



Haemochromatosis
International

HI BOARD - PRESIDENT'S REPORT HOWARD DON

			
			
			
			

2022-2023 ACTIVITIES

- **WORLD HAEMOCHROMATOSIS WEEK**

- “LIGHT UP RED” – TOTAL 242 VENUES WORLDWIDE
- MOST GOT SOME, AND MANY IMPROVED
- AUSTRALIA - TOP
- SPAIN – WOW!

PATIENT NEEDS SURVEY PUBLISHED – MAYKA SANCHEZ & TEAM

WORK ON STRATEGIC PLAN



STRATEGIC PLAN 2023-2026

ACCEPTED BY HI BOARD ON 03-08-2023

- **MISSION STATEMENT**
- **ORGANISATIONAL OBJECTIVES (Constitutional)**
- **PRIORITIES (Website)**
- **STRATEGIC OBJECTIVES 2023-26**
- **THANKS TO PAUL JOHNSTON**



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.

- Sweden and Iceland progressing in Europe, (EFAPH)
- USA. - HI to support where needed.
- Support New Zealand and, possibly, South Africa to re-establish N.Os.
- South America – Brazil re-establish links.
- Argentina and Uruguay.

2. TO INCREASE THE IMPACT OF WORLD HAEMOCHROMATOSIS WEEK

- Target increasing the number of venues lit up by 5% year on year.
- Recruit more volunteers to distribute posters.
- QR code linking to the HI website, increase “hits”
- Multi language Posters on “resources” webpage



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)**
- The International Society of Blood Transfusion
- Alliance of Blood Operators

4. MAINTAIN OUR THERAPEUTIC RECOMMENDATIONS IN HFE HAEMOCHROMATOSIS

- Our Joint Scientific Committee will ensure our recommendations remain current

5. TO INCREASE INCOME BY EXPLORING ALTERNATIVE REVENUE STREAMS.

- Cannot rival our member M. Os.
- Bequests and donations welcome.
- Long term aim - international donors. Specific Projects?
- Currently have funds - establish a demonstrable track record.
- GP suggestion of new patient handbook under discussion.



STRATEGIC OBJECTIVES 2023-26 CONT

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

- i) Be truly representative of our membership - geographical diversity.
- ii) Range of experience in – Governance, Patient advocacy in national organisations and clinical or research experience.

7. COMMUNICATION AND COLLABORATION:

- i) Facilitate communication, collaboration and sharing of resources.

ii) Website

- Keep current.
- Expand members resources section.
- Regularly update news section.
- Target increasing the number of hits year on year by 5%.
- Donations via Paypal.

iii) Social Media

- The Facebook group will continue to be a closed group - HI members only.
- LinkedIn and Twitter - target increasing follower numbers by 5% year on year.



2022-2023
Treasurer's Report
Rob Evans

- Accounting period: 1st April, 2022 to 31st March, 2023. The financial position will be reported up to 31st March, 2023
- 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	2021-2022 £ GB
Opening balance	1979.67	1317.65
Income	6484.52	896.15
Expenditure	(606.68)	(234.13)
Closing balance	7857.51	1979.67

<u>Income</u>	2022-2023 £	2021-2022 £
Subscriptions	782.09	355.86
Grants	0	0
Donations	5702.43	540.29
Total	6484.52	896.15

<u>Expenditure</u>	2022-2023 £	2021-2022 £
Charitable activity	606.68	234.13
Governance	0	0
Administration	0	0
Professional fees	0	0
Total	606.68	234.13

<u>Current financial position</u>		2023-2024	£
Opening		7874.79	
Subscriptions		486.43	
Charitable donations		71.55	
	Expenditure owing (estimated)	477	
Total expenditure		477	
Estimated available funds		7955.77	

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.

Looking forward, we need to continue to increase our income through numbers of subscriptions, recruiting more members and from corporate support. If we are to be able to continue funding to attend international meetings, we must urgently seek more funding.

Any ideas?