



MINUTES OF THE 2021 ANNUAL GENERAL MEETING
Zoom – November 18th, 2021

Present: Miriam Forde, (IHA Ireland/HI), Brigitte Pineau (FFH France), Dianne Prince (HA Australia, HI), Graça Porto (APH Portugal, EFAPH/HI), Howard Don (HI, EFAPH), Ketil Toska (NHF Norway/EFAPH), Maria Abele (HBE Hungary), Patricia Evans (HI), Robert Evans (HI), Robert Sorrill (Italy), Emerencia Teixeira (APH Portugal/HI), Ray Fynes (Canada/HI), Liz Charyna (CHS Canada), Kate Carkner (Canada), Christine O Leary (HI)

Apologies: Paulo Santos (Brazil/HI), Mayka Sanchez (Spain/EFAPH), Nils Milman (Denmark), Prof Pierre Brissot

Agenda (Appendix)

Welcome: Dianne Prince welcomed all participants to the Zoom AGM.

Minutes of 2020 AGM: No issues or corrections were raised from the Minutes of the 2020 AGM. HD proposed acceptance of the minutes, seconded by RE. Minutes were therefore accepted.

As the meeting was presented in powerpoint slides which will be available on the HI website, the 2020 minutes will only show content in addition to these slides.

Treasurer's Report: RE went through his report on HI's finances following the slide sequence (4-13). Finances are in a very slightly better position due to lack of spending during the pandemic. There remains a great need to obtain more funding particularly from international bodies. These are seen as more likely to fund an international organisation such as HI and HI does not want to adversely impact funding available to national associations within their countries.

Comments and questions: Dianne Prince (DP) mentioned that, despite the issue being raised last year, an HI sub-committee for obtaining funding had not yet been set up. This should hopefully get set up in the coming year. DP reported that 'Benevity' is a platform where projects for funding can be registered pro bono. A confirmatory letter from a bank is necessary to register. Paul Johnson from the Canadian group might be willing to help as he has an accounting background. Other funding sub-committee nominations include treasurer RE and Ray Fynes. DP moved a motion to set up a funding sub-committee which was seconded by RE.

PE commented that the website had now been changed to reflect the new subscription of 50 GB pounds rather than 50 euros. Having subscriptions in different currencies coming into the bank account and Paypal had proved difficult. Smaller societies with limited funds would still be able to have their subscriptions waived and subscriptions could still be paid at face to face meetings to avoid onerous bank charges when these meeting recommence.

DP moved a motion to accept the treasurer's report which was seconded by Brigitte Pineau (BP) and HD.

Election of Trustees:

Clause 13 of the HI Constitution requires that each year the closest number to one third of the Trustees must retire in rotation to their length of service. Slides 14 and 15 show the longest serving trustees who have to retire. Retirees can restand with all retirees opting to restand except for Paulo Santos retired from his position. There being no further nominations at the AGM Miriam Forde proposed the re-election of the retiring but restanding trustees and also the ratification of trusteeship of Christine O'Leary. Ray Fynes (RF) seconded the

motion which was duly passed. HI is extremely grateful to outgoing Trustee and former president of HI Paulo Santos for all his valuable input and hard work in taking HI forward and wishes him every success in future ventures (slide 16).

Report from HI/EFAPH Scientific Committee (Graça Porto: slides 17 and 18):

The Joint Scientific Committee of HI and EFAPH has 24 members from 15 countries and all continents. Its membership comprises medical, health economics and scientific research experts as well as patient representatives. Member opinion on a number of issues was sought on line with good response rate. A list of current activities is shown in slide 18. The paper on nomenclature is now available as an on line Blood journal publication. This is a very prestigious journal and the changes in nomenclature were consensual across a range of experts.

The HARI Euler initiative began in London in January 2020 where the last pre-Covid face to face meeting was held. Members of HARI reached a consensus about classification of haemochromatosis arthropathy where difficulties in classifying symptoms were causing problems recruiting patients to clinical trials.

Another initiative has been on the value of population screening, raised again recently by the Irish Association. After three Delphi rounds involving the Committee and many other recognised experts, the Committee is now in a position to publish the results. This publication will be important as it could be used to inform politicians and other health officials. The conclusion was that screening is necessary in populations where there is a high prevalence of the mutation(s) causing haemochromatosis. However there was no consensus reached on the method of screening nor the age at which screening should commence. Generally it was felt that screening should be carried out before the age of thirty with follow-up 5 years later.

The Scientific Committee is also involved in establishing the European Association for the Study of the Liver (EASL) guidelines. The last version was published in 2010. The new guidelines will be more comprehensive and will be published in a different format.

HI Board Report: (Given by DP: Slides 19-22)

HI's aims are as given in slide 19 with the most important being to promote awareness of HH.

