

Vaughan Gething AC/AM
Y Dirprwy Weinidog Iechyd
Deputy Minister for Health



Llywodraeth Cymru
Welsh Government

Ein cyf/Our ref: MA - P/VG/1263/16

Suzy Davies AM
Member for South Wales West
National Assembly for Wales
Cardiff Bay
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9 March 2016

Dear *Suzy*

On 2 March during plenary, I undertook to respond to you about research and new developments in respect of hepatitis and pernicious anaemia. I am pleased to provide an update following the Minister for Health and Social Services' letter to you in April 2015.

A report was issued last October summarising the developments facilitated by the Wales Blood Borne Viral Hepatitis Action Plan 2010-15 and this is available at:

<http://gov.wales/docs/phhs/publications/151030reporten.pdf>

Work is continuing through a priority commitment in the Liver Disease Delivery Plan to:

Take forward the legacy of the Blood Borne Viral Hepatitis Action Plan in all relevant settings and continue the effort to eradicate viral hepatitis; including working to identify and treat individuals with a diagnosis of hepatitis B or C infection and working with the Welsh Health Specialised Services Committee and the All Wales Medicines Strategy Group on the phased introduction of new hepatitis C drugs.

Wales is engaged in research activities related to blood borne viral hepatitis currently being undertaken:

- a UK project to develop the evidence based psychosocial intervention to reduce blood borne virus and increase transmission knowledge among people who inject drugs;
- a Medical Research Council funded consortium that aims to use patient information to establish the most effective and cost-effective treatment for patients with hepatitis C (HCV);
- development of proposals and application for funding for three pilot studies designed to:
 - investigate the feasibility and effectiveness of a strategy for treating networks of HCV positive individuals who are actively injecting recreational drugs;
 - investigate the feasibility of delivering treatment in a prison setting;
 - investigate the prevalence of HCV in patients attending Accident and Emergency Departments.

In the last three years, Health and Care Research Wales has funded projects looking at or focussing on various levels of blood related disorders (total combined funding of over £400,000) includes Cardiff University's work on cross-interaction of the innate immune response (complement system) with coagulation proteins in blood disorders and in respect of preventing generation of pro-thrombotic and pro-coagulant extra cellular vesicle populations in blood via a simple dietary intervention.

Funding opportunities are available through the Welsh Government's National Institute for Social Care and Health Research (NISCHR) competitive grant schemes and recruitment of a Welsh Specialty Lead in Haematology is underway to help drive both research development and Welsh engagement in clinical trials in this area.

In the last year, research studies have begun in Wales in respect of haemophilia and other bleeding disorders:

- a commercial collaboration with Roche is investigating a novel agent to treat patients with factor VIII inhibitors and Wales recruited the first patient in the UK into the study;
- a commercial collaboration with Novo Nordisk to look at the use of enhanced half-life factor VIII to treat people with severe haemophilia at the time of surgery;
- a UK study to investigate how pharmacokinetics can help to individualise treatment of severe haemophilia;
- a collaboration with researchers from the Netherlands (Opti-Clot) looking at how best to treat people with haemophilia B who need surgical operations;
- a study in collaboration with the Sanger Institute (Bridge) looking at the genetic causes of rare bleeding disorders

Professor Peter Collins, Consultant Haematologist at University Hospital Wales' Arthur Bloom Haemophilia Centre has again kindly offered to meet with any Assembly Member who would like to discuss the research in more detail. Please let me know if you would like my officials to arrange a meeting.

Advice from the Haematology National Specialist Advisory Group is that a three monthly cycle of B12 injections is the British National Formulary's recommended therapeutic regime for pernicious anaemia. While there is increasing evidence to suggest that in the majority of cases, treatment with oral B12 supplements at adequate doses may provide effective replacement, there is no UK licensed product at present. However, following representations from the Minister for Health and Social Services, the Department of Health's Medicines and Pharmacy Industry Group is looking at persuading companies to introduce new formulations to treat pernicious anaemia through a licensed oral preparation of adequate dose in a single tablet. We are awaiting the outcome of its efforts.

A copy of my response is also being sent to the National Assembly for Wales library.

Yours sincerely



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