



Minutes of Haemochromatosis International AGM  
26th November, 2025.

Attendees: Maria Abele (Hungary), Emma Barker (New Zealand), Lars Peter Brunse (Denmark), Samuel Dawes (Australia), Howard Don (HI Board), Rob Evans (HI Board), Miriam Forde (Ireland), Carol Harley (Portugal), Julie McHenry (Italy), Brigitte Pineau (France), Graca Porto (Join Scientific Committee), Dianne Prince (HI Board), Mayka Sanchez (EFAPH), Dag Erling Stakvik (Norway), Emerencia Teixeira (HI Board), Ketil Toska (HI Board), Andres Vadillo (Spain), Paul Johnston (HI Board)

Apologies: Barbara Butzeck, Christine O’Leary, Paulo Santos, Melissa Yssel

The meeting opened at 7pm UTC and closed at 8.45 pm.

HI President Dianne Prince opened the meeting and welcomed attendees.

The agenda included the approval of minutes from the previous annual general meeting, committee reports, and member updates.

HI Treasurer Robert Evans, presented a detailed financial report, indicating that HI started the financial year with just over £9,000 and has projected an estimated income of £12,000 for the current year. He noted that HI received £640 from subscriptions and over £1,400 in donations last year. Despite the positive trend, Rob acknowledged the challenge of reaching a target of £25,000 in donations and emphasized the need for fundraising while avoiding competition with other associations.

The motion to accept the Minutes of the 2024 AGM was put by Rob Evans and seconded by Howard Don.

The motion to approve the Treasurer’s Report was put by Howard Don and seconded by Dianne Prince.

The motion to approve the re-appointment of Rob Evans, Miriam Forde and Ketil Toska as Trustees of the Board was put by Howard Don and seconded by Dianne Prince.

## **REPORTS**

### **EFAPH/HI Joint Scientific Committee, presented by Professor Graça Porto**

Graça provided an overview of the Joint Scientific Committee's recent achievements, including the publication of a position paper on screening and an e-booklet on hemochromatosis, which has been translated into Portuguese, Hungarian and now Spanish as Prof Mayka Sanchez advised. Translation into German is underway. Graça encouraged requests for further translations and discussed ongoing communication regarding adaptations.

### **Discussion on Genetic Variants and Hemochromatosis**

Graça also spoke about the paper on the H63D variant's relevance in diagnosing hemochromatosis, clarifying misconceptions about its association with the disease and stressing the need for accurate medical practices.

Mayka explained that the initiative arose from confusion caused by misinformation online, particularly regarding the so-called "H63D syndrome." She noted that the paper aims to clarify the variant's role and its lack of association with hemochromatosis risk, which has led to misdiagnoses. As a geneticist Mayka is very concerned about people, children and adults, being labelled with the flag of hemochromatosis when they don't have hemochromatosis, asserting it is one thing to underdiagnose the disease and another thing to over-diagnose it.

Lars asked Mayka and Graça about the H63D variant and its association with hemochromatosis, noting its rarity in Denmark. Mayka agreed to send him the publication and elaborated on the commonality of arthropathies in older populations, suggesting that their occurrence alongside genetic variants may be coincidental. She also highlighted the importance of educating medical professionals about the implications of genetic testing in children.

Graça commented that the reason that there has been so much confusion about H63D over many years and why people have been confounding things is that this variant may have some impact on cellular iron metabolism that is not yet clarified. Several groups are still investigating the role, for instance, in the neurological system and in other tissues, but at the cellular level. However, this has nothing to do with hemochromatosis, it is completely separate. It does not mean that this variant has no interest for iron metabolism. There is still ongoing work find out what is the relevance of this variant in iron metabolism, but it is not a risk for hemochromatosis. Mayka spoke about another issue happening now, where some

countries, the UK and Iceland, have started to do whole exome sequencing in the whole population, and they are undertaking genetics studies of everything.

