A 2018 review of EFAPH member associations

Françoise Courtois

Pat Evans , Dianne Prince

15th Annual General Assembly

Heidelberg, May 9-10 th, 2019

CANADA
www.toomuchiron.ca

USA
www.irondisorders.org

EUROPE
www.efaph.eu

UK
www.haemochromatosis.org.uk

IRELAND
www.haemochromatosis-ir.com

BELGIUM
www.haemochromatose.be

SPAIN
www.hemocromatosis.es

PORTUGAL
www.aphemocromatose.org

NORWAY
www.hemokromatose.no

GERMANY
www.haemochromatose.org

HUNGARY
www.hemokromatozis.hu

ITALY
www.emocromatosi.it

FRANCE
www.hemochromatose.org
www.hemochromatose.fr

BRAZIL
www.hemocromatosehereditaria.com

AUSTRALIA
www.ha.org.au

NZ

Haemochromatosis International

Therapeutic recommendations

HealthPathways

Accredited education

Therapeutic blood donations

Access to treatment

Screening and testing

Parliamentary friends

Health professionals

Governments

Researchers

Communities

Research support and sponsorship

Patient voice and participation

70,000
social media followers

9,000
members

Patient information and support

International collaboration

Highlights

1. HH International Awareness week
2. Cross border regional / national actions
3. Government lobbying
4. Nice initiatives
5. Other awareness actions in Europe
6. International initiatives

World Haemochromatosis Week

International collaboration made it a success!

Logo designed by HUK (in 11 languages & 2 formats – PNG/EPS)

Media release prepared by HA
Is the world pumping too much iron?

Activities in many countries

MEDIA RELEASE

IS THE WORLD PUMPING TOO MUCH IRON?

World Haemochromatosis Week 04 – 10 June 2018

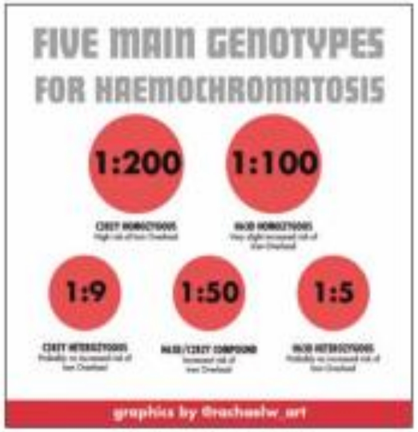
New research and new guidelines recommend early diagnosis and treatment for one of the world's most common genetic conditions.

Haemochromatosis Australia
inherited iron overload disorder

Haemochromatosis Awareness Week
04 – 10 June 2018

Our sincere thanks to Sir Peter Cosgrove, Governor-General of Australia and Lady Cosgrove for helping raise awareness of haemochromatosis during World Haemochromatosis Week. They are pictured here proudly sporting our OVERLOAD collection cuff-links and brooch.

Sign at Newtown Fire Station, Sydney



An example of a graphic created by Rachael Wheeler

Haemochromatosis

is a common genetic condition
causing too much iron.

Tricky to say
Easy to test
Simple to treat
Tragic to ignore

Find out if your iron level is right.
www.ha.org.au

GRUPO BRASILEIRO DE
HEMOCROMATOSE HEREDITÁRIA

World
Haemochromatosis
Week
04 – 10 June 2018

- **Activities in blood centers informing health professionals about HH**

GRUPO BRASILEIRO DE
HEMOCROMATOSE HEREDITÁRIA

World
Haemochromatosis
Week
04 – 10 June 2018

Activities in parks

Lectures

Algumas ações

HH International Awareness week in Europe:

