



AGM
29TH OCTOBER 2024
7pm UTC

AGM NOTES

- **QUESTIONS WELCOME AT END OF EACH PRESENTATION**
- **RECORDING?**
- **MOTIONS - VOTING PROCEDURE**
 - i) Members and Member Organisation Reps. Only
 - ii) Proposer
 - iii) Seconder
- **ZOOM POLLS**
- **For Trustee Appointments and Confirmations**
- **Presidential Election**

• WELCOME, INTRODUCTIONS & AGENDA	HOWARD DON
• MOVE TO ACCEPT MINUTES OF PREVIOUS AGM	PAT EVANS
• TREASURER’S REPORT	ROB EVANS
• REPORT FROM EFAPH/HI JOINT SCIENTIFIC COMMITTEE	GRACA PORTO
• HI BOARD REPORT	
• VOTES OF THANKS	HOWARD DON
• MEMBER ORGANISATIONS UPDATE	MEMBERS
• BOARD TRUSTEE APPOINTMENTS	HOWARD DON
• PRESIDENT ELECTION	
• AOB?	ALL
• THANKS AND CLOSE	HOWARD DON



2023-2024
Treasurer's Report
Rob Evans

- Accounting period: 1st April, 2023 to 31st March, 2024. The financial position will be reported up to 31st March, 2024
- 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

<u>Summary</u>	2022-2023 £ GB	2023-2024 £ GB
Opening balance	1979.67	7857.51
Income	6484.52	806.81
Expenditure	(606.68)	(809.74)
Closing balance	7857.51	7854.58

<u>Income</u>	2022-2023 £	2023-2024 £
Subscriptions	782.09	622.34
Grants	0	0
Donations	5702.43	184.47
Total	6484.52	806.81

<u>Expenditure</u>	2022-2023 £	2023-2024 £
Charitable activity	606.68	709.02
Governance	0	100.72
Administration	0	0
Professional fees	0	0
Total	606.68	809.74

<u>Current financial position</u>		2024-2025	£
Opening		7854.58	
Subscriptions		540.49	
Charitable donations		1354.29	
	Expenditure owing (estimated)	612.65	
Total expenditure		612.65	
Estimated available funds		9136.71	

FINANCIAL SUPPORT

- Novartis (2015) US \$15,000 (£12,688.75)
- DRG Germany and DRG USA (2017) Euro 3,000 (£2,496.88)
- Resonance Health Analysis Services Australia (2019) (£532.62)

Most of these funds were used to help towards attendance costs of various Committee members at AGM meetings.

Member Organisations for this accounting period

Germany, Portugal, USA (paid subs 2022), Norway, Canada, Italy, Hungary, Australia, Ireland, Spain, EFAPH, France (France Fer and AFH), Brazil, New Zealand and Denmark.

- Our subscription fee is kept purposefully low (50 GB pounds) so that all organisations may join, and we also offer waived subscriptions for groups that need it. There have been difficulties using the euro currency, hence the change to GB pounds
- We remain reliant on corporate grants such as these from Novartis, DRG and Resonance Health to fund our larger cost activities but these have not been forthcoming recently. However, we have been very fortunate to receive large charitable donations this year which is probably attributable to increased awareness
- Expenses related to attending meetings to further our charitable aims were formerly paid and accounted for most of the expenditure. In the absence of further grant funding, our main expense is now the HI website
- As an internet-based organisation, administration costs are very low/zero, and no salaries are paid to any of our trustees, nor do they receive any other form of reimbursement for their work

HI is a Charitable Incorporated Organisation (CIO), registered in the UK

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

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



Haemochromatosis
International

HI BOARD - PRESIDENT'S REPORT HOWARD DON

			
			
			
			



STRATEGIC PLAN 2023-2026

ACCEPTED BY HI BOARD ON 03-08-2023

- **MISSION STATEMENT**
- **ORGANISATIONAL OBJECTIVES
(Constitutional)**
- **PRIORITIES (Website)**
- **STRATEGIC OBJECTIVES 2023-26**

MISSION STATEMENT

- **OUR MISSION IS TO PROMOTE AND PROTECT THE HEALTH OF PEOPLE WITH HAEMOCHROMATOSIS IN ANY PART OF THE WORLD VIA A MUTUALLY SUPPORTIVE NETWORK OF NATIONAL ASSOCIATIONS, ENHANCED BY CLINICAL, SCIENTIFIC AND PATIENT EXPERTISE.**



OBJECTIVES

CONSTITUTION

1. INCREASE AWARENESS AND MEDICAL KNOWLEDGE OF HAEMOCHROMATOSIS, WORLDWIDE.
2. PROMOTE ADVANCES IN DIAGNOSIS, TREATMENT, AND PREVENTION OF HAEMOCHROMATOSIS.
3. PROMOTE INTERNATIONAL CONSISTENCY IN THE DIAGNOSIS AND TREATMENT OF HAEMOCHROMATOSIS.

