



## Working with Stakeholders Policy

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### About Haemochromatosis International

Haemochromatosis International (HI) is an alliance of haemochromatosis associations throughout the world. Our aim to advance the health of people with haemochromatosis by improving awareness of haemochromatosis, its diagnosis, treatment and management.

Membership of Haemochromatosis International is restricted to haemochromatosis associations representing the interests of people with haemochromatosis in their countries. Each member organization of Haemochromatosis International is managed by volunteer committees or boards and relies primarily on individual membership subscriptions to support its work. No member organisations currently receive significant funding from their respective governments. Ad hoc donations support the work of member organisations.

This document presents our policy on external (ie. non-member) stakeholder engagement.

## Haemochromatosis International Stakeholders

External stakeholders with an interest in Haemochromatosis International include governments and healthcare agencies, researchers, donors and benevolent trusts or foundations, other non-profit organisations with shared objectives, and corporate sponsors and supporters, which include but are not limited to, pharmaceutical and bio-medical companies, diagnostic services providers and laboratories, and venesection service providers. It is critical to our reputation as an independent advocacy organization, that we are clear about how and under what circumstances, we engage with external stakeholders. Haemochromatosis International recognizes that each stakeholder brings its own specific interests and unique perspectives to the relationship. Before engaging with external stakeholders Haemochromatosis international will assess their potential value and utility, and that of their own networks, in helping achieve our objectives.

Haemochromatosis International accepts unrestricted financial support for specific conferences, meetings, projects, publications, education and research where the focus is clearly on advancing the health of people with haemochromatosis. The trustees of Haemochromatosis International reviews all offers of sponsorship and financial support. Approvals of financial agreements are to be made by committee decision. A record of all arrangements with financial sponsors will be maintained, and a register of sponsors and their support will be published on our website.

### Governments and healthcare agencies

While individual member organisations engage with the governments and health departments on behalf of their members, Haemochromatosis International does not seek to establish relationships at national government levels. Haemochromatosis International however supports the efforts of its individual member organizations establishing relationships with governments and healthcare practitioners in their respective countries wherever possible.

### Researchers

Haemochromatosis International values the work of research organisations in identifying, testing and bringing new treatments to individuals with haemochromatosis. We welcome information from these organisations to ensure we maintain awareness of current and emerging research data and therapeutic options.

## Individual Donors and benevolent trusts or foundations

Haemochromatosis International welcomes gifts and financial support from individual donors and independent benevolent trusts or foundations. We acknowledge that individual donors may want donations to be linked to a specific project and will provide them with milestone reports on such initiatives. We will recognize individual contributions in our annual report except in cases where donors have requested anonymity.

## Commercial Supporters

Haemochromatosis International gratefully acknowledges the support of Novartis, DRG Germany, and DRG USA with the start-up and running of this Charitable Incorporated Organisation and welcomes unrestricted financial sponsorship to help us continue.

While acknowledging the benefits of working collaboratively with sponsors to advance the health of people with haemochromatosis, Haemochromatosis International also understands the commercial interests of potential sponsors in establishing relationships with our organization. Unless carefully managed, relationships with commercial entities could be detrimental to the credibility of Haemochromatosis International as an independent advocacy organization working to advance the health of people with haemochromatosis.

Haemochromatosis International will not align with a single commercial entity nor endorse any products, nor allow the HI logo to be published on products or product information. We will not comment on media releases on behalf of commercial entities on specific products related to the diagnosis and treatment of haemochromatosis