- 14 countries in February 2019

- Switzerland just gave up (March 2019)
- We hope someone will get involved soon

HAEMOCHROMATOSIS

Genetic iron overload disorder

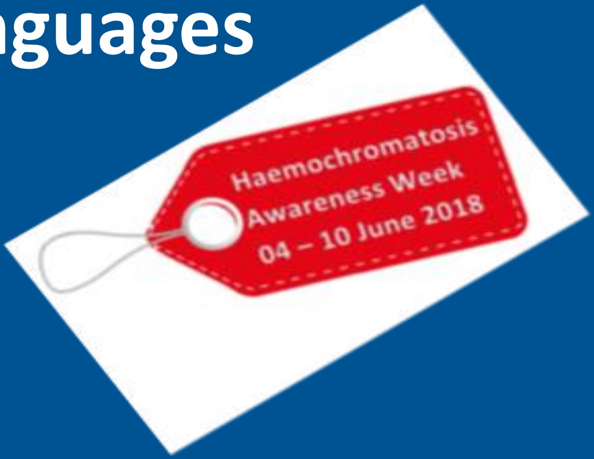
Information - Prevention Treatment

EFAPH European Federation of Associations of Patients with Haemochromatosis
EURORDIS Rare Diseases Europe
EPF European Patients Forum
HI Haemochromatosis International

HH International Awareness week in Europe:

- **HI initiative** (special congratulations from Margaret!)

- **04 – 10 June 2018**
- **Special logo proposed by David Head**
- **The labels are available in 11 languages and 2 formats**



- **HI sent a common message to every member organisation**
- **Which translated it into their own language**
- **A nice communication tool to be used :**
  - in press articles
  - on websites
  - by institutional partners
  - ….

EFAPH
European Federation of Associations of Patients with Haemochromatosis

HI Haemochromatosis International

MEDIA RELEASE

IS THE WORLD PUMPING TOO MUCH IRON?

World Haemochromatosis Week 04 – 10 June 2018

New research and new guidelines recommend early diagnosis and treatment for one of the world's most common genetic conditions.

Iron overload or haemochromatosis, is a serious condition in which too much iron is absorbed and stored in the body. It can cause liver cirrhosis, liver cancer, arthritis, diabetes and general fatigue.

World Haemochromatosis Week, which kicks off today, aims to strengthen awareness of iron overload as early diagnosis will result in better health outcomes for individuals as well as huge savings for a country's health care system[1].

Haemochromatosis groups worldwide, including European Federation of Associations for Patients with Haemochromatosis EFAPH, have joined in a push to raise awareness and improve the rate of early diagnosis of this prevalent but all too often overlooked condition.

Through international collaboration, a task force of haemochromatosis experts has agreed upon an objective, simple and practical set of therapeutic recommendations for managing hereditary haemochromatosis, which are applicable around the globe[2].

President Dr. Barbara Butzeck of EFAPH welcomes this landmark guideline, noting that although haemochromatosis the most common genetic disorder in Europe it is still widely under-diagnosed. *"About one in 200 people of European origin have the genetic predisposition for haemochromatosis and additionally, one in 7 people are carriers of the gene that causes it"*

"Haemochromatosis is under-diagnosed, partly because public awareness of the condition is low but also because its symptoms, including fatigue, depression and joint pain, are confused with a range of other illnesses. When undetected and untreated, iron overload can result in premature death," said *Dr. Barbara Butzeck.*

Although haemochromatosis is detected by simple blood tests, support groups around the world continue to hear familiar stories from people with significant health problems caused by a late diagnosis. Recent research by the Murdoch Children's Research Institute (MCRI) has shown that haemochromatosis should be treated even when iron stores are only mildly elevated.' [3]

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[1] De Graff, B et al. (2016, November 16*). Population Screening for Hereditary Haemochromatosis in Australia: Construction and Validation of a State-Transition Cost-Effectiveness Model.* PharmacoEconomics.

[2] Adams, P. et al. (2018, March 27). *Therapeutic recommendations in HFE hemochromatosis for p.Cys282Tyr (C282Y/C282Y) homozygous genotype*. Hepatology International.

[3] Ong, Sim Y et al. *Reduction of body iron in HFE-related haemochromatosis and moderate iron overload (Mi-Iron): a multicentre, participantblinded, randomised controlled trial* The Lancet Haematology, Volume 4 , Issue 12 , e607 - e614 https://goo.gl/6ijumL

HH awareness week june 2018 in Europe (1)