PRIORITIES

WEBSITE

- 1. THE GEOGRAPHICAL EXPANSION OF THE ALLIANCE**
- 2. TO MAINTAIN AND DISSEMINATE INTERNATIONALLY RECOGNISED GUIDELINES**
- 3. FACILITATE SIGNPOSTING TO UP TO DATE RESEARCH AND THINKING ON HAEMOCHROMATOSIS**
- 4. FACILITATE COLLABORATION BETWEEN MEMBER ORGANISATIONS AND THE SHARING OF BEST PRACTICE**
- 5. TO CONTINUE TO DEVELOP AND EXPAND THE IMPACT OF WORLD HAEMOCHROMATOSIS WEEK**



STRATEGIC OBJECTIVES

SEPTEMBER 2023 TO AUGUST 2026

1. TO EXPAND MEMBERSHIP TO STRENGTHEN OUR IMPACT.

- EFAPH - report good activity in Europe
- USA. - HI to support where needed.
- New Zealand – good support from NZ Blood for WHW
- South Africa – No activity other than patient contact
- South America – Brazil re-established links with Paulo
- Argentina. – Gone quiet, Facebook group disappeared
- Mexico - KT found FB Group – HD has contacted and been accepted.

2. TO INCREASE THE IMPACT OF WORLD HAEMOCHROMATOSIS WEEK

- Target increasing the number of venues lit up by 5% year on year.
 - **TOTAL 476 VENUES WORLDWIDE - UP FROM 242 – 97% INCREASE**
 - **SPAIN 1ST**
 - **AUSTRALIA 2ND**
 - **GREAT EFFORTS FROM IRELAND, CANADA,**
 - **USA, HUNGARY, FRANCE, PORTUGAL & UK**
- Recruit more volunteers to distribute posters. **Success hard to measure**
- QR code linking to the HI website, increase “hits” **No evidence need tools**
- Multi language Posters on “resources” webpage **English Spanish, Hungarian, Polish – more next year?**

STRATEGIC OBJECTIVES 2023-26 CONT.

3. ADVOCATE FOR ABILITY TO ACCESS VENESECTIONS AS THERAPEUTIC DONORS FOR PATIENTS IN EVERY COUNTRY.

Develop relationships with:-

- **The International Federation of Blood Donor Organizations (IFBDO) HD contacted. Mtg Emerencia to discuss Friday 01-11-24**
- The International Society of Blood Transfusion
- Alliance of Blood Operators

4. MAINTAIN OUR THERAPEUTIC RECOMMENDATIONS IN HFE HAEMOCHROMATOSIS

- Joint Scientific Committee will ensure our recommendations remain current - **ONGOING**

5. TO INCREASE INCOME BY EXPLORING ALTERNATIVE REVENUE STREAMS.

- Funds raised this year additional to member subs.:-
- **World Week sponsored walk "Family FB group raised - £780 approx.**
- **Bank matched funding for above - £500 Thanks to Alma Morse!**
- **More of this?**
- Long term aim - international donors. Specific Projects?
- Establish a demonstrable track record. - **FAQ E- booklet in production now -ideal**

6. TO MAINTAIN A DIVERSE AND KNOWLEDGEABLE BOARD OF TRUSTEES TO SECURE OUR FUTURE.

- i) Be truly representative of our membership - geographical diversity. **Board well on target to achieve this**
- ii) Range of experience in – Governance, Patient advocacy in national organisations and clinical or research experience. **Proposed board has wide experience and skillset.**

7. COMMUNICATION AND COLLABORATION:

- i) Facilitate communication, collaboration and sharing of resources. **Ongoing**
- ii) **Website**
 - Keep current.
 - Expand members resources section. **Posters, FAQ e-booklet coming**
 - Regularly update news section. **CDB**
 - Target increasing the number of hits year on year by 5%. **How to measure?**
 - Donations via Paypal. **Had hoped to boost during WHW – needs more thought**
 - **Needs a revamp – suggest professional help would be a good use of funds**
 - **Patient Queries coming in – how to handle – signposting not always enough**
- iii) **Social Media**
 - The Facebook group will continue to be a closed group - HI members only.
 - **Great informal support from The Family Facebook Group - Alma**
 - LinkedIn and Twitter - target increasing follower numbers by 5% year on year.
 - **In truth, probably could be more active – room for improvement.**

END – QUESTIONS?