on patient care and discuss future collaborations. Many of the delegates stayed on in Cardiff to attend this event and were joined by others with an interest in this field.

Living with Genetic Conditions

This educational session begins with a genetic counsellor, or other health professional, giving a talk on genetics and inheritance. This include a brief refresher covering some basic genetics concepts, along with more specific information about the genetic condition on which the session will focus e.g. cystic fibrosis.

Someone affected by a particular genetic condition, either an individual with the condition, a family member, or carer, then presents a personal narrative. This gives an insight into the impact a
genetic condition can have on an individual or family, and provides a powerful account of how it affects them on a daily basis. Speakers often describe how their condition was diagnosed, their medical regime, treatment and management, and how it can affect them on a social or psychological level. Educationally it can help to link theory and practice, and highlight the relevance of genetics to healthcare.

Following the talks, there is a question and answer session, which usually elicits a range of interesting questions from the audience. Genetic conditions that have been the subject of these sessions include cystic fibrosis, tuberous sclerosis complex, and Huntington's disease.

Originally intended for, and delivered to, Year 12 and 13 school pupils, the sessions have recently been extended to undergraduate students on nursing degree courses at Welsh universities including Cardiff University and University of South Wales. These undergraduate sessions have been positively received by both the students and educators. They have evaluated extremely well, with the vast majority of students reporting that they felt more informed about genetics and wanted to know more about the subject. Anecdotal feedback from the speakers indicates that this is also a valuable opportunity for them to enhance their teaching experience and highlight the role of genetics services, for the patients and family members to have a voice and to improve knowledge and understanding amongst future health professionals and others of what it is like to live with a genetic condition.
Management of inherited cardiac conditions is currently one of the most rapidly evolving areas in cardiology. The last decade has seen a major change in our recognition of these conditions from apparently rare isolated disorders, to a group which collectively are common and which may be associated with the tragedy of unnecessary sudden death. The AICC aims to provide consistent, top quality education and training, advice on management and best practice, as well as acting as a forum for data collection, audit and collaborative research. Membership is open to clinicians, nurses, counsellors, scientists and professions allied to medicine, as well as to persons from organisations and charities involved in support of such families.

The AICC held its first Annual Meeting & AGM in Cardiff in 2011. It was organised to coincide with the established Cardiff Cardiovascular Genetics meeting. This year the meeting took place in London, being held in Cardiff on alternate years. Over 135 delegates from across the UK attended the meeting to find out about the latest advances and to network and share their expertise.

Data Management Workshop
17th June, Michael Griffiths Lecture Theatre, Heath Park, Cardiff

More than ever, a good Data Management Plan is essential to secure grant funding, so Wales Gene Park bioinformaticians presented a series of talks and arranged one-to-one sessions on how to manage research data more effectively and develop good data management plans.

Topics covered included:
• Data management and how to put together a successful Data Management Plan.
• Resources and support available within the University to help you succeed.
• How to manage your research data throughout the lifespan of your project and beyond.
Schools & Colleges

Schools’ Genetics Roadshow

Wales Gene Park Schools’ Genetics Roadshow is a free event offered to all schools and colleges throughout Wales, providing an opportunity for A-level biology students to hear cutting-edge genetics talks from experts including researchers, health professionals and scientists. As well as enhancing the content covered by their syllabus, the roadshow aims to give students an insight into the latest research and advances in the fast-moving field of genetics, offer information on related courses and careers, and can provide material for university interviews.

Held every two years at schools and colleges across the country, each event comprises up to three speakers talking on their subject of expertise, with an opportunity for the students to ask questions and talk to the scientists afterwards. Since it began in 2009 the roadshow has visited every local authority in Wales, with the 2015 event reaching over 3600 A-level students in 54 schools and colleges.

Each roadshow is evaluated by students, teachers and speakers, and their comments used to inform future events. Feedback is very positive, with many schools and speakers taking part in successive roadshows. As well as enriching the students’ genetics learning, the roadshow provides researchers with a chance to engage with school audiences about their work. Additionally, as a result of taking part in the roadshow, several speakers have gone on to enrol as STEM Ambassadors and developed ongoing links and activities with schools.