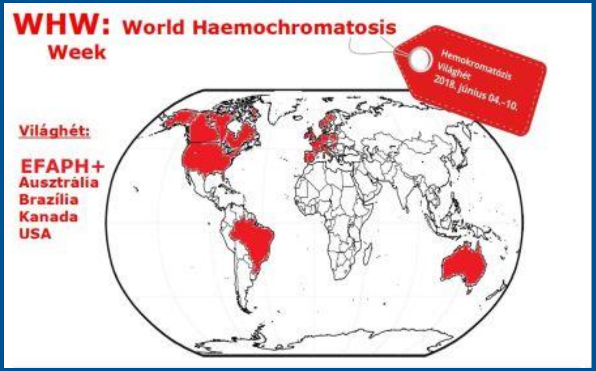
Ireland

HAEMOCHROMATOSIS AWARENESS DAY JUNE 7TH

- Stands at over 30 venues nationwide
- Articles in the Irish Time and Irish Independent
- Dr Pat Kenny was interviewed on more than 13 regional radio shows highlighting HH signs, early diagnosis, …

- Mini Marathon June 3rd 2018

HH International awareness week June 2018 in Europe (2)



Hungary

Budapest
Meeting and stands

Hungary regional TV

HH International awareness week June 2018 in Europe (3)

France

- 2nd National hemochromatosis awareness Week - DETECT/FER

DETECT/FER
Semaine nationale de l'Hémochromatose

Dissemination targeted at health professionals with the support of 17 health institutions : the French national medical Council (CNOM), learned medical societies, colleges of physicians, biologists, nurses…).

1. International Therapeutic Recommendations in HFE translated into French
2. Video clip : https://www.hemochromatose.org/?s=clip+video

Broadcast on:

- channel 33 (2000 doctors' waiting rooms, labs ...),
- social networks,
- learned societies', biologists', GPs' and physicians colleges' websites…

HH awareness week: Brittany in full swing!

11 stands in the main hospitals

1 golf competition

3 radio and TV interviews

14 newspapers articles (40 issues): Ouest France, Télégramme de Brest, local news papers…

Semaine mondiale de l'hémochromatose…
Un bilan 2018 dont nous sommes fiers - 4 au 8 juin 2018

Hémochromatose : trop de fer peut tuer

L'excès de fer dans l'organisme peut tuer. Pour le détecter, un bilan sanguin suffit. Bonne nouvelle, le traitement est simple et efficace.

Recueilli par Jean-Pierre LE CARROU.

Finistère 4 et 5 juin

Quimper - Jacqueline et un médecin de l'hôpital

Edouard, délégué du Finistère en pleine discussion

Hôpital du Scorff
Lorient 7 juin

Daniel, délégué Lorient et Germain, adhérent bénévole

Semaine mondiale de l'hémochromatose
Rennes Pontchaillou 6 juin
Hôpital Sud 7 juin

Les essais d'un traitement contre l'excès de fer

La Bretagne en bref

Jacqueline, déléguée Ille et Vilaine et le Pr Bardou-Jacquet

Le Pr Guggenbuhl, Chef de Service Rhumatologie nous rend visite sur notre stand

« L'hémochromatose est la 1ère maladie génétique de France »

Centre hospitalier Saint-Malo
5 Juin 2018

Jacqueline et Nicole en compagnie d'une infirmière

Semaine mondiale
Pays de la Loire
5 et 6 juin 2018

Lien pour visualiser l'interview TLC Cholet du 6 juin 2018 : http://www.tlc-cholet.com/video-27374382/-journal-du-mercredi-06-juin-2018

La Semaine mondiale de l'hémochromatose en Vendée les 5 et 6 juin 2018.
Les équipes médicales nous encouragent

Jacqueline, déléguée Maine et Loire

Laurent, délégué Vendée

Compte - rendu journée du 7 juin
Centre Hospitalier - Saint-Brieuc

Hémochromatose. Sensibiliser pour dépister

Jacqueline, Janine et une adhérente sur le stand

Une journée pour alerter les usagers sur l'hémochromatose
Vannes le 7 juin 2018

Ils ont une surcharge de fer dans le corps

Alexandre, délégué du Morbihan en compagnie d'Irène

Alexandre Lecorfec
Délégué Morbihan

CHBA. S'informer sur l'hémochromatose jeudi

HH International awareness week June 2018 in Europe (4)

Portugal

- **Interviews** : - Portuguese TV
  - Radio channels
- **National press** : special reports

June 2018: a picture of the extended family featuring haemochromatosis patients along with their friends and families on Haemochromatosis Day at Esposende