**Report from the Danish Association presented by Lars Peter Brunse, Chairman of the Danish Association.**

Lars, the new chairman of the Danish Association, reported on efforts to implement population screening for hemochromatosis, highlighting challenges in discussions with health authorities. Screening must be done in an appropriate way, and they are still struggling at which age and how they're going to do it. They are hoping to define a PhD study investigating the cost of illness and cost benefits of screening early. Lars is looking for information from other member organisations on approaches.

Graça suggested academic demonstration projects to enhance credibility, while Dianne referenced previous studies that could inform Lars's work. Mayka addressed the evolving economics of screening and genetic testing, noting the complications arising from the disease's low penetrance.

The Danish Association is relatively small with only 170 members and like other organisations, it is quite limited by the few numbers of active people in the organization. Many of its members are relatively older and often have less interest and energy for working in the association.

The Danish Association is trying also to engage not only the patients, but also the patient's family or relatives in discussions at regional meetings. They have held regional meetings four times in Denmark and believe they are successful, especially in the phase where people are diagnosed, informing the family on how to manage these health situations.

**Report from New Zealand presented by Emma Barker, Blood Cancers New Zealand and Dianne Prince on behalf of Melissa Yssel, HI Board Trustee.**

Blood Cancers NZ supports a small group of Haemochromatosis patients in New Zealand with about 53 on its database and about 100 on its Facebook page. Emma updated the meeting on regional discrepancies in venesection guidelines. Some haematologists in New Zealand are not venesectioning patients with a Serum Ferritin below 1000.

Dianne reported on behalf of HI Board Trustee Melissa Yssel. Dianne discussed the challenges faced in hemochromatosis treatment in New Zealand, including varying health pathways and screening inconsistencies across regions. Melissa emphasized the need for collaboration to improve patient outcomes. Melissa, a pathologist in New Zealand, is advocating for better harmonization in patient care through her involvement with the newly established national clinical network.

### **Report from Australia - presented by Samuel Dawes**

Sam, the new president of Haemochromatosis Australia, reported on the organization's achievements, including increased national visibility and ongoing advocacy efforts. Sam also mentioned the establishment of a new Parliamentary Friends Group to support the advocacy work of Haemochromatosis Australia, and mentioned they have recently joined a Genetic Alliance particularly in relation to combatting genetic discrimination in insurance, against individuals with hemochromatosis.

He noted challenges such as a declining membership base and the need to diversify funding sources, particularly through federal health grants. Haemochromatosis Australia currently has 445 members nationally. However, its website attracts about 6,000 unique visitors each month and they receive between 30 to 40 calls to our info line each month. The InfoLine is open during business hours 5 days a week and calls are answered by trained volunteers.

### **Report from Brazil presented by Dianne Prince on behalf of Prof Paulo Santos**

Work has started on a key new project - a scientific investigation of perceptions of haemochromatosis patients on the relationship between diet and haemochromatosis. A literature review is underway and they may look to HI member organisations to expand the study.

### **Report from the Portuguese Association presented by Prof Graça Porto**

Graça shared updates from the Portuguese Association, including their involvement in World Haemochromatosis Week and the annual patients' meeting held in Ponte Lima. She discussed the implementation of a targeted biochemical screening program for bank employees which was promoted by the National Union of bank workers. Graça reported that it was by chance in one of its patient meetings that a family member of one of the patients approached them and said she had contacts with the union which represents all the bank workers in the country, so why not contact them about a screening project. The union asked the association to write to them, outlining the program and they then organised a very simple project that they could put on the work health program.

The association undertook several initiatives with the local health centre at Ponte Lima where they have been systematically invited to participate on various medical and science meetings.

Graça introduced Carol Harley at the new president of the Portuguese Association.