DP wondered whether HI should set up a sub-committee for social media. She has signed up to Canva which has 10 licences. EFAPH does most of the work with expansion in Europe. HI is continuing efforts to establish new contacts in South Africa. The New Zealand Leukaemia and Blood Cancers organisation currently supports people with HH in that country via its telephone Helpline and Facebook page Clinicians in countries where there are no formal patient support organisations are instrumental in setting up associations. DP raised the idea of an international patient registry and still favoured setting up an on line library but this would be a big project and would mainly consist of links rather than actual articles. Information on current practices in venesection could also be included. 3-4 webinars are also proposed for HI member organisations. These will be advertised via social media and on the HI website. Suggestions for topics are welcome.

Member Organisation Reports:

France Fer Hemochromatose (FFH formerly FFAMH, given by Brigitte Pineau, see slides 39-43 for summary)

Several national sites of the pharmaceutical company Sanofi were involved in an awareness raising project using the app KLAXOON devised by a Sanofi project manager. The project was set up through a doctor's conference and interested parties could meet doctors and representatives of FFH in private rooms at the companies sites. The full impact of this initiative is not yet known but there will be a review in 6-8 months' time. This has been a pilot project and has provided know-how on how to approach other organisations.

DP commented that the link for the Klaxoon app had been sent to Canada. DP suggested people talk to Brigitte directly if looking into this type of approach to companies.

Hungary (Given by Maria Abele MA)

The Hungarian Society has a number of clinical and scientific videos available on its YouTube channel. Hungary actively promoted and participated in HI's WHW online photographic expo. It is a very popular awareness raising initiative there.

Norway (Given by KT)

The Norwegian Society held no physical events during HH week instead focussing on a paid promotion on Facebook which resulted in 30 – 40 new members. New posters had been prepared for 2020-2021 but were not used due to the pandemic.

Brazil: see slide 34.

USA (Given by Christine O'Leary, CL)

USA's main HH organisation is the Iron Disorders Institute which distributes articles in 'Iron News'. They also have an email forum which appears to be more popular than its social media presence. DP is on their mailing list. A student project in Santa Rosa California might provide some insights on ways of extending activities into other US states via school and other educational support.

Ireland (Given by MF)

Members of the Irish Society were encouraged to campaign locally and there was a great initiative in organising public buildings and assets to light up Red for WHW. The IHA also has had several very successful GoRed for Christmas social media campaigns.

Australia (Given by DP: slide 33)

DP presented HA's report card for activities in 2020-2021. A 5 hour accredited online learning module hosted by 'Think GP' was targeted at GPs. A series of 'Iron Matters' podcasts and videos have been downloaded around 5,000 times. Social media, twitter and facebook accounts are used to target different audiences. There was an intensive 'light up' campaign (thanks to MF for the idea!). Iconic public buildings, monuments and bridges were lit up in major cities. There was also some billboard lighting pro bono but this had to be used when offered. The Overload Art Exhibition started in Tasmania 8 years ago will be extended in 2022 to Queensland and NSW. It's hoped that over time this will become a national annual event with exhibitions in capital cities and major regional centres.

World Haemochromatosis Week events (slides 23-24)

MF commented on the success of the IHA's Light Up red campaign and the need for volunteers to help organise. The IHA had a professional photographer at some sites to ensure good quality photos. Slide 23 shows a Canadian building lit up and also a sign in Ottawa. CL commented that they would like to do this in the US particularly in the Philadelphia and Pittsburgh areas. Representatives from Norway and Canada asked MF if they could have copies of emails and letters sent out requesting light-ups, to use as templates. MF also noted that most of the work involved is finding the right people to contact who are among the following: CEOs, marketing or facility managers, lord mayors, councillors and corporate affairs personnel. DP will include this information on the 'members only' section of the HI website. There will be another HI online photographic expo which creates member and public engagement opportunities and builds a library of photographic assets for use of member organisations. Themes for the expos have been Rust Never Sleeps (202) and Inheritance or Heritage (2021). Logos for WHW are now available in many languages (slide 24) for the use of member organisations

EFAPH (Given by KT)

The Board and Executive Committee of EFAPH is shown in slide 25 and EFAPH's activities for the period October 2020 until September 2021 are shown in slides 26 to 32.

Canada (Given by Kate Carkner slides 35-38)

May is Hemochromatosis Awareness month in Canada. One very successful awareness raising initiative over the past few years has been the postcard chain mail where local artists shared their work with members to send on to others. For other activities, see slides 35 to 38.

Patient Needs Survey (Mayka Sanchez)

A summary of the overall international findings is included – see slides 39 -40.

Strategic Priorities review (Given by DP: slides 41 -45)

DP outlined why membership of HI is important (slide 41) and then highlighted the strategic priorities for the coming year.

Closing remarks (Given by DP: slide 46)

DP thanks all members especially for their diligence during the pandemic.

HD proposed a vote of thanks to Dianne for all her hard work in organising and preparing for the AGM and over the past year and a half.

End of meeting