HH International awareness week June 2018 in Europe (5)

Spain

08 June 2018- Blood donation day at the Hospital Clínic in Barcelona

09 June 2018- AGM AEH - Visit to Sagrada Familia - attendance of patients >75 persons!!!

HH International awareness week June 2018 in Europe (6)

Germany

A dedicated hotline animated by the scientific board for a few hours several days over the HH week

Highlights

1. HH International Awareness week
2. **Cross border regional / national actions**
3. Government lobbying
4. Nice initiatives
5. Other awareness actions in Europe
6. International initiatives

Regional / national actions : Norway and the Scandinavian group!

1: DK 2016
2: SW 2018

Thanks Ketil!

New Sweden team: Marten, Ing Marie and Eleonor

Highlights

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Government lobbying (1)

DANISH
HEMOCHROMATOSIS
ASSOCIATION
DHA

The Danish National Board of Health has decided that haemochromatosis be assigned to the speciality of gastroenterology and hepatology.
Consequently, a much larger number of HH patients were diagnosed (+++)

Reform of the 'third sector' paved the way to a comprehensive revision of how non-profit organisations are registered and operated.
This will affect the Italian association constitution, the membership rules, operational methods and financial affairs.

Government lobbying (2)

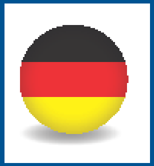
Phlebotomy

A close cooperation between FFAMH, the French Blood Establishment (EFS) and the French Health Authorities lead to an amendment to open to HH patients the possibility for blood donation in the 124 EFS blood bank sites nationwide.

May 2018 - Modification of decree 10/88 of 2005 on Donation by a Royal amendment that allowed the use of all the blood of people with hemochromatosis.

Government lobbying (3)

the cost of phlebotomy



Negotiations by HVD (scientific committee) + German Hepatology and Rheumatology societies with the new German Health minister to obtain free access to phlebotomy

16 months of negotiations without much success with the Irish Minister for Health regarding an 80€ charge for venesection in certain hospitals.
An unfair and prohibitive charge mainly affects patients without a medical card or private health insurance.
…. *This issue is currently being taken into account!*

Following the gradual cessation of phlebotomies in most hospital care services and EFS for financial reasons (low reimbursement cost), FFAMH submitted a file to the Ministry for Health for a reassessment of the act (the same quotation for all partners)...
A "titanic" fight!

Highlights

1. HH International Awareness week
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5. Other awareness actions in Europe
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Nice initiatives (1)

The « Iron Games » a great event !

- 11 teams for construction firms (with Irish rootswill) compete in 4-sport tourney
- 4 Iron Cups sponsored by the Toureen Group
- It brought out significant funding -> HUK will propose to run a 3-year-HH Education programme

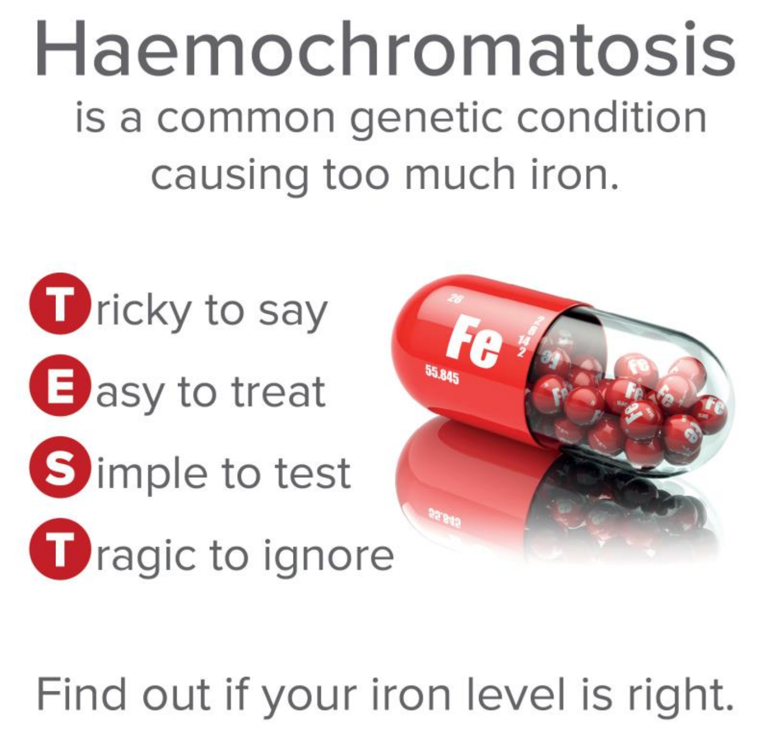
football

hurling

soccer

golf

Nice initiatives! (2)



Haemochromatosis

is a common genetic condition causing too much iron.