The 2015/16 Genetics Roadshow concluded in spring 2016 with a series of events delivered to schools and colleges throughout Wales and the borders including Blaenau Gwent, Caerphilly, Cardiff, Carmarthenshire, Conwy, Isle of Anglesey, Pembrokeshire, Rhondda Cynon Taf, and Birmingham. Between January and March 2016 the roadshow reached over 850 year 12 and 13 pupils and talks included epigenetics, genome sequencing, biodiversity and conservation, genetic testing in sport, cancer genetics, antibiotic discovery, and ethical dilemmas in genetic counselling.

Sixth Form Conference

The Sixth Form Conference, ‘A Journey through Genetics and Genomics’ was held in November 2016 in north and south Wales. Over 2000 year 12 and 13 students from schools and colleges in Wales and the border counties attended the events which took place at St David’s Hall, Cardiff and Glyndwr University, Wrexham.

In Cardiff, students heard talks from expert speakers on ‘Living in a DNA-driven world’, Genomics in Practice: Diagnosis of Rare Diseases, Living with Genetic Conditions: young people’s panel, Using DNA in wildlife crime; Athletes – Born or Made?
In Wrexham cutting-edge talks covered topics including, ‘The ABC of DNA’, Genetics in Rugby – injury risk, physical performance and playing position; Malaria - a Ménage à Trois Genomes, Why is a 3-parent baby so controversial; Gene Delivery for Applications in Neuroscience and The Brave New World of CRISPR Gene Editing.

Stands at both events included hands-on activities and genetics-related careers information. Exhibitors included Bangor University, Cancer Research UK, Cardiff Metropolitan University, Cardiff University, Cardiff University Libraries, Careers Wales, Glyndwr University, HealthWise Wales, National Centre for Mental Health Cardiff University, Royal Society of Chemistry, Swansea University, University of South Wales, Wales Cancer Research Centre, and Wales Gene Park.

Throughout the day students were invited to take part in a genetics quiz based on the information presented in the talks, with the winners (who came from schools in Anglesey, Wrexham, Merthyr Tydfil and Porthcawl) receiving high street vouchers.

An article on the Wrexham conference was published on the Glyndwr University website:
Other Events

In addition to the regular programme of events delivered to schools and colleges throughout Wales and the borders, the Education and Engagement team also took part in several other activities including: Cardiff University School of Medicine’s ‘Science in Health Live!’ event for year 12 and 13 pupils as part of National Science Week 2016.

- Careers showcases: these included events at Bassaleg School Mary Immaculate School; a Teach First STEM Careers day; Cardiff University’s STEM Careers event. Secondary school pupils and teachers had an opportunity to visit Wales Gene Park’s interactive stand to have a go at some hands-on genetics activities and learn more about relevant courses and career opportunities.

- Cardiff University School of Medicine’s ‘Science in Health Live!’ event for Year 12 and 13 pupils as part of National Science Week 2016
'What’s the point of gene editing?' event at the Darwin Centre, Pembrokeshire College in partnership with the Royal Society of Biology. Wales Gene Park took an interactive stand to this event, which featured exhibits and talks on the science behind gene editing, medical advances, and the ethics of its use.

The Tenby Observer covered the event:
http://www.tenbytoday.co.uk/article.cfm?id=108807&headline=It%E2%80%99s%20all%20in%20the%20genes&sectionIs=news&searchyear=2016
Schools’ screening of GATTACA and post-film genetics talk; over 150 pupils from schools across north Wales attended a special screening of GATTACA hosted in collaboration with Into Film and Pontio Arts and Innovation Centre, Bangor. The film was followed by a talk on genetic engineering and gene editing, ‘Could genetic design make me a better PlayStation player?’, from Dr Thomas Caspari, Bangor University.
Public Events

Genetics and Genomics for the Third Generation Conference (3G Conference)  
22nd June, Cardiff and 29th November, Wrexham

Wales Gene Park hosted its first 3G (Genetics and Genomics for the Third Generation) public genetics conferences in Cardiff in June and in Wrexham in November. The conferences are primarily aimed at members of the public over the age of fifty, providing them with an opportunity to learn about genetics and genomics related research and advances.

The programmes comprised a series of short genetics-focused talks from expert speakers, as well as interactive stands - from organisations including HealthWise Wales, National Centre for Mental Health, Wales Cancer Research Centre, Genetic Alliance UK, Tenovus, Cancer Research UK, Cardiff Universities Libraries, and Same but Different – the Rare Project, for the public to enjoy. The events not only provided an opportunity for the public to hear about some of the latest cutting-edge science which is taking place throughout Wales, but also gave Welsh researchers and health professionals a chance to engage with the public about their work. Topics included: An introduction to genetics and genomics, Ancestry and the DNA Cymru project, Poisons and Medicines – do your genes matter, What Genetics can tell us about Welsh history and How to clone a Prime Minister.

