All Party Parliamentary Group for Genetic Haemochromatosis (Iron Overload)

appg.haemochromatosis.org.uk

Minutes of Meeting 001
Wednesday 16 January 2019, 14:30-15:30, Portcullis House, Westminster

In attendance

Parliamentarians	Guests
Mr Mark Pawsey, Conservative	Prof Janusz Jankowski, Gastroenterologist
Mrs Julie Elliott, Labour	Dr Jeremy Shearman, Consultant Hepatologist
Lord Francis Maude	Ms Corrina Towers, Chair, HUK
Mr Ben Lake, Plaid Cymru	Mrs Michelle Weerasekera, HUK Trustee and Lead APPG link
Mr Mickey Brady, Sinn Fein	Dr. Roseanna Brady, Health Psychologist and HUK Trustee
Mrs Pauline Latham, Conservative	Ms Lisa Flude, HUK Trustee
Mr Gavin Newlands, SNP	Mr Neil McClements, HUK Trustee
	Mr David Head, Chief Executive, HUK
	Mrs Deborah Knight, HUK (Minutes)

1. Welcome and Introductions.

Mr Mark Pawsey (MP) opened by welcoming everyone and thanking them for attending. MP explained he has an interest in the condition because Haemochromatosis UK is based in his constituency. MP asked each attendee to introduce themselves and explain their interest in the subject.

2. Formalisation of the formation of the new APPG

MP explained that 5 parliamentarians from both the Government and opposition are needed to officially form an APPG. He noted that this criteria was met.

3. Election of Chair

Mrs Pauline Latham (PL) nominated MP for the role of APPG Chair. Mrs Julie Elliott (JE) seconded the nomination and the motion was passed.

4. Election of other officers.

JE was nominated as Vice Chair by MP, seconded by PL and the motion was passed. MP advised that Dame Cheryl Gillan (CG) had expressed a willingness to become a Vice Chair but was unable

to attend the first meeting. CG was nominated as Vice Chair in her absence by MP,seconded by PL, and the motion was passed.

Mr Ben Lake (BL) offered himself as a Vice Chair and this was unanimously accepted.
Lord Francis Maude (FM) offered himself as a Vice Chair and this was unanimously accepted.

The meeting understood that Alex Norris (AN) had expressed an interest in becoming an officer but was unable to attend the initial meeting. This was agreed unanimously assuming his confirmation.

NB: On 21/1 AN confirmed his acceptance of this role.

5. Approve HUK as providing a secretariat service to the APPG.

Passed by all.

6. What is Hemochromatosis? An opportunity to ask questions of the advisers present.

Haemochromatosis: (noun, medical) a genetic disorder causing the body to absorb excessive iron from the diet. Characterised by joint pain and disease, chronic fatigue and weakness, cognitive and psychological difficulties, sexual health issues, skin problems, abnormal liver function, diabetes, and cardiomyopathy. Orig. Gk haima (blood) khroma (colour) osis (pathology)

MP invited the medical advisers to begin by giving an overview of the condition. Dr Jeremy Sherman (JS) explained haemochromatosis and that it is the most common genetic disorder in the UK. He commented that left untreated it has serious consequences including liver cancer and early death, but if detected and treated in a timely manner, normal life expectancy can be restored. He explained that the treatment (venesection) is safe, cost effective and widely available.

PL asked JS about the cancers associated with Haemochromatosis. JS described the link with Liver cancer and the other common factors that also affect the liver, such as alcohol and diet.

JS went on to say that the age at which GH is identified varies significantly and that there is a wide variation in presentation. JS commented that cascade (family) screening was very effective.

JE asked JS how patients are identified if not found by genetic tests. JS explained the most common symptoms of GH and the tests used in primary care including the iron panel test. Janusz Jankowski (JJ) added that the tests cost less than £10 and that early diagnosis could save our health services huge costs.

MP asked how many people are affected. JJ answered that 1 in 200 people is a conservative estimate and that there are undoubtedly many patients affected we do not know about due to delayed and missed diagnosis.

MP asked about the treatment. JJ explained the process of venesection and noted that the blood removed is suitable for transfusions, so could actually save the NHS money. JS described the usual frequency of venesection including the intensive initial period, followed by the maintenance period. JS noted that cascade screening is particularly advantageous because it can remove or reduce the need for the intensive venesection phase. This is because if GH is identified before serious build-up of iron stores takes place, the removal of iron does not need to be so intensive, which reduces the impact of GH on quality of life and pre-empts damage to patients that cannot be reversed.

FM explained his interest in GH comes from his father, diagnosed in the 80s. He commented that at the time the diagnosis was very slow and this resulted in his father developing further symptoms.

