



**All Party Parliamentary Group for  
Genetic Haemochromatosis  
(Iron Overload)**

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[appg.haemochromatosis.org.uk](http://appg.haemochromatosis.org.uk)

**Minutes of Meeting 002**

**Wednesday 15 May 2019, 14:30-15:30, Portcullis House, Westminster**

***In attendance***

<b>Parliamentarians</b>	<b>Guests</b>
Mr Mark Pawsey, Conservative	Prof Janusz Jankowski, Gastroenterologist
Mr Ben Lake, Plaid Cymru	Dr Jeremy Shearman, Consultant Hepatologist
Mrs Pauline Latham, Conservative	Ms Corrina Towers, Chair, HUK
Mrs Nicola Boyle, Senior Parliamentary Assistant to Mark Pawsey MP	Mrs Michelle Weerasekera, HUK Trustee and Lead APPG link
	Mr Neil McClements, HUK Trustee
	Mr David Head, Chief Executive, HUK
	Mrs Deborah Knight, HUK (Minutes)

***1. Welcome and Introductions.***

MP opened by welcoming everyone and thanking them for attending. Apologies from Lord Francis Maude and Mrs Julie Elliott, Labour.

***2. Approval of Minutes***

Minutes from meeting 001 were approved.

***3. Presentation of non-binding clinical guidelines for GH***

TF presented on the clinical guidelines including background, recommendations and current compliance. (See attached appendix 1)

MP asked for clarification on the recommendation for a 'Specialised Service'. TF replied that he envisions a network sharing information and best practice i.e. a 'communication network' rather than a formalised service.

It was also noted that historic objections by the NHSBT service to accepting GH donors, particularly in the induction phase are becoming less important as the age and stage of diagnosis reduces. NHSBT service have expressed a willingness to work with HUK to facilitate more donors with GH.



**4. Discussion: What can the APPG do to encourage**

**a) ...the consistent application of clinical guidelines where they exist.**

PL added there is a need to make more ministers aware of the problem and suggested we request an audience for a delegation of patients.

MP noted that an adjournment debate had been requested. The requests have been unsuccessful to date but the debate can and will be requested again.

JS reaffirmed the need to connect the specialities and consider the other drivers for change.

MP suggested the APPG could write to NHS Trusts to find out if they are currently following the guidelines.

**b) ...NICE to approve binding clinical guidelines for GH**

JJ indicated that NICE guidelines are a strong possibility and would be more forceful but will take 2-3 years to complete if agreed.

**5. Agree action points in respect of clinical guidelines**

**Action: MP to contact Seema Kennedy MP to request an audience for GH patients.**

**Action: DH to investigate and report on the practicalities of writing to all relevant NHS trusts**

**6. Discussion of papers for information.**

**a) GH in the context of health service priorities.**

DH presented a paper which shows how HUK's aims align with the current NHS priorities. (See attached appendix 2)

MP noted the need for figures to show how much the NHS would save if diagnosis and treatment of GH improved. JS suggested this would require an independent cost analysis, but there may be the opportunity to use figures already produced for liver disease.

JJ an analysis could cost between 40-60K (anywhere up to 100K) and though it would be done by NICE as part of their guideline formation this will take time so it would be helpful to have something in the interim.



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**7. Potential topics for future meetings.**

MP advised that the practicalities of obtaining a cost/benefit analysis can be discussed further at the next meeting.

CT briefly explained the NCIMI trail taking place, looking into the use of artificial intelligence in the future of healthcare and suggested a representative for the organisation could be invited to the next meeting.

**Action: DH to invite representative for NCIMI to attend the next APPG meeting.**

CT raised the issue of food supplements and the lack of contraindication on supplements that contain high levels of iron. TF indicated that it may not best use of limited resources to pursue this at the current time and suggested focusing on the clinical issues. NM suggested inviting a trade association to an APPG meeting to discuss.

MP indicated that he agreed that the clinical issues need to take priority at present and that other issues could be revisited at some point in the future.

**8. Agree date of the next meeting**

The suggested date of 23<sup>rd</sup> October 2019 is no longer possible so another date will be agreed and circulated. (NB subsequently agreed as 30<sup>th</sup> October)

MP noted that HUK members should lobby their MP's to attend future meetings.

MP thanked all present and closed the meeting at 15:30.

**END**