The Cardiff conference also provided an excellent opportunity to launch the new Wales Gene Park Public Genetics Network. Members of the network will receive a biannual e-newsletter, informing them of genetics-related news, activities and events from the Wales Gene Park and beyond, and potential opportunities to become involved in research and policy consultations. Longer-term, the 3G Conference and Public Genetics Network will become an integral part of the Gene Park’s education and engagement strategy.

Both days were a great success, with over 170 members of the public attending and signing up to the Public Genetics Network. Evaluation of the events generated overwhelmingly positive feedback from delegates, speakers and exhibitors alike, with many already expressing a desire to be involved again next year! Following the events, several community groups have already signed up for genetics talks from the Gene Park and from other researchers, whilst other attendees were keen to find out more about initiatives such as HealthWise Wales. Similar events will be held in both north and south Wales in 2017.
Funding of £3000 towards these events was obtained from the Wellcome Trust Institutional Strategic Support Fund at Cardiff University.

Feedback from the participant evaluations included:

“Most stimulating”
“This event had it just right. Not too long in duration and excellent informative speakers”
“Fantastic to hear parent’s experience”
“Very interesting, useful starting point for further investigation”
“An excellent event - interesting, informative, stimulating”
“Thank you for enabling us to come to such an entertaining and informative event”
“A very big thank you from me for this opportunity”

Community Group Talks

A series of genetics-related talks were delivered to community-based organisations including community library groups, Women’s Institute, Probus, and University of the Third Age (U3A) groups throughout Wales. Topics included genetics and genomics in everyday life, Rare Diseases and Living with Genetic Conditions, environmental genomics, stem cells, DNA and forensic science, and The King’s DNA: Richard III, from car park to cathedral. One of the talks also included a hands-on DNA extraction activity, which was well–received by the attendees.

Participating groups were: Newbridge WI, Brecon U3A, Bangor U3A, Panteg Probus, Pontllanfraith Probus, Monmouth U3A, The Vale Probus, Cardiff Bay Rotary, Whitchurch WI, and Rhiwbina Library.

Extracting DNA from strawberries at one of the community group events

Monmouth University of the Third Age Science Group
Wales Gene Park hold several talks a year, which aim to engage with the general public about genetics-related topics and issues. Attendees are from various backgrounds and range from school pupils and medical students through to retired members of the public.

Three public talks were held during 2016:

- **Gene discovery in epilepsy: the role of biobanks in patient research (Swansea)**
  Professor Mark Rees, Dr Owen Pickrell, Mark Baker, Dr Sian Wood and Dr Seo-Kyung Chung (all from Swansea University) gave talks on: Patients in the neurology clinic; Recruiting patients to a research Biobank; Looking after the DNA samples and archives, and Genetic discoveries from Biobanks.

- **The Angelina Jolie Effect: Exploring how breast cancer runs in families (Wrexham)**
  Charlotte Jaggard (All Wales Medical Genetics Service), Dr Julie Jones (North Wales Cancer Treatment CENTRE) gave talks on Familial Breast Cancer and Karen Graham-Dosanjh (BrCa Support Liverpool) gave a talk about her personal experience of inherited breast cancer. The event was supported by the Wrexham Tenovus Choir.

“I felt I was ‘updated’ with a lot of new information”
“Excellent talk by lady who has been through cancer”
“We were given a lot of very good information”
• **Genomic Medicine: What it is & how the 100,000 Genomes Project can help the NHS deliver it**

As part of the Science in Health Public Lecture Series at Cardiff University, Wales Gene Park hosted a public talk on genomic medicine and the 100,000 Genomes Project, given by Dr Tom Fowler (Genomics England) to an audience of over 200 members of the public.

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**Welsh Government Festival of Innovation**

Several Wales Gene Park events were held under the umbrella of the Wales Festival of Innovation. These included the Cardiff 3G Meeting, the public Talk on Epilepsy in Swansea, the schools’ film screening of GATTACA in Bangor, and the public talk on Breast Cancer in Wrexham.

