## ResearchandDevelopment

Edition 24

Cardiff and Vale UHB November 2018 Newsletter

# Research and Development Twitter Account



The Research and Development office Twitter account is now up to 589 followers.

Join in and follow us on Twitter <a href="https://www.twitter.com/@CAV\_Research">www.twitter.com/@CAV\_Research</a> and get the latest R&D news and learn about new research opportunities that you can be a part of.

#### Regional Governance Group documents (RGG)

The below documents have recently been updated / revised:

**SR-RG-011** Investigating and Handling Allegations of Research Misconduct v3 – published 21/08/2018.

### Excess Treatment Costs (ETCs) Application

A reminder to all Researchers applying for ETCs that the ETC application must be a minimum total value of £250 to be progressed at Cardiff & Vale UHB.

#### Cardiff & Vale Research Forum

The Cardiff & Vale Research Forums are to be held on a quarterly basis. This will be an opportunity to:

- hear from Research Staff about the exciting work they are doing and the challenges they have faced
- keep up to date with important information
- be involved in forming a collaborative Research Community in Cardiff and Vale contributing towards raising awareness of the importance of research and the impact it has on our patients and services

The next Research Forum —Support and Share will be held on the 27 November 2018 2-4pm —Main Hospital Building, Obs & Gynae Seminar Room UGF past C-Block. This will be an informal setting to bring challenges in research along to discuss with peers. Please contact Zoe Boult -zoe.boult@wales.nhs.uk if you have something you would like to bring along to discuss, or if you would like to offer your expertise to support others. This will help to match support to the challenges you are dealing with currently.

Some example areas include:

- Setting up research projects
- Approvals and amendments
- Recruiting patients
- Trial delivery
- Time management and organisational skills
- Communication
- Training and Development

We have also organised Induction Training for New Staff. There will be three half day workshops for staff, new to research which will be held at the beginning of December 2018. If you have new staff in post who would benefit from induction training to develop some basic knowledge and skills, get in touch with Zoe Boult to find out more – zoe.boult@wales.nhs.uk

#### **Metrics Matter**

Thank you to all the Principle Investigator's and study teams that have responded to the email requests for recruitment information. This information is essential to ensure that the metrics reported to Welsh government are correct and we receive the right amount of funding.

Next year we will be introducing a new way in which you can upload this information directly, watch this space for further updates.



### Congratulations to Professor Zaheer Yousef in Cardiology for his recent publication

Professor Zaheer Yousef in Cardiology has had his work published recently in the world's leading research journal (Impact Factor 79.258) the New England Journal of Medicine (2018 Aug 9;379, 524-34). Zaheer and colleagues using physical examination, ECG and echocardiography screened for causes of possible sudden death in 11,168 "fit and healthy" adolescent footballers in a study funded by the English Football Association. They identified 42 (0.38%) footballers had sudden death predisposing conditions with an additional 225 (2%) as having congenital or valvular abnormalities. 23 actual deaths occurred in the screened cohort included 8 sudden deaths where 6 had previously had a normal cardiac screen. Cardiomyopathy which occurred after screening, was the cause of sudden death in 7 adolescent footballers.

# Research for Patient and Public Benefit (RfPPB)

RfPPB has now launched and closes 5th December 2018. However due to an anticipated high number of applications, Cardiff and Vale UHB has set an **internal deadline of 7.30 am on Tuesday 20th November 2018** – 2 weeks before the deadline. However it is expected that potential applicants need to work with the R&D office to identify costs, much earlier than that. If you are interested in applying please do not hesitate to contact pat.tamplin@wales.nhs.uk.

As part of the 2018 calls, Health and Care Research Wales would particularly welcome applications addressing the following themes:

- Improving value based healthcare
- Improving healthcare system safety



# Children and Young Adults' Research Unit – 12 months on



The Children and Young Adults' Research Unit (CYARU) celebrated its first birthday on 11th October 2018. The Unit, based in the Children's

Hospital for Wales, provides support for commercially and non-commercially sponsored high quality child health research studies.

With 17 studies already running the Unit is about to open the BATCH study (<a href="https://www.cardiff.ac.uk/centre-for-trials-research/research/studies-and-trials/view/batch">https://www.cardiff.ac.uk/centre-for-trials-research/research/studies-and-trials/view/batch</a>).

BATCH hopes to show that using PCT testing for children with bacterial infection can reduce antibiotic usage and length of hospital stay. The study will see the CYARU research nurses working closely with the clinical teams in the Children's Hospital and in the Paediatric Emergency Department relying on the networks built up during the CAP IT Study.