## Notes

The discussion pointed to a lesson for all of us, to go to the associations' membership and say, how can you help in your workplace? Those who have aging members, who are no longer in the workplace, have daughters and sons and possibly grandchildren who might be willing to promote the condition and raise awareness in their workplaces. Brigitte Pineau previously reported on a similar successful workplace initiative undertaken by FFH in France a Partnership agreement between FFH France with TotalEnergies Group, a company with 10,000 employees. You can read Brigitte's report on the HI website. [HI-AGM-PRESENTATION-29TH-OCTOBER-2024.pdf](#)

### **Report from EFAPH (the European Federation of Associations for Patients with Haemochromatosis) presented by Prof Mayka Sanchez.**

Mayka reported on the restructure of the EFAPH board. Julie McHenry from Italy, Stefan Blumenrode from Germany and Andres Vadillo from Spain joined as board members. They are going to hold new elections using a new voting system for all the members. In addition to the face to face in person meeting in Innsbruck, the AGM will be online on Saturday 6<sup>th</sup> December. All are welcome to join the meeting.

### **Discussion on Screening and Genetics in Haemochromatosis**

Mayka Sanchez discussed the advancements in screening and genetic testing for haemochromatosis, emphasizing that while studies support screening, the disease's low penetrance poses challenges. Graça pointed out potential conflicts of interest and referenced a Canadian study indicating that many patients did not follow up on incidental findings, suggesting that effective communication is crucial for successful screening programs.

### **Discussion on Ferritin Levels and Venesection Guidelines**

Emma Barker highlighted the inconsistency in venesection guidelines related to ferritin levels, advocating for a review of these standards. Howard Don noted that UK guidelines recommend maintaining ferritin around 50, while Graça Porto argued that evidence of liver iron overload should be assessed at lower levels, such as 200 for young women and 300 for young men. Mayka Sanchez added that waiting for levels to reach 1,000 poses a risk of fibrosis.

## **HI Board report presented by Dianne Prince and Howard Don**

Dianne reviewed 3 strategic objectives and reported on related activities. A new initiative in 2025 was the organisation of the very successful Patient Conference held in the UK, lead by Howard Don. Howard presented key aspects of the conference including the program, evaluation feedback and financial report. (slides attached).

The event was an outstanding success with 106 delegates registered, although some were unable to make it due to weather-related travel issues. The total income from the event was £10,000 against costs of £8,049, resulting in a surplus of £2,436. He noted that the feedback was excellent, with no negative comments received.

### **Discussion of Motions**

1. To form joint social media/communications committee with volunteers from Member Organisations. This supports Strategic Objective 1. The role would be to develop a strategic communications plan for EFAPH & HI, sourcing agencies or consultants to run social media campaigns as approved by both boards. The committee would have oversight over web updates, social media and WHW activity. Next steps for the committee, as identified by EFAPH
  - Brainstorm joint objectives and agree on those
  - Define scope of the work, a framework and next steps
  - Construct a needs assessment (brainstorm list of needs) and an overall step by step approach
2. To work with EFAPH on investigating the possibility of a single website to serve both entities and our member organisations, while maintaining independent identities and visibility. This supports Strategic Objective 1 and would form part of the work of the Joint Communications Committee.
3. To plan & source funding to organise Patient Conferences as satellite meetings for relevant research or clinical conferences eg. EIC 2026 Dublin, Blood 26 Auckland NZ, WONCA Nov 2027 Capetown South Africa, Biolron Milan 2027 (Strategic Objectives 2 & 3)
4. To investigate establishing an international patient registry, recording genetics, symptoms, complications, biochemical levels and other diseases, and including D282Y homozygous patients, C282Y/H63D heterozygotes and haemochromatosis in Asian populations eg UK Pakistani young men and others with non-HFE Haemochromatosis.

5. To run a global campaign for free phlebotomy and therapeutic blood donations.

The meeting concluded with Dianne thanking everyone on behalf of the patient organisations for their fantastic efforts in the past year to progress the mission of HI and mentioning Prof Graca Porto and Prof Mayka Sanchez for their enormous efforts with the Joint Scientific Committee. She closed by congratulating Howard Don on the outstanding success of the Patient Conference, moving a vote of thanks for his enormous commitment to driving the patient conference in the UK.

**Key questions for follow up:**

- What are the next steps for the translation of the e-booklet on hemochromatosis into other languages?
- What are the current ferritin levels that indicate venesection in New Zealand?
- How can the Portuguese Association's screening project be replicated in other countries?