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**Exhibition Stands**

Wales Gene Park also had its interactive stand at numerous other events throughout the year including the Wales Cancer Research Centre marketplace, Involving People Network Annual Meeting, Health and Care Research Wales Conference, Cardiff University Division of Cancer and Genetics Away Day, Rhiwbina Library, *Techniquest After Hours* events.
Techniquest After Hours

Several times a year Techniquest opens its doors ‘after hours’ to an exclusively adult audience. Often the evening is themed and the Wales Gene Park took the interactive stand to two of the science-themed evenings.

Our next stop was with Wales Gene Park, who were utterly excellent! The lady on the stand explained DNA to me in a succinct and simple way and I actually understood it! Then she encouraged us to make a DNA strand with beads; I found out later I’d chosen Dolphin DNA and Warren had chosen Cat DNA.

Before we left the ladies were kind enough to give us two sets of DNA Origami, something I’ll be having a look at with the kids in the next few days 😊

Health & Care Research Wales Involving People Network Meeting

The Wales Gene Park was voted winner of the “Most Engaging Stand” at the Health and Care Research Wales Involving People Network annual meeting 2016 held at the Cardiff City stadium on 1st February 2016. Delegates attending the meeting were asked to visit the stands throughout the day and vote for the most engaging exhibit. The WGP interactive stand featured hands-on activities relating to DNA and genetics, including a DNA lucky dip, where visitors to the stand created a DNA sequence using beads before finding out which organism the sequence originated from, as well as DNA origami and giant DNA blocks. The stand also featured information and literature about the Wales Gene Park, including its education and engagement programme, and the laboratory services it offers. Many thanks to all those who visited the stand and voted for us.
Genomics in NHS Wales

The Genomics for Precision Medicine Strategy sets out the Welsh Government’s long term aims for developing new genetic and genomic technologies and services. The Development Officer for Wales met with Vaughan Gething, Deputy Minister for Health regarding Stratified Medicine in NHS Wales and also represented the patient and public perspective on the Genomics for Precision Medicine Taskforce set up by Welsh Government.

The Development Officer led on stakeholder engagement by supporting the organisation of consultation events across Wales with a range of stakeholders including patients and the public, the genetics service, health professionals, researchers and industry. The lead was also taken on drafting the workforce section of the Strategy. The Strategy is key to developing a modern NHS and investing in health, research and education, a Welsh Government priority in its programme for government, Taking Wales Forward.

Rare Disease Implementation Group

The Development Officer for Genetic Alliance UK sits as a third sector representative on the Rare Disease Implementation Group which is responsible for oversight of the delivery of the Welsh Implementation Plan for Rare Diseases. An annual event was held on 28th February 2016 to highlight progress made to date with implementation of the plan. The Development Officer spoke about findings from a survey of rare disease patients and families experiences of accessing information, support and services.

Pledge for Patients Campaign

Genetic Alliance UK’s Pledge for Patients campaign was launched in Wales ahead of the elections that took place in the devolved nations in May. The campaign aimed to engage with prospective parliamentary candidates to pledge support for:

- Effective implementation of the UK Strategy for Rare Diseases
- Improved diagnosis opportunities for families with undiagnosed conditions
- Removing barriers which prevent the uptake of innovation by the NHS

Help was sought from our patient organisation members and the patients and families that they support in order to ensure that prospective Assembly Members were signed up to the pledge card. Tools were provided on the Pledge 4 Patients website, including contact information for parliamentary candidates and template letters.

20 elected Assembly Members signed up to our Pledge campaign.

For further information, please visit the website: [http://www.pledgeforpatients.org.uk/](http://www.pledgeforpatients.org.uk/)

Pictured L-R: Clare Clements, Kirsty Williams AM, Alistair Kent OBE & Hayley Cleaver
Access to orphan and ultra-orphan medicines

External funding of £30,000 of external funding was attracted to deliver a project, which will generate and communicate the perspectives and priorities of patient groups on access to medicines for rare diseases in Wales. The project brought together up to 20 rare disease patient groups with experience of evaluation processes to a one day workshop in November 2016 where they examined and discussed the new systems of appraising and commissioning orphan and ultra-orphan medicines and the Individual Patient Funding Request process.