MP asked if particular sections of the community are affected. JS explained that GH mainly affects Caucasians, particularly those of Irish decent, but that new genetic strains are being identified.

7. What are the typical pressing issues? An opportunity to ask patient members of HUK.

MP invited Corrina Towers (CT) to share her experience. CT explained she was diagnosed by a nutritionist after over 20 years of missed diagnosis and being prescribed iron supplements. PL asked CT what improvement she felt after diagnosis. CT described the relief of some symptoms and relief in knowing what was causing the symptoms. CT also advised she stopped drinking and changed her diet with the aim of easing symptoms.

MP invited Dr Roseanna Brady (RB) to speak about her experience. RB explained her experience of GH and diagnosis. She commented that she is a compound heterozygote. She also explained her professional interest as a Health Psychologist. She spoke about the importance of communication of information and said that the APPG could address ways of encouraging people to seek treatment without alarming them, and the potential issue of patients attributing all symptoms to GH which can lead to other health issues being missed.

JE asked if abstaining from alcohol is generally recommended. JS explained the sensitivity of the liver and he dual effect of alcohol and iron on the liver.

JJ added that sugar also damages the liver so there are often multiple attacks on the organ. RB noted that it is not just the liver that is affected by GH; we must focus on other symptoms too.

JE asked which types of arthritis are associated with GH. RB responded that knuckles and ankles are most commonly severely affected but other joints can also be affected. LF reaffirmed that symptoms can be ongoing and chronic and have significant impact on people and families.

Mr Mickey Brady (MB) explained that his father was affected and asked about the Celtic link. JS explained gene mapping and the believed origins of GH in Ireland. He added that the genetics of haemochromatosis is still being researched.

MB asked if, as the symptoms mirror other conditions e.g. Fibromyalgia, GH could be a contributing factor? JS responded that it is easy to attribute all symptoms to GH, but patients could simply be affected by more than one condition. RB noted that screening could be improved to make sure patients are not misdiagnosed with a similar condition.

JE asked, how aware are GPs? JS replied that there are regional differences and more work is needed to improve knowledge of GH. CT added that because GH is still often perceived as a rare condition, GPs may not think of it automatically. JS commented that secondary care is key to education and improved diagnosis. CT described the GP e-learning HUK is developing with RCGP but added that other elements are also needed.

JS observed that empowering patients with knowledge of GH and the correct treatment will help improve the situation. Mrs Michelle Weerasekera (MW) agreed and described her experience, adding that often patients normalise the symptoms and do not push for treatment.

8. Discuss and approve terms of reference for the group (paper 1)

MP referred to document 1 and asked if all present were happy with the terms outlined. Unanimously approved.

9. Discussion document: proposed topics for papers at next meeting.

MP invited Mr David Head (DCH) to talk about the early issues the APPG might address. DCH referred to document 2, specifically the need for better application of clinical guidelines.

He explained the difficulties in getting the current guidelines implemented across the country. CT expanded on this by referring to survey results which show big gaps in application of the guidelines, for example only 27% of patients are offered family screening.

PL asked why family screening does not always happen. CT said there are a number of issues some of which could be financial concerns or lack of knowledge.

JE asked if there were examples of good practice in other countries that we could look at. Neil McClements (NM) responded that Southern Italy and Ireland may have some lessons but that they face different issues to the UK population. JS pointed out that because haemochromatosis is treated by different specialities, e.g. hepatologists, haematologists and gastroenterologists, there is a need for consistency of guidelines across all specialities in order to raise standards.

MP suggested inviting the authors of the guidelines to a future meeting to discuss this further. DCH confirmed that Prof Ted Fitzsimmons had wished to attend but was unable to come to this initial meeting.

Action point: Invite guideline authors from different specialities to next meeting.

MP mooted the possibility of inviting international contributors. CT added that HUK are currently undertaking a survey of specialists about adopting guidelines and will report at the next meeting.

DCH continued by talking how the APPG could begin to look at the cost to the NHS of missed diagnosis. More evidence is needed.

Action point: A Health Economist is to be invited to attend the next meeting.

JE stated: if we can improve diagnosis, prevent damage, save patient suffering and save the health service money it seems like a “no brainer”. JJ added that no randomised trials have been done to confirm the cost savings but there are other options, for example retrospective studies. NICE needs strong evidence to inform the development of further guidelines.

Action point: MP to invite a Health Minister to the next meeting.

10. Agree date of the next meeting

MP suggested termly meetings, and that the next will be held in April/May, the exact date to be confirmed. Unanimously agreed. MP thanked all present and closed the meeting at 15:30.

END