If you have a study you wish to discuss with the CYARU team contact Rhian Thomas-Turner — rhian.thomas-turner@wales.nhs.uk

# Cardiff & Vale UHB Research & Development Equipment Bid

Cardiff & Vale UHB R&D office has opened bids for equipment. The scheme is to obtain equipment directly relevant to improving the quality of research in your area.

The cost of each item of equipment detailed within the application form must not exceed £5,000 (inclusive of VAT) and matched funding/ part payment for an item is not permitted. The deadline for bids is 5pm Friday 30th November 2018. No bids will be accepted after this date.

All bids must go through your Directorate/Clinical Board R&D Lead and must not be submitted directly to the R&D office. All information regarding the Equipment Bid 2018-2019 has been sent to the Directorate and Clinical Board R&D Leads.

#### **RESTART Study**



We are delighted to announce that, the University Hospital of Wales is one of 5 sites to have been awarded a data quality award for their overall provision of good quality data, excellent

communication and recruitment throughout the restart study. They have been giving funding for a nurse to attend the UK Stroke Forum in December as a reward for all their hard work.

UKSF registration is now open

https://www.stroke.org.uk/professionals/uk-strokeforum/uksf-conference Watch out for details of the Edinburgh Stroke Trials stand and RESTART and

SoSTART poster sessions in the final programme.

# Wales' leading role in kidney transplant research

A young boy, who has a rare genetic disorder, defied all the odds when he received a kidney donation from a stranger through Facebook following one failed transplant and eight years on the waiting list.

Matthew, like over 1000 others in the UK, is highly 'sensitised', meaning he has a higher risk of rejecting the new kidney. That's because his immune system is highly geared to producing defensive molecules, called antibodies, against foreign material entering the body. These molecules stick to the new, 'foreign' kidney,

marking it for destruction by the body's immune system.

With a transplant lasting around 15 years, Matthew may need more than one in his lifetime. Hope for his future comes from an innovative research study in Cardiff that could make it easier for him to be matched with a kidney donor.

#### The research

'Improving Transplant Opportunities for Patients who are Sensitised' (ITOPS), funded by Kidney Research UK as a part of their 'Make Every Kidney Count' campaign, aims to assess whether controlling antibody levels through a combination of three treatments could enable sensitised patients to be transplanted.

38 participants will receive either the three treatments that all aim to reduce sensitisation, or no such treatment, on a random basis to avoid unintended bias. Researchers will then compare the two groups to find out if the treatment has decreased their antibody levels.

The study is led by Dr Siân Griffin, an investigator affiliated with the Wales Kidney Research Unit, funded by Health and Care Research Wales.

Siân said: "sensitisation is one of the main challenges in transplantation today. Patients face a long wait on dialysis before a suitable organ is identified, and tools for immunological risk assessment are lacking. "This project aims to reduce uncertainty for sensitised patients and increase their chances of receiving a transplant."

#### **Current treatments**

Our kidneys perform the vital function of removing waste from the blood. If the kidneys lose this ability, waste products can build up to toxic levels.

Kidney transplants allow patients to lead a normal life and are the treatment of choice for kidney failure, but it's difficult for highly sensitised patients to be matched to a donor due to their higher rejection risk.

That often leaves long term dialysis, removing toxins by machine, as the only option. But that has a big impact on patients personally, socially and economically with up to three four-hour in-clinic sessions a week, or using home-based machines several times a day or overnight.

Clearly, for the thousands affected, new and innovative methods are needed to improve their quality of life and options.

#### Potential impact

The ITOPS study could be life-changing for those affected, giving them better prospects for successful transplantation.

Nicola, Matthew's mum who campaigned for three years on Facebook, explained: "I still can't believe Matthew's had a transplant. He had actually become antibody sensitive to 99 per cent of the UK population, making Edward [Matthew's donor] a very unique individual that was a match, but was also medically fit enough and willing to help."

"Matthew may need more than one kidney transplant in his life so we will need this research in the future."

With the odds stacked against him, Matthew was incredibly lucky. Other highly sensitised patients aren't. With the help of ITOPS, it could become easier for patients like Matthew to find a match.

You can read more about Matthew's story on his Facebook page: A million likes for a kidney for Matthew.

Find out more about the ITOPS study here.

# World first at Cardiff and Vale UHB in new treatment for type 1 diabetes

A ground-breaking clinical trial has been launched in Cardiff to help prevent and manage the chronic autoimmune disease Type 1 diabetes.

The Clinical Research Facility (CRF) at Cardiff and Vale University Health Board (UHB) has dosed the first patient in the world with the new investigational drug. The drug aims to help the regrowth of insulin making 'beta' cells of the pancreas, which are lost in patients living with the disease. Despite being an early phase trial, the CRF has now dosed two patients with this new drug.