- **T**ricky to say
- **E**asy to treat
- **S**imple to test
- **T**ragic to ignore

Find out if your iron level is right.

Haemochromatosis Australia
Inherited Iron overload disorder

?

What about translating into other languages ?

Nice initiatives! (3)

Germany

2018 Annual week end in Black forest for Haemochromatosis Patients – HVD members and family

Highlights

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4. Nice initiatives
5. **Other awareness actions in Europe**
6. International initiatives

Clinicians and general public awareness actions in Europe (1)

Large meeting at The House of Commons, Westminster (London) organized by Haemochromatosis UK (HUK) : 31st October 2018

Clinicians and general public awareness actions in Europe (2)

Hungary : 2 large conferences + new leaflet 500 GPs/2000 GPs

Denmark : 1 dedicated folder send to 4000 GPs

HÆMOKROMATOSE

Genetisk disposition til jernoverskud

Portugal: 2 symposia of 150 GPs : 300 GPs

France : 1 symposium (National Biology days) 1000 Biologists

Ireland: 5 large information meetings: Dublin, Kikenny, Letterkenny, Tullamore, Mayo

UK: 3 Patient Information Days (PIDs): Belfast, Liverpool, Edimburg

Deployment of actions in the regions…

This year, the Associazione per lo Studio dell'Emocromatosi e delle Malattie da Sovraccarico di Ferro, set up regional representatives in :

- Lazio
- Veneto
- Tuscany

A promising initiative that has already been proven by some EFAPH country members

Awareness and information for students and nurses in Europe

🇬🇧 1 seminar (1 day) for best practices for venesection (nurses)

🇩🇪 2 educational lectures for students in Heidelberg and Bonn about HH given by 2 HVD members as « undiagnosed patients »

🇫🇷 7 meetings organised with the support of the nurses'college in the Parisian area

World day of Rare diseases in Europe

Juan Bedmar (AEH Delegate in Madrid) had a privileged contact with the Spanish Queen

Different stands in Pécs (2018/2019) and in Szeged medical university (2019)

Highlights

1. HH International Awareness week
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3. Government lobbying
4. Nice initiatives
5. Other awareness actions in Europe
6. **International initiatives**

International initiatives

International Recommendations drivers by Paulo

Hepatology International (2018) 12:83–86
https://doi.org/10.1007/s12072-018-9855-0

GUIDELINES

Therapeutic recommendations in *HFE* hemochromatosis for p.Cys282Tyr (C282Y/C282Y) homozygous genotype

Paul Adams[1] · Albert Altes[2] · Pierre Brissot[3,4] · Barbara Butzeck[4,5,6] · Ioav Cabantchik[7,8] · Rodolfo Cançado[9] · Sonia Distante[10] · Patricia Evans[4,5] · Robert Evans[4,11,12] · Tomas Ganz[13] · Domenico Girelli[14] · Rolf Hultcrantz[15] · Gordon McLaren[16] · Ben Marris[4,17] · Nils Milman[18] · Elizabeta Nemeth[19] · Peter Nielsen[20] · Brigitte Pineau[21] · Alberto Piperno[22,23] · Graça Porto[24,29,33] · Dianne Prince[4,17] · John Ryan[25] · Mayka Sanchez[2] · Paulo Santos[4,26,27] · Dorine Swinkels[28] · Emerência Teixeira[4,24,29,34,35] · Ketil Toska[4,30] · Annick Vanclooster[31,36] · Desley White[4,32] · Contributors and Hemochromatosis International Taskforce

Received: 19 December 2017 / Accepted: 8 March 2018 / Published online: 27 March 2018

Abstract
Although guidelines are available for hereditary hemochromatosis, a high percentage of the recommendations within them are not shared between the different guidelines. Our main aim is to provide an objective, simple, brief, and practical set of recommendations about therapeutic aspects of *HFE* hemochromatosis for p.Cys282Tyr (C282Y/C282Y) homozygous genotype, based on the published scientific studies and guidelines, in a form that is reasonably comprehensible to patients and people without medical training. This final version was approved at the Hemochromatosis International meeting on 12th May 2017 in Los Angeles.