Feedback and recommendations were collated into a 'Patient Charter' document to directly inform and influence the work of the All Wales Medicines Strategy Group, All Wales Therapeutics and Toxicology Committee and the Welsh Health Specialised Services Committee. The Charter will be launched alongside a public affairs campaign to promote findings to the responsible agencies, Assembly Members, the Welsh Government’s Pharmacy Division, industry and the wider patient and patient group community with the aim of their adopting the recommendations into policies and practice. A media and social media strategy will ensure maximum dissemination and coverage of the issues, helping to further understand the remaining challenges and gaps around appraising and commissioning medicines for rare diseases.

Consultation Responses

- **The Implications for Wales of exiting the European Union**
  The Committee’s report is available here: http://www.assembly.wales/laid%20documents/crld10912/crld10912-e.pdf

- **IPFR Review**
  An IPFR is a request to a local health board or the Welsh Health Specialised Services Committee (WHSSC) to fund an intervention, device or treatment for patients that fall outside the range of services and treatments routinely provided across Wales. Genetic Alliance UK along with a number of other stakeholders, including patients, carers and patient organisations provided evidence to the independent panel conducting the review into the IPFR process. A response was submitted to the consultation and oral evidence provided. The full report is now available to view here: http://gov.wales/topics/health/nhswales/funding/?lang=en

  The report highlights a number of problems raised by Genetic Alliance UK in its submissions including the criterion of 'exceptionality' on which the process is based. For rare conditions, there is often limited evidence available to prove that a patient is different to a population about which little is known. The criterion puts an onus on clinicians to provide evidence that the patient’s condition is different from other patients with the same condition; that definition is usually impossible to apply to patients with rare or very rare conditions because of the very rarity of the condition.

  The report has made a number of positive recommendations - particularly around the need for better commissioning processes so that the IPFR process is not used in inappropriate situations.

Building Rare Communities – Wales

Patient support groups are an excellent tool to support patients and their families, to provide information to newly diagnosed patients and to raise awareness among health and social care
professionals. Patient support groups are also critical to driving research forward and to ensure that patient voice is at the heart of research and commissioning. The Building Rare Communities project empowers patient support groups to be a reliable and sustainable source of information and support. The project also empowers patients and families to develop an organisation to meet patients’ needs.

In 2016, Genetic Alliance UK in Wales worked with a number of patients and families affected by rare and genetic conditions locally to help develop patient support groups including:

- Rare Inherited Eye Disease
- Tuberous Sclerosis Complex
- Restless Legs Syndrome
- 16p11.2 Syndromes

Events

**Rare Inherited Eye Disease Annual Meeting**

8th January

Over 90 patients, families, patient organisations and health professionals gathered for the 2nd Annual Patient Day for Inherited Eye Disease in Wales. The event included presentations from prestigious speakers within the field presenting on topics such as access to genetic counselling services, access to work, the Wales Low Vision Service and research priorities. Alastair Kent, Director of Genetic Alliance UK, provided an update on the progress made so far in implementing the UK Strategy for Rare Diseases.

Genetic Alliance UK has been working with a group of patients in Wales affected by a number of different rare inherited eye diseases to develop a patient support group. A key element of the day was an opportunity for patients to meet with others with the same rare condition. There was also a patient panel and Q&A session with the audience.

**Annual Rare Disease Day Reception, The Senedd, Cardiff Bay**

23rd February

On Tuesday 23 February, the first Rare Disease UK Parliamentary Reception took place at the Senedd, the National Assembly for Wales. The event was sponsored by Shadow Health Minister, Darren Millar AM and attracted over 110 stakeholders from across the rare disease community including patients, carers, patient organisation representatives, health professionals, academics and industry.

Darren Millar AM welcomed delegates to the event and Alastair Kent OBE, Director of Genetic Alliance UK and Chair of Rare Disease UK, informed those in attendance about our new report, 'The Rare Reality'. The event included presentations from speakers including Dr Andrea Edwards, Clinical Director of the All Wales Medical Genetics Service, Tony Esmond, a patient affected by the ultra-rare condition Alkaptonuria and Ceri Hughes, mother of Isaac who has the ultra-rare condition Moebius Syndrome and has set up the photography project ‘Same but Different’ to highlight the people behind rare conditions.
Alongside the photography exhibition, there was an exhibition of the Expressions of Hope art work - this project was an opportunity for those within the community of rare genetic conditions to tell their own unique story through art. Both exhibitions were extremely popular with delegates.