**Action Items:**

- Dianne Prince to send out a poll for voting on agenda items within the next few days.
- Graça Porto to send the Spanish translation of the e-booklet on hemochromatosis to Mária for incorporation into the PDF.
- Graça Porto to follow up with Maria for an editable copy of the Haemochromatosis e booklet.
- Mayka Sanchez to send the publication link of the H63D paper to Lars Brunse after the meeting.
- Dianne Prince to send a copy of the therapeutic guidelines on C282Y hemochromatosis to Emma Barker.
- Dianne Prince to send Lars Brunse a copy of Barbara de Graaf's Cost of Illness Study and Prof Martin Delatycki's screening studies.
- Dianne Prince to send a letter of thanks on behalf of the HI Board to all involved in organising and delivering the Patient Conference.

### Addendum post AGM poll

ID2	Moton 1	Motion 2	Motion 3	Motion 4	Motion 5
	3 Yes	Yes	No	Yes	Yes
	4 Yes	Yes	Yes	Yes	Yes
	5 Yes	No	Yes	Yes	Yes
	6 Yes	Yes	Yes	Yes	Yes
	7 Yes	No	Yes	Yes	Yes
	8 Yes	Yes	Yes	Yes	Yes
	9 Yes	No	Yes	Yes	Yes
	10 Yes	No	Yes	Yes	Yes
	11 Yes	No	Yes	Yes	Yes
	12 Yes	Yes	Yes	Yes	Yes
	13 Yes	No	Yes	Yes	Yes
	14 Yes	Yes	Yes	Yes	Yes

Motions 1, 4 and 5: agreement in favour

Motion 3: 1 against, 11 in favour

Motion 2: 6 against, 6 in favour





AGM  
November, 2025

- Welcome and introductions (Dianne Prince)
- Minutes of 2024 AGM (Dianne Prince)
- Treasurer's Report (Robert Evans)
- Joint Scientific Committee Report (Prof Graça Porto)
- HI Board Report and action items (Dianne Prince)
- EFAPH and Member organisations updates Australia, Brazil, Denmark, EFAPH, Portugal, New Zealand
- Election of HI Board trustees (Howard Don)
- Vote of thanks and close (Dianne Prince)

As a CIO (Charitable Incorporated Organisation), the object of HI is to promote and protect the health of people with haemochromatosis in any part of the world, in particular by:

- Increasing awareness of haemochromatosis
- Promoting advances in diagnosis, treatment, and prevention of Haemochromatosis
- Contributing to basic and clinical research in the field of iron metabolism, through a network of collaborating national haemochromatosis associations throughout the world.



- Accounting period: 1st April, 2024 to 31st March, 2025. The financial position will be reported up to 31st March, 2025
- As HI does not have an income over £25,000, its accounts are not required to be independently examined, but need to be formally accepted by the board at the AGM

Summary	2024-2025 £
Opening balance	7,868.53
MetroBank	7,221.97
PayPal	646.56
Income	2,050.86
Expenditure	768.29
Closing balance	9,151.10
Metro Bank	8,578.35
PayPal	572.75



	Income 2024-2025 £	Expenditure 2024-2025 £
Subscriptions	640.11	
Grants	0	
Donations	1410.75	
Charitable activity		768.29
Governance		0
Administration		0
Professional fees		0
Total	2050.86	768.29

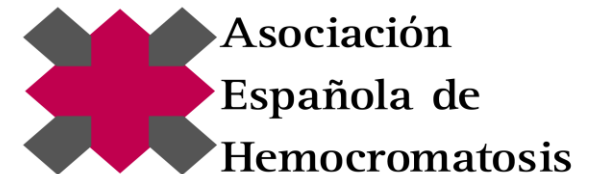


Current financial position	2025-2026 £
Opening balance	9,151.10
MetroBank	8,578.35
PayPal	572.75
Subscriptions (estimated)	500.00
Charitable donations (estimated)	2,703.92
Opening balance + estimated income	12,355.02
Expenditure (estimated)	1,766.36
Estimated available funds	10,588.66