Introduction

Although guidelines are available for hereditary hemochromatosis (HH), a high percentage of the recommendations within them are not shared between the different guidelines [1]. Our main aim is to provide an objective, simple, brief, and practical set of recommendations about therapeutic aspects of *HFE* hemochromatosis for p.Cys282Tyr (C282Y/C282Y) homozygous genotype, based on the published scientific studies and guidelines, in a form that is reasonably comprehensible to patients and people without medical training.

The final version of these recommendations was approved at the Hemochromatosis International meeting on 12th May 2017 in Los Angeles.

Whom to treat and when to start

Patients with *HFE* p.Cys282Tyr (C282Y/C282Y) homozygous genotype and biochemical evidence of iron overload, i.e., increased serum ferritin (> 300 µg/L in male and postmenopausal female and > 200 µg/L in premenopausal female) and increased fasting transferrin saturation (≥ 45%) [2, 3].

Considerations

- A judgement has to be made for each individual patient taking into account their ferritin level (according to local reference value), age, gender, and co-morbidities.
- Patients with other genotypes should be referred for further advice.
- Recent studies observed a beneficial effect of early and sustained management of patients with iron excess, even when iron load is mild or moderately elevated serum ferritin [4, 5].
- Elevated serum ferritin values are very common and the most frequent causes are not associated with HH, but with metabolic syndrome inflammation (ferritin is an acute-phase protein), alcoholism, and liver damage. Thus, it is critical to investigate rigorously the cause of

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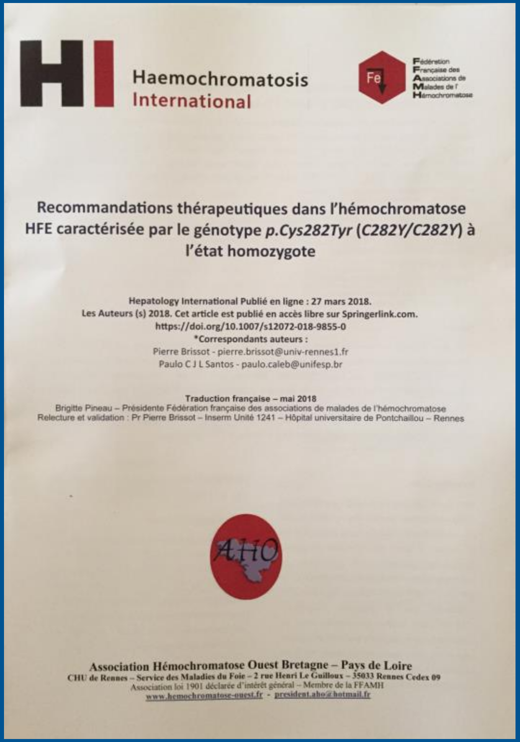
Extended author information available on the last page of the article

Translation in severeal languages

…



Haemochromatosis
International

Fédération
Française des
Associations de
Malades de l'
Hémochromatose

Recommandations thérapeutiques dans l'hémochromatose HFE caractérisée par le génotype *p.Cys282Tyr* (*C282Y/C282Y*) à l'état homozygote

Hepatology International Publié en ligne : 27 mars 2018.
Les Auteurs (s) 2018. Cet article est publié en accès libre sur Springerlink.com.
https://doi.org/10.1007/s12072-018-9855-0
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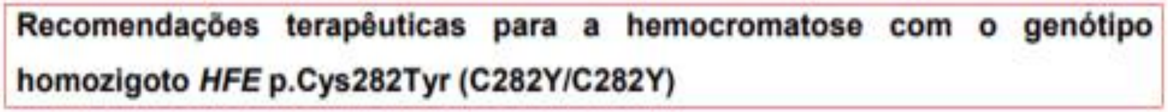
Traduction française – mai 2018
Brigitte Pineau – Présidente Fédération française des associations de malades de l'hémochromatose
Relecture et validation : Pr Pierre Brissot – Inserm Unité 1241 – Hôpital universitaire de Pontchaillou – Rennes