Alastair also launched the Genetic Alliance UK Pledge for Patients campaign for Wales. The campaign involved canvassing support from prospective parliamentarians to ensure that, whoever forms the next Government will be committed to ensuring patients affected by rare, genetic and undiagnosed conditions get access to the right care and treatment.

**Rare Disease Photography Exhibition**

The Wales Gene Park Development Officer for Wales exhibited some of the photography from the ‘Same but Different’ project at Techniquest and also in the Concourse at the Heath Hospital, Cardiff in March in order to raise awareness amongst patients and the public attending the hospital.

The Same but Different organisation uses the arts to raise awareness of disability and counteract prejudice. It encourages people to look beyond first impressions and provides signposting to support organisations.

**Twitter Takeovers**

Dr Graham Shortland, Medical Director at Cardiff and Vale UHB and Chair of the Rare Disease Implementation Group & Marie James, parent of a son with tuberous sclerosis complex/ former trustee of the Tuberous Sclerosis Association/ Ambassador for the TSA in Wales engaged with the rare disease community on Twitter!

Marie James, carer, patient advocate, and Tuberous Sclerosis Association Ambassador took over the RDUK twitter to discuss patient/carer experiences of setting up their own support groups where none previously existed, involvement in research and the importance of family support. Here are some of the tweets talking about families being an integral part of many rare disease patients' journeys.
Tuberous Sclerosis Family Day
10th July

This family event, which took place at the Future Inn, Cardiff, was attended by approximately 48 people from 14 families. It began with a live music workshop run by Icaris Duo, part of the Live Music Now network during which individuals and families could participate in making music and playing instruments. During lunch, the audience was entertained by a magician, who gave everyone the opportunity to get involved in some amazing tricks.

The afternoon session began with an excellent patient perspective presentation from Gerwain Wilson, which was very received by the audience with many giving positive feedback. This was followed by a presentation from Prof Julian Sampson from Cardiff University on the latest research into TSC and an opportunity for the audience to ask questions on the latest scientific and clinical findings. Families, charities and researchers were able to network throughout the day, making new contacts and exchanging information during what was a very successful and well received event.

Evaluation forms asked carers about their experience of attending the event with 100% rating the event 'excellent'.

The evaluation forms included a number of positive comments describing what families enjoyed about the event including:

'First class speakers and fantastic entertainment for the children'

'Great day, well organised and an added bonus I could speak Welsh to the adviser'

'Friendly and informative'

16p11.2 Family Day
22nd October

As part of the Helping Patients Project a family day for 16p11.2 Syndromes was held in Cardiff. The event was attended by 23 families (58 individuals) plus the research teams and patient organisations that were in attendance. In total, approximately 78 individuals attended the event. The feedback received verbally and through the feedback forms has been great - many people have requested that the event is extended over a longer time with some practical workshops as part of the event too.
Genetic Alliance UK delivered a presentation on the Helping Patients Project and families were keen to be involved in developing a support group for 16p11.2 - Beverly Searle from UNIQUE suggested that we work together to help establish a UK wide support group for this condition due to the rare nature of the syndrome.
Annual Rare Disease Patient Network Meeting
8th December

The second annual meeting of the rare disease patient network was held in December and attended by over 70 delegates including patients, families, patient organisation representatives and researchers. The theme was focused on advances in genomics. The programme was full of inspirational speakers from consultants and genetic counsellors to patients and researchers. It was a great way to bring together the patient community and celebrate a successful 2016!

Consultation Events for Genomics for Precision Medicine Strategy

The Wales Gene Park supported the organisation of three consultation events across Wales to engage with stakeholders about the development of a Welsh Government Genomics Strategy for Precision Medicine. These took place at venues in north and south Wales during September and October.

Dr Angharad Kerr, Welsh Government presented an overview of the Genomics Taskforce, which has been working at pace to deliver the Strategy. Angharad commented that the Strategy will be based on principles outlined in the Statement of Intent (published in March 2016) and will focus on four key areas – Clinical and Laboratory Genetics Services, Research / Innovation, Strategic Partnerships and Workforce. Dr Rachel Butler (All Wales Medical Genetics Laboratory) summarised current service provision in the All Wales Medical Genetics Service and outlined the technologies which are applied to support these services. Rachel commented that future development of the service must, above all else, focus on patient benefit and be evidence-based.

