

HEALTHPATHWAYS, HEALTH CONSUMERS, AND HEALTH LITERACY: The Hereditary Haemochromatosis example

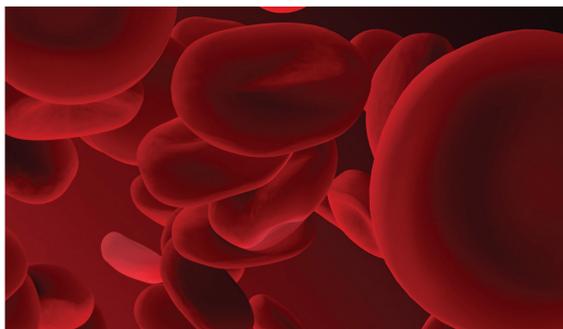
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BACKGROUND

Haemochromatosis Australia (HA) is an all-volunteer, non-profit, registered charity that advocates for early detection and treatment of hereditary haemochromatosis (HH) to prevent harm caused by iron overload. HA has been the driving force for disseminating Australian best practice information about diagnosis and management of HH.

HH symptoms and signs are non-specific in early disease and so diagnosis is often made later in the disease when substantial organ damage has already occurred. In addition, evidence from a survey conducted by HA in 2012 across 20 venesection centres showed that a significant number of patients undergoing treatment for HH had poor understanding of the condition.

Early diagnosis and treatment prevents organ damage and results in normal life expectancy.



BACKGROUND

In 2013, Haemochromatosis Australia (HA) approached Hunter New England (HNE) HealthPathways to collaboratively develop the first Australian HH HealthPathway to:

- raise awareness of HH and increase rates of early diagnosis
- ensure national uniformity and availability of quality information for GPs on the HH management & treatment
- prevent the consequences of missed diagnoses as well as incorrect referrals for venesection for genotypes not associated with iron overload
- provide ready access to high quality patient resources with appropriate health literacy levels
- raise awareness of HA and the services available.

HOW DID WE PROMOTE THE PATHWAY

HA has been raising awareness of the HH HealthPathways and accompanying patient information with local health professionals, primarily via PHN newsletters and Twitter, and with the general community via the HA website, newsletter and social media.

OUTCOMES ACHIEVED

The initial successful collaboration with HNE HealthPathways was used as a catalyst to encourage and assist other HealthPathway regions to localise a HH Pathway. There are now 15 live HH Pathways nationally, with others under development. GPs in these areas now have ready access to:

- clinical information on HH
- the High Ferritin App, the Australian Red Cross Blood Service (ARCBS) online referral for therapeutic donors
- information on local services providing venesection
- resources for patients and family members

Recent analysis from 4 pathway regions has shown:

HealthPathway Region	Time period	Page views	Average time on page
HNE	April 2016-April 2018	1316	6 min 56 sec
Sydney	Jan 2016- Jan 2018	548	5 min 22 sec
Tasmania	Nov 2016-March 2018	277	6 min 15 sec
ACT/SNSW	Jan 2016-Jan 2018	132	4 min 1 sec

In addition, Haemochromatosis was one of the top ten searched terms for Melbourne HealthPathways in December 2017.

A 2017 report by the Health Care Consumers Association showed that consumers are more likely to contact a support organisation if it is recommended by their health practitioner and that it is important to provide support group information on HealthPathways. Direct access for health consumers to patient resources on hereditary haemochromatosis is readily available via a number of HealthPathway consumer portals.

FUTURE DIRECTIONS

HA have embraced the opportunity to collaborate internationally by initiating discussions with Haemochromatosis UK to promote a HH Pathway in South Tyneside UK, as they appear to have similar information and resource issues there. There is also an opportunity to share the experience of this collaboration with other condition specific patient support associations who are keen to promote other HealthPathways.

HA are committed to:

- providing support to HealthPathway teams that are localising HH pathways
- providing ongoing support to HealthPathway teams reviewing HH pathways
- promoting HealthPathways to GPs and patients

To facilitate this, HA would like to establish communication with the HealthPathways community to receive notification of when the HH pathway is being localised or reviewed by a pathway region. As HA is a volunteer organisation with limited resources, they would also like to work more closely with HealthPathway teams to share the uptake & usage figures to enable more targeted promotion.

ACKNOWLEDGEMENTS

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