AHO

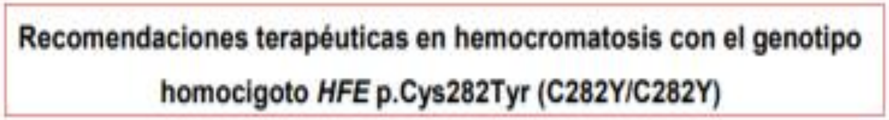
Association Hémochromatose Ouest Bretagne – Pays de Loire
CHU de Rennes – Service des Maladies du Foie – 2 rue Henri Le Guilloux – 35033 Rennes Cedex 09
Association loi 1901 déclarée d'intérêt général – Membre de la FFAMH
www.hemochromatose-ouest.fr - president.aho@hotmail.fr

GRUPO BRASILEIRO DE
HEMOCROMATOSE HEREDITÁRIA

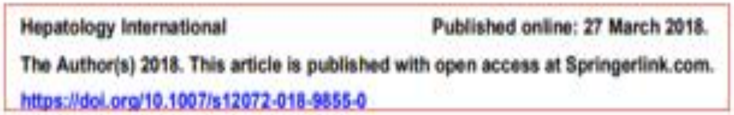
- **Portuguese and Spanish Translations of Therapeutic Recommendations**



Recomendações terapêuticas para a hemocromatose com o genótipo homozigoto *HFE* p.Cys282Tyr (C282Y/C282Y)



Recomendaciones terapéuticas en hemocromatosis con el genotipo homocigoto *HFE* p.Cys282Tyr (C282Y/C282Y)



Hepatology International

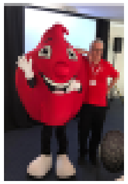
https://doi.org/10.1007/s12072-018-9855-0

- **2018:** 925 individuals registered as patient on the site.

- **Challenges:** more involvement of patients as members and with the actions of the group.

Haemochromatosis Australia

Inherited Iron overload disorder

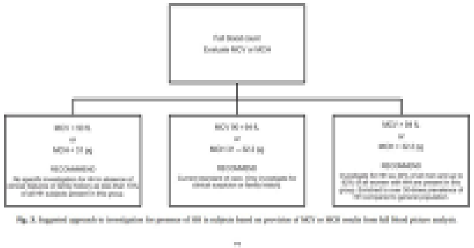


Researchers

- Biennial haemochromatosis conference
- Prof Olynyk's research
- NHMRC submission for screening

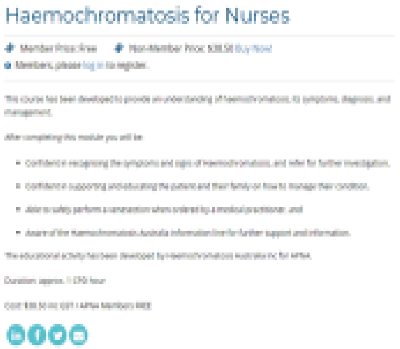
Blood Cells, Molecules and Diseases

Detection of HFE Haemochromatosis in the clinic and community using standard erythrocyte tests



Health professionals

- APNA module published online
- Haemochromatosis HealthPathways in 17 Primary Health networks around Australia
- Closer relationship with Australian Red Cross Blood Services – Red 25 group & challenge, presentations to ARCBS centre staff
- Clinical trials underway in several states
- Presence at health conferences including Blood 2018, APNA, The Australian Rural Health Conference, GPCE



Haemochromatosis for Nurses

Member Price: Free   Non-Member Price: $38.50 Buy Now!

