



Patrick Wild Centre – Our First Year!

The Patrick Wild Centre for Autism, Fragile X Syndrome and Learning Disabilities was officially launched just over a year ago. In that time the Centre has achieved several major milestones. Development has been very swift and we have been working extremely hard to launch our new projects. Below are just a few of our activities in the past year.

Scottish Fragile X Register

In January 2011, the Centre held its first public meeting. The two Centre Directors, Professor Peter Kind and Dr Andy Stanfield, welcomed friends and families to hear about the setting-up of a new Fragile X Syndrome register and to learn about the PWC's research programmes.

We have established a Fragile X Registry for families affected by Fragile X Syndrome with funds generously provided by the RS MacDonald Charitable Trust. The register, which provides detailed standardised clinical and demographic information, will become a valuable resource for future clinical trials.

Clinical Trials

Providing a platform for running clinical trials is a primary objective of the Centre and, excitingly, work has already begun on this. The major pharmaceutical company Novartis is now collaborating with the University to establish the effectiveness of an existing drug on adults and adolescents with Fragile X Syndrome. These trials are currently recruiting participants and are progressing well.

Public Engagement

Professor Eve Johnstone, Assistant Principal of the University and a Principal Investigator of the PWC, has taken charge of public engagement for The University's College of Medicine and Veterinary Medicine. Public engagement has been very important for the Centre this year and in October Professor Peter Kind delivered a public lecture in the "Medical Detectives" series, entitled "Solving Fragile X Syndrome: Looking for Clues in Brain Development".

Dr Andy Stanfield has spoken to several groups and professional organisations about the work of the PWC. He is also a member of the Scottish Autism Reference Group, which recently launched the [Scottish Strategy for Autism](#).



Milestones

- Held first Patrick Wild Centre public meeting
- Established connections with geneticists throughout Scotland
- Established clinical trials of therapeutics in adults and adolescents
- Conducted pilot projects using functional brain imaging, which shows how the brain works in people with autism or learning disability
- Piloted clinical trial of social skills training in adults with Asperger's Syndrome (funded by the R S MacDonald Charitable Trust)
- Raised over £1.1M from philanthropic gifts
- Established a collaboration with Seaside Therapeutics examining whether STX-209 can prevent altered brain development in preclinical models of FXS (results coming soon!)
- Funded 6 "seedcorn" grants to researchers at the University of Edinburgh to encourage novel research programs into Autism Spectrum Disorders with funds generously provided by the RS MacDonald Charitable Trust.



Plans for 2012

Several new recruitments will take place in 2012 thanks to a very generous donation by The Shirley Foundation. This significant gift will also enable the Patrick Wild Centre to establish the Shirley Foundation Imaging Laboratories for Autism Research and will build on the existing consortium of researchers within the PWC devoted to understanding the neurological basis of autism.

Our clinical trials, in conjunction with Novartis, will continue and expand and possibly include a younger group of individuals with Fragile X Syndrome. Following our pilot studies, we will begin a major study in Fragile X Syndrome using brain imaging to investigate the functioning of the living brain. We also hope to complete the initial work required for a National Fragile X Register for Scotland in early 2012.

We will also be developing novel preclinical models of FXS and other forms of Autism to further our understanding of the causes of these neurological disorders with the hopes of developing novel therapeutic interventions. We will also continue and expand upon our collaborations using preclinical models to examine whether novel pharmaceutical interventions can prevent and/or reverse the neuropathology associated with neurodevelopmental disorders.

2012 kicks off with our second public meeting at which we will be feeding back more details on our activities this year. This was a great success in 2011 and we hope it will be well attended.

Patrick Wild Centre – Friends' Meeting

2.30 - 4.00 pm, Tuesday 7th February 2012
Informatics Forum
10 Crichton Street Edinburgh EH8 9AB

The afternoon will begin with a short presentation on the highlights of 2011 and our plans for next year. Although things have gone very well in 2011, many challenges, of course, remain. After the presentation, we will be joined for refreshments by a number of PWC staff so that you can talk to the researchers on a one-to-one basis if you wish.

We are inviting everyone we know who has an interest in the Centre; although you are welcome to pass on this invitation, please note that spaces are limited and will be allocated on a first come first served basis. For catering purposes please RSVP to Kerry Mackay, by Friday 27th January 2012, at kerry.mackay@ed.ac.uk / 0131 650 9221.