The Taskforce was keen to gather external opinions on its plans and consulted with a range of key opinion leaders. The workshops provided an ideal opportunity for delegates to feed into this discussion. After the presentations, delegates were split into groups for discussion sessions. Groups considered a series of questions based around the four key areas.

Networks

The Teachers’ Genetics Network was started in 2004. The aim was to sign teachers up to the network to make communication easier and increase participation in our schools’ events. We now have over 400 teachers in the network and our aim is to have a representative from every school with a sixth form in Wales included.

A termly newsletter is circulated to all network members, which provides them with updates on the latest advances in genetics, new initiatives and websites with useful teaching resources. Members are encouraged to write articles for the newsletters so that communication is two ways. When consultations on genetics matters are issued from organisations such as HFEA or Welsh Government, network members are contacted to ask if their pupils would like to participate.

Following on from the success of this Teachers’ Network, networks were set up for our other non-health professional groups. In 2015, the Rare Disease Patients’ Network was launched, followed by the Public Network in 2016. These two groups receive a bi-annual newsletter, along the lines of the TGN newsletter, but customised for each group. As well as informing people of the latest issues in genetics they are encouraged to attend and participate in consultations, clinical trials and research projects.
Conference Attendance

European Conference on Rare Diseases and Orphan Products, Edinburgh
Game Changers in Rare Diseases – Delivering 21st Century Healthcare to Rare Disease patients

The Wales Gene Park Education & Engagement team had 3 posters accepted for this conference.

This successful conference has been organised biennially for many years. It is the event at which to connect and share with all other members of the rare disease community. Over the years this event has united all rare disease stakeholders from across Europe – patients, patient representatives, healthcare professionals and researchers, industry, regulators and policy-makers alike, in the fight against rare diseases.

The posters were also accepted for the Rare Diseases Conference and International Conference on Rare Diseases & Orphan Drugs (RARE X and ICORD) held in Cape Town, South Africa in October.

Awards

Cardiff University School of Medicine STAR Award

Wales Gene Park has been named as winner of the ‘Outstanding Contribution to Engagement’ award at Cardiff University School of Medicine's inaugural STAR awards ceremony.

The awards, which recognise the achievement of excellence by members of staff across the School of Medicine, were presented by Jayne Dowden (Chief Operating Officer, Cardiff University) at Cardiff's City Hall on October 18th.

The WGP Education and Engagement Team were delighted to have received this award for the genetics engagement programme which they've delivered to health professionals, schools & colleges, patients and the general public, throughout Wales for over 13 years.

Pictured with the award are (left to right) Jayne Dowden, Emma Hughes (Wales Development Officer, Genetic Alliance UK), Angela Burgess (Education and Engagement Project Manager, Wales Gene Park), Rhian Morgan (Education and Engagement Officer, Wales Gene Park) and Professor Ian Weeks (Associate Dean of Clinical Innovation, Cardiff University).
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<th>Month</th>
<th>Event</th>
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<td>Teach First STEM Careers Fair</td>
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<td>May</td>
<td>WGP Genomics Talk, Swansea University</td>
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<td>Film Event - GATTACCA Bangor (WG Festival of Innovation Event)</td>
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<td>August</td>
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<td>Community Group Talk - Cardiff Bay Rotary</td>
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<td>Community Event - Stand at Rhiwbina Library</td>
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<td>September</td>
<td>Community Group Talk - Whitchurch WI</td>
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<td>TQ After Hours does Cancer Research</td>
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<td>Genomics Engagement Events with Welsh Government</td>
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### October

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<td>100,000 Genomes Talk for PUSH</td>
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<tr>
<td>Gene Editing Workshop for Schools, Haverfordwest</td>
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<tr>
<td>Medic SSC Students Workshop</td>
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<td>Sickle Cell Awareness Day</td>
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<td>16P11.2 Family Day</td>
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### November

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<td>Sixth Form Conference, Wrexham</td>
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<td>Rhiwbina Library Community Talk</td>
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<td>Access to Medicines Workshop</td>
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<td>Community Group - Pontllanfraith Probus</td>
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### December

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<th>Totals</th>
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<td>Total Attendees at WGP Events 2003 - 2016</td>
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<td>Numbers of People Reached</td>
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<td>Attendees by Category</td>
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A total of **7178** people attended WGP Education & Engagement events in 2016