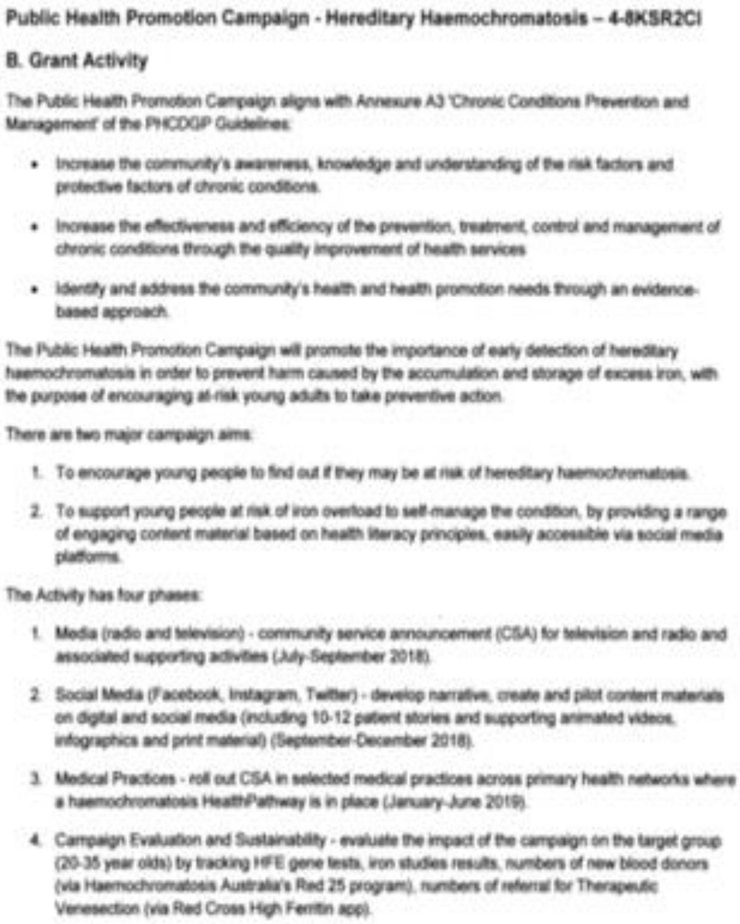
Members, please log in to register.

Challenges

- Inequities in access to treatment across the continent
- Capacity constraints of volunteer organisation
- Organising face to face patient information days now considering FB Live for specific topics

Haemochromatosis Australia
Inherited Iron overload disorder

Governments



Public Health Promotion Campaign - Hereditary Haemochromatosis – 4-8KSR2CI

B. Grant Activity

The Public Health Promotion Campaign aligns with Annexure A3 'Chronic Conditions Prevention and Management' of the PHCDGP Guidelines:

- Increase the community's awareness, knowledge and understanding of the risk factors and protective factors of chronic conditions.
- Increase the effectiveness and efficiency of the prevention, treatment, control and management of chronic conditions through the quality improvement of health services
- Identify and address the community's health and health promotion needs through an evidence-based approach.

The Public Health Promotion Campaign will promote the importance of early detection of hereditary haemochromatosis in order to prevent harm caused by the accumulation and storage of excess iron, with the purpose of encouraging at-risk young adults to take preventive action.

There are two major campaign aims:

1. To encourage young people to find out if they may be at risk of hereditary haemochromatosis.
2. To support young people at risk of iron overload to self-manage the condition, by providing a range of engaging content material based on health literacy principles, easily accessible via social media platforms.

The Activity has four phases:

1. Media (radio and television) - community service announcement (CSA) for television and radio and associated supporting activities (July-September 2018).
2. Social Media (Facebook, Instagram, Twitter) - develop narrative, create and pilot content materials on digital and social media (including 10-12 patient stories and supporting animated videos, infographics and print material) (September-December 2018).
3. Medical Practices - roll out CSA in selected medical practices across primary health networks where a haemochromatosis HealthPathway is in place (January-June 2019).
4. Campaign Evaluation and Sustainability - evaluate the impact of the campaign on the target group (20-35 year olds) by tracking HFE gene tests, iron studies results, numbers of new blood donors (via Haemochromatosis Australia's Red 25 program), numbers of referral for Therapeutic Venesection (via Red Cross High Ferritin app).

Communities

- ➢ Social media followers are growing
- ➢ Facebook followers appear to prefer simple, graphical content or stories they can relate to on a personal level - Facebook is almost like a support group
- ➢ Increase in social media following does not result in increasing membership or donations
- ➢ Campