



Haemochromatosis International is the global alliance of haemochromatosis associations, established to advance the health of people with haemochromatosis in any part of the world. Current member organisations are:

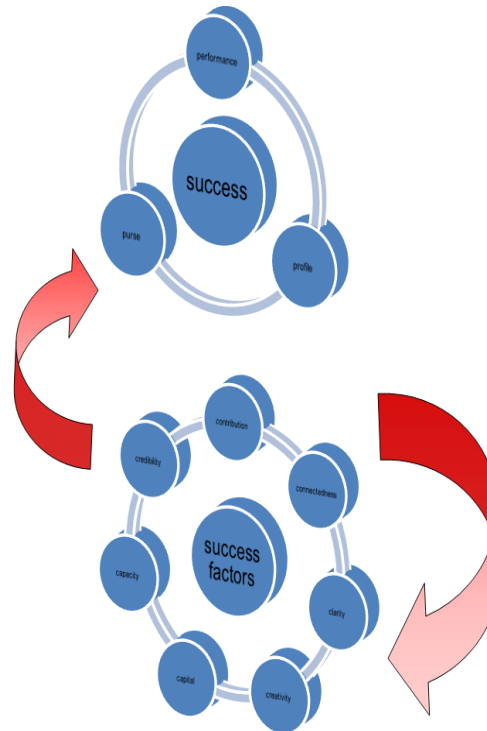


Membership of the international alliance enables an organisation

- to benefit from a global view and access to international medical experts and researchers, resources and guidelines
- to be part of a supportive network, connecting & collaborating with other societies; exchanging ideas, and sharing information, best practices, therapeutic and clinical strategies and communication strategies; and to learn how other members resolve the same and different problems
- to enhance its public profile, to advocate more strongly for access to treatment and health practice changes, and to influence health policy through preparing international guidelines together
- to amplify awareness of HH worldwide through participating in joint international awareness raising initiatives during WHW, using common logo for WHW interacting with other stakeholders on social media

Strategic Objectives

- To improve awareness of haemochromatosis throughout the world by facilitating the sharing of best practices among member organisations
- To support geographical expansion of the alliance and the development of new organisations
- 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



Factors influencing success

Clarity - mission, vision, values, goals, strategy, processes, communication, structure, roles

Contribution - value to and of stakeholders

Credibility – committee & advisors, quality outcomes, results

Connectedness - to stakeholders, members, donors, sponsors, governments, researchers, partners

Capital - financial, intellectual, human, social

Capacity - people, infrastructure, resources

Creativity - resourcefulness, innovation

Strategic Objective 1:

To improve awareness of haemochromatosis throughout the world by facilitating the sharing of best practices among member organisations.

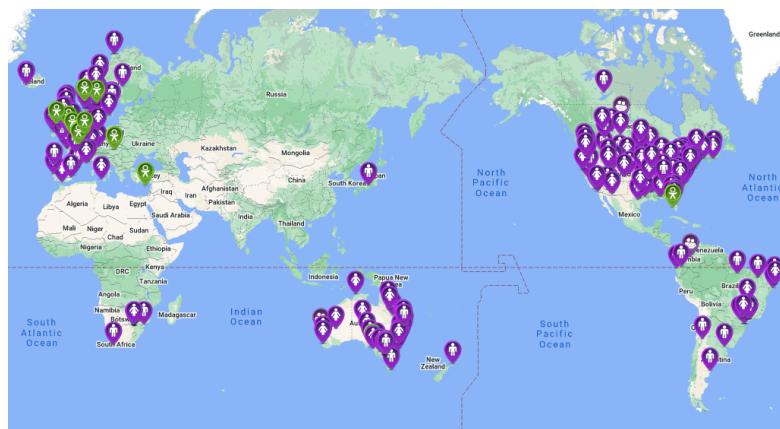
- Support member organisations in their campaigns by sharing information via social media channels (Twitter, Facebook, Instagram)
- Maintain resources page on HI website with information & materials which can be re-used by other MOs
- Post calendar of events – quarterly board meetings plus MO webinars via zoom or MS teams
- Share experts' presentations on HI website
- Provide HI logos for MOs to use on their websites & social media channels
- Establish social media/communications sub-committee from MOs.



Strategic Objective 2:

To 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
- Share resources on how to set up organisation, administration & governance
- Facilitate introductions between member organisations
- *Contact individuals who register on Disease Map in countries where no support organisation currently exists?*



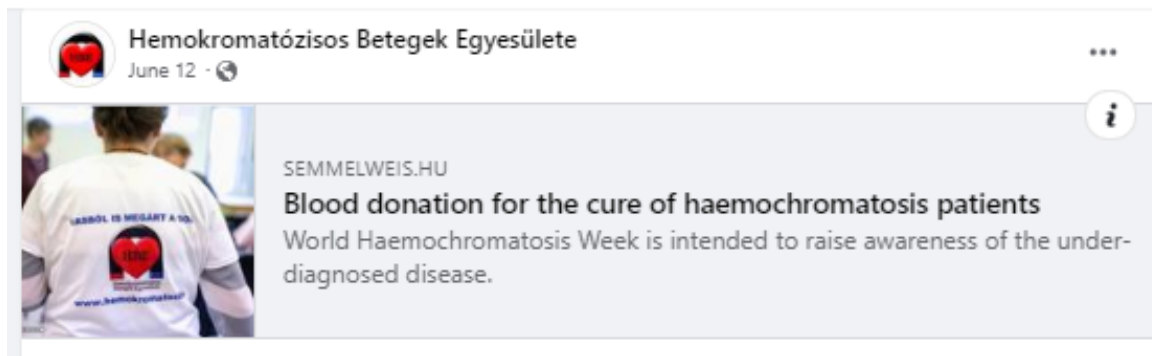
- Iceland
- USA
- New Zealand
- South Africa
- Central and South America

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



As of today, August 1 The American Red Cross is now accepting hemochromatosis donors after not accepting them for years.





Factors influencing success: Clarity ✓

Our very clear shared Vision: to prevent harm from iron overload

Canada

An end to suffering and premature death related to hemochromatosis in Canada.

Ireland

Our vision is to ensure that no one in Ireland goes undiagnosed or untreated

Australia

No Australian will suffer harm from haemochromatosis

Our Vision

No Australian will suffer harm from haemochromatosis.

Our Mission

As the primary advocacy group for Australians affected by haemochromatosis we provide support and promote awareness, early diagnosis and research.

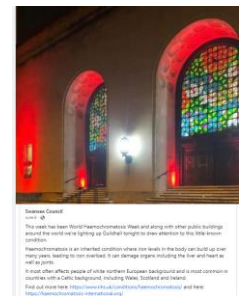
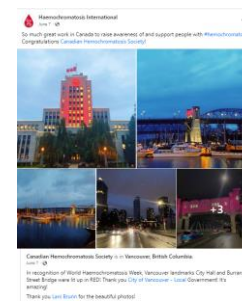
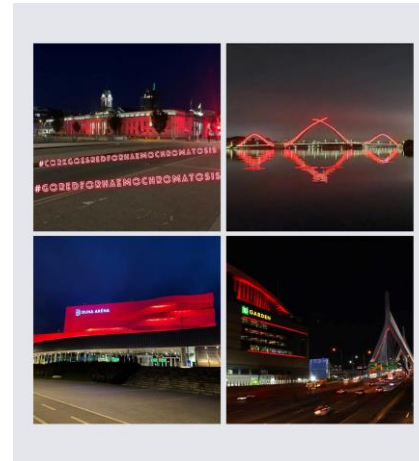
Our Values

We believe that people with haemochromatosis are entitled to:

- The same quality of life and life expectancy as other Australians
- Diagnosis before symptoms occur
- Well informed health and medical services
- Easy access to the knowledge, support and services they need

Factors influencing success: Creativity ✓

Elsie's Road Trip, Virtual Balloon Race, Light Up Red & FotoFeXPO



Factors influencing success: Connectedness ✓

Identifying and Connecting with stakeholders who can help



EIC Latest Haemochromatosis News,
Mayka Sanchez
Vice President EFAPH



Parliamentary Friends of
Haemochromatosis Co-Convenors



Senator Catryna Bilyk



Hon Nola Marino MP



Researchers and Clinicians



Haemochromatosis International AGM
December, 2022

Factors influencing success: Contribution ✓

Recognising and promoting our value to stakeholders



Le patient hémochromatosique est gagnant
l'EFS est gagnant
l'hôpital est gagnant

FAISONS-LE SAVOIR



Arthritis and Haemochromatosis

A webinar presented by
Haemochromatosis Australia and Arthritis NSW

Public Health and Chronic Disease Program
Haemochromatosis – National Patient Registry

Grant Opportunity Guidelines
GO5431

Opening date:	2 March 2022
Closing date and time:	2:00pm (Canberra time) on 16 March 2022
Commonwealth policy entity:	Department of Health (department)
Administering entity:	Community Grants Hub
Enquiries:	If you have any questions, contact the department via email: grant.afm@health.gov.au . Questions should be sent no later than 5:00pm (Canberra time) on 10 March 2022.
Type of grant opportunity:	Closed non-competitive

Haemochromatosis Australia
www.ha.org.au
PROJECT: Iron Matters

build, manage and promote a National Patient Registry

- a cloud-based haemochromatosis national patient registry (HNPR)
- a resource for clinicians and iron researchers
- increased quantitative and qualitative data available on iron overload
- greater community and health professional awareness of haemochromatosis



The NPR will collect information on patients & their experience



to inform

- research into the impact of iron on the liver, pancreas, joints, heart, lungs, brain and sexual function
- policy makers and clinicians to ensure early diagnosis and access to appropriate treatment



Haemochromatosis Australia QIMR Berghofer
 Edith Cowan University Queensland University of Technology

EDUCATION AND TRAINING (CPD)



ThinkGP Haemochromatosis: Preventing harm caused by iron overload with timely diagnosis and best practice management – free online CPD learning modules for GPs

Accredited for CPD by RACGP (40 points) and ACBIM (5 hours). The modules sponsored by Haemochromatosis Australia are provided free to GPs and allied health professionals.

Haemochromatosis: Preventing harm caused by iron overload with timely diagnosis and best practice management | ThinkGP



2021-2022
Treasurer's Report
Rob Evans

- Accounting period: 1st April, 2021 to 31st March, 2022. The financial position will be reported up to 31st March, 2022
- 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>	2020-2021 £ GB	2021-2022 £ GB
Opening balance	1011.98	1317.65
Income	407.64	896.15
Expenditure	(101.97)	(234.13)
Closing balance	1317.65	1979.67

<u>Income</u>	2020-2021 £	2021-2022 £
Subscriptions	407.64	355.86
Grants (Resonance Health)	0	0
Donations	0	540.29
Total	407.64	896.15

<u>Expenditure</u>	2020-2021 £	2021-2022 £
Charitable activity	101.97	234.13
Governance	0	0
Administration	0	0
Professional fees	0	0
Total	101.97	234.13

<u>Current financial position</u>		2022-2023	£
Opening		1979.67	
Subscriptions		782.09	
Charitable donations		5252.72	
	Expenditure owing (estimated)	370	
Total expenditure		370	
Estimated available funds		7644.48	

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), UK (left Aug 2021), 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, 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, 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?

These accounts were accepted by the Board of Trustees at the AGM of 8th December 2022

Robert W. Evans.

10/1/2023