Type 1 diabetes is a serious, lifelong condition where blood glucose levels are too high because the body cannot make a hormone called insulin. Those with Type 1 diabetes are dependent on insulin but if this clinical trial works, the regrowth - or regeneration - of beta cells may mean those with Type 1 diabetes becoming far less dependent on insulin injections. The benefits of the new drug would reduce lifelong conditions and complications associated with the chronic disease.

Patients who have taken part in the trial so far have spoken very highly of the treatment and the overall experience they have received at Cardiff and Vale UHB. The first patient to receive the dose said; "I'm really grateful that I was given the opportunity to take part in this study. I hope that my participation will help with the management of Type 1 diabetes for future generations."

So far, the drug appears to have had no major side-effects, but it is too early to say if it has been effective. Cardiff's CRF team are hoping to attract up to eight adult volunteers to take part in the clinical trial who have had diabetes for more than two years.

Dr Mohammad Alhadj Ali, who is the sub investigator working on the study in Cardiff said: "despite everything achieved in diabetes care, advances in prevention haven't really occurred. More insulin-producing beta cells are

needed for those with this form of diabetes and it is estimated that 90% of patients with Type 1 diabetes have less than 5% of insulin making cells left."

Professor Dayan, who is leading the team in Cardiff said, "the CRF team have made it possible to closely monitor the patients for 72 hours after their dose and I am proud of the team for their commitment in making sure this clinical trial happens as smoothly as possible."

Dr Graham Shortland, medical director at Cardiff and Vale UHB said: "Cardiff and Vale UHB is committed to being a leading organisation for Research and Development in Wales, the United Kingdom and wider. This development demonstrates their commitment and the exciting work being done in our dedicated Clinical Research Facility and Cardiff and Vale more generally."

The results of this innovative trial in diabetes treatment could be ground-breaking and is part of a wider programme of studies to preserve and regrow the insulin making cells in Type 1 diabetes being pursued by the Cardiff team, with trials in both adults and children.

Carys Thomas, interim director of Health and Care Research Wales, said: "developing new treatment options for patients living with diabetes is a top priority for Health and Care Research Wales. It is essential that the NHS works closely with the pharmaceutical industry on research like this to develop drugs that could make a big difference to people's lives.

"The Clinical Research Facility in Cardiff is not only leading the way in this ground-breaking study but the team's hard work also shows that Wales is competing successfully on an international level to attract global pharmaceutical companies and commercial investment. It will also pave the way to bring more high quality research into Wales, which could help treat other conditions."

For more information and to get involved, please visit <a href="https://www.type1diabetesresearch.org.uk">www.type1diabetesresearch.org.uk</a>

# ResearchandDevelopment

### Joint Research and Development Service

Len Richards (CEO) recently announced that we are working with Cardiff University to establish a single research service for human research studies. This new service, launching in autumn 2019, promises to significantly improve research and development activity across the two organisations, benefiting patients and clinical research now and in the future. Our *vision* is to create an environment where we are able to improve the health and well-being of the people in Wales and beyond through research excellence.

This is an exciting opportunity which will enable us to deliver our **ambition**, which is to become a world leader within the areas of medical and healthcare education, clinical and biomedical research, and clinical innovation.

This *mission* will drive us to provide a collaborative and responsive research and development service, which will encourage and support the delivery of high quality and high impact research to secure improvements in both clinical setting, and clinical services in the broader social environment.

We will **focus** on new ways of working, embracing the positive changes needed to create a service which facilitates collaborative research and to enable research outcomes to translate into improvements in health and clinical services.

We will continue and improve the way that we

- Support researchers to tackle major health challenges with targeted research which will benefit the health and wellbeing of people in Wales and improve patient outcomes;
- Align our research services and priorities to maximise our shared capabilities for supporting clinical activities, research, education and training;
- Develop relationships with grant funders, industry, Health Boards, Higher Education Institutes and the Government.

The concept has been based on an "integrated team model" that has been successfully implemented in a number of places in England, including London (UCL and Imperial), Oxford, Newcastle, Birmingham and Manchester.

All Staff Open Meeting: 13th November, 11am at Heath Park.

Graham Shortland (Medical Director) and Gary Baxter (Pro-Vice Chancellor) will be hosting an Open Meeting for staff from CAVUHB and CU, to include both staff involved in conducting and delivering research, alongside those that provide research support service. Further information and registration details will be circulated and available on the intranet shortly.

Please contact Allison Hanbury, Senior Project Manager, if you would like to find out more  $\frac{\text{hanburya2@cardiff.ac.uk}}{\text{more }}$