**advancing knowledge of haemochromatosis  
through global alliances, partnerships, influence and expertise**





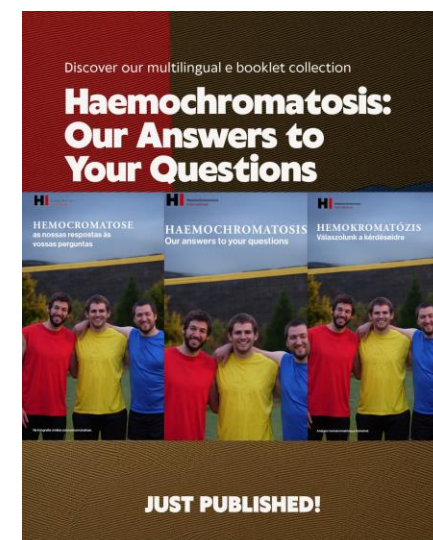
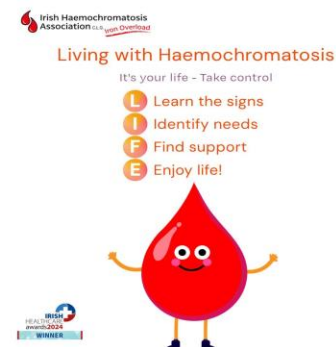
## Strategic Objective 1:

Improve awareness of haemochromatosis throughout the world by sharing best practices among member organisations.

- Support member organisations in their campaigns by sharing information via social medial channels (Twitter, Facebook, Instagram)



- Maintain resources page on HI website with information & materials which can be re-used by other MOs
- Post calendar of events on HI website
- Share experts' presentations on HI website
- Provide HI logos for MOs to use on their websites & social media channels
- **2025 Patient Conference - new initiative (HD)**



# Welcome to Haemochromatosis 2025



A conference bringing patients and experts together  
15 November 2025, Birmingham UK

Welcome to Haemochromatosis 2025, a patient conference presented by Haemochromatosis International with the support of five expert speakers, and made possible through the support of our sponsors. Please explore this website and book your place using the button at the top of your screen.

# Presenters

- Dr Jeremy Shearman
- Dr Janic Atkins
- Dr Prabhsimran Singh
- Kim Hicks, RN
- Professor Patrick Kiely

# The conference

- The event was an outstanding success with 106 delegates registering.
- Unfortunately some were unable to make it due to weather-related travel issues.
- The total income from the event was £10,000 against costs of £8,049, resulting in a surplus of £2,436.
- Feedback was excellent, with no negative comments received.

## Strategic Objective 2:

Support geographical expansion of the alliance and the development of new organisations

- Establish contacts with clinicians in identified countries where no patient support organisation exists
- Establish contacts with local informal groups on social media
- Facilitate introductions between member organisations
- Share resources on how to set up organisation, administration & governance





## Strategic Objective 3:

To encourage the adoption of best clinical practices by developing and disseminating internationally recognised guidelines for the diagnosis and **treatment of hereditary haemochromatosis**, and by supporting clinical trials and research