We very much look forward to welcoming you on 7th February.



Spotlight on Staff

Dr Andrew McKechnie started with the Patrick Wild Centre as a Clinical Research Fellow in September 2011. As an Honorary Consultant Psychiatrist with NHS Lothian, he works as a learning disability psychiatrist in central Edinburgh. Alongside his clinical duties, Andrew will be conducting brain imaging studies in individuals with Fragile X Syndrome and Intellectual Disabilities.

Functional Brain Imaging

Another major achievement this year was the piloting of a major project that uses brain imaging techniques to investigate the physiological basis of autism and learning disability and enable objective assessment of the effect of treatments. Researchers now use a powerful tool called fMRI, which can show exactly what is happening in a living human brain and enable researchers to make comparisons between the brains of people affected by these conditions and those of controls. Comparisons can also be made to assess whether new treatments are making a difference. PWC staff conducted a pilot study with people who have Fragile X Syndrome and will be developing this into a full-scale study in 2012.



Fundraising

We would like to pass on our sincere thanks to everyone who has contributed to the Patrick Wild Centre. Some examples of the very generous gifts are:

The Shirley Foundation

Dame Stephanie 'Steve' Shirley has pledged £1 million towards creating a state-of-the-art imaging suite that will enable scientists to study autism in new ways.

Dame Stephanie, whose late son Giles suffered from autism and epilepsy, said "Research has moved beyond looking at its [autism's] consequences to examine how biology, genetics and behaviour all link together. Results cannot be guaranteed but my hope is that this imaging suite will attract more quality researchers to focus on autism."

Dr Andrew Stanfield, consultant psychiatrist and co-director of the Centre, said: "We are incredibly grateful to Dame Stephanie for this generous gift, which we hope will play a part in developing better treatments for people with autism and related disorders."



The Helen Maude Garfit Fund

The Helen Maude Garfit Fund was set up earlier this year by Maude Brownlie and her family to support research into Fragile X Syndrome (FXS) and Fragile X Associated Tremor Ataxia Syndrome (FXTAS).

Helen Maude Garfit, a 1908 All England Lawn Tennis Ladies Doubles Champion, was Maude Brownlie's grandmother and the genetic alteration that causes FXS and FXTAS can be traced back to her. This fund is in memory of Helen Maude and in acknowledgement of the family's efforts to raise awareness and funding for research.



The University of Edinburgh is extremely grateful for this thoughtful and meaningful support.

To raise funds for The Helen Maude Garfit Fund, Sandy and Maude Brownlie organised a charity clay pigeon shooting competition on 4th September, which raised £54,000.

sahara4x

In 2008, Gus Alusi, his wife Reem and twelve friends spent six days climbing Mount Kilimanjaro, raising £60,000 for research into Fragile X syndrome, a genetic condition that affects their son, Kenz.

Earlier this year they decided to take their fundraising efforts a step further. "We wanted to do something even harder than Kilimanjaro," says Mr Alusi, "and landed on the idea of getting ourselves from London to the remotest town on Earth, Timbuktu, in cars that cost less than £1,000 each." Mr Alusi meticulously planned the route and organised armed escorts to accompany them through the most dangerous regions. Over three weeks, the 20-strong team drove through Europe and across northwest Africa, facing daily temperatures as high as 42°C (108°F) and numerous patience-testing mechanical breakdowns.



Gus and Reem Alusi kindly pledged a six-figure sum towards the Centre and their Timbuktu adventure raised an additional £60,000.



The Patrick Wild Centre

for Research into Autism, Fragile X Syndrome & Intellectual Disabilities



Dr Alfred Wild

The Patrick Wild Centre received enthusiastic support from University of Edinburgh graduate Dr Alfred Wild, whose family has been affected by autism. The Centre has been named in memory of Dr Wild's brother Patrick, who was severely autistic, and as a tribute to the brothers' parents, who cared for Patrick throughout his life.

The RS Macdonald Charitable Trust

Thank you to the RS Charitable Trust for their very generous support. The Trust has donated over £100,000 to six different research programmes since the Centre opened last year.

fabric4x

Huge thanks to Katie Riding for organising a great event at London nightclub Fabric, which raised both awareness of Fragile X Syndrome and funding for research into the condition.

Further information

Fundraising Events

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Donating / Press & PR

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