### Miscellaneous

#### EULAR 2025 classification criteria for haemochromatosis arthropathy

Patrick DW Kiely<sup>1,2,\*</sup>, Stephanie Finzel<sup>3</sup>, Bayram Farisogullari<sup>4</sup>, Graeme J. Carroll<sup>5</sup>, Geraldine McCarthy<sup>6,7</sup>, John Stack<sup>6</sup>, Simone Parisi<sup>8</sup>, Graça Porto<sup>9</sup>, Pascal Richette<sup>10</sup>, Gyorgy Nagy<sup>11,12,13</sup>, Marton Weidl<sup>11</sup>, Ann Rosenthal<sup>14</sup>, Pascal Guggenbuhl<sup>15,16</sup>, Katarzyna J. Banaszekiewicz<sup>17</sup>, Svenja Engelhardt<sup>3,18</sup>, Jeremy D. Shearman<sup>19</sup>, David Mitchell<sup>20</sup>, Jane Barker<sup>21</sup>, Valerie Brueton<sup>21</sup>, Barbara Butzeck<sup>21,22</sup>, Philip Coathup<sup>21</sup>, Howard Don<sup>21,23</sup>, Jacqueline Dowsett<sup>21</sup>, Marie Duncan<sup>21</sup>, Tracey Dunleavy<sup>21</sup>, Ian Fish<sup>21</sup>, Allin Hoggarth<sup>21</sup>, Mark McKinnon<sup>21</sup>, James Minter<sup>21</sup>, Tim Osborne<sup>21</sup>, Marguerite Smith<sup>21</sup>, Christine Wright<sup>21</sup>, Pedro M. Machado<sup>4,24,25</sup>

### Perspective

#### HFE and Hemochromatosis: Time to Reconsider the Diagnostic Role of the p.His63Asp Variant

Jeremy Shearman<sup>1</sup>, John K. Olynyk<sup>2</sup>, Sonia Distant<sup>3</sup>, Graça Porto<sup>4,5,6</sup>, Mayka Sanchez<sup>7</sup>

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- <sup>3</sup> Department of Medical Biochemistry, Oslo University Hospital, Rikshospitalet, 0027 Oslo, Norway
- <sup>4</sup> Centro Hospitalar Universitário de Santo António, European Reference Networks for rare diseases ERN-EuroBloodNet, Porto, Portugal
- <sup>5</sup> Instituto de Ciências Biomédicas Abel Salazar, Universidade do Porto, Portugal
- <sup>6</sup> Centro de Genética Preditiva e Preventiva, Instituto de Biologia Molecular e Celular (CGPP-IBMC), Porto, Portugal
- <sup>7</sup> Department of Biomedical Sciences, Faculty of Medicine and Health Sciences, Iron metabolism: Regulation and Diseases Group. Universitat Internacional de Catalunya (UIC). Sant Cugat del Vallès, 08195, Spain

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### HI/EFAPH Scientific Committee

experts from a broad range of clinical and research backgrounds and people living with haemochromatosis



**Population screening for haemochromatosis:  
A position paper by the HI/EFAPH Joint Scientific Committee**

## Motions to support strategic objectives

- Motion 1: to form joint social media/communications sub-committee with volunteers from member organisations (Strategic Objective 1).
- Motion 2: to work with EFAPH on investigating the possibility of a single website to serve both entities and their member organisations, while maintaining independent identities and visibility (Strategic Objective 1)
- Motion 3: to plan & source funding to organise Patient Conferences as satellite meetings for relevant research or clinical conferences eg. 2026 EIC Dublin, Blood 26 Auckland NZ, WONCA Nov 2027 Cape Town SA, Biolron 2027 Milan. (Strategic Objectives 2 & 3)
- Motion 4: to investigate establishing an international patient registry, recording genetics, symptoms, complications, biochemical levels and other diseases, and including C282Y homozygous patient populations, C282Y/H63D compound heterozygote patient populations and haemochromatosis in Asian populations eg UK Pakistani young men and others with non-HFE haemochromatosis. Two registries currently exist ( the non-HFE registry established by Heinz Zoller's team in Innsbruck and the Australian Haemochromatosis Registry)
- Motion 5: to conduct a global campaign for free access to phlebotomy for all HH Patients



## Election of board trustees

- 1/3 of the trustees shall retire from office. Since the total total number of trustees is 10, 3 shall retire from office. Those who have been longest in office since their last appointment or re-appointment are required to resign. Vacancies arising may be filled by the decision of members at the AGM. Any trustee who retires by rotation is eligible for re-appointment.
- This AGM 3 trustees are stepping down and have indicated they are standing for re-appointment.
- They are Rob Evans, Miriam Forde and Ketil Toska
- No new nominations have been received.

Motion: To approve the re-appointment of Rob Evans, Miriam Forde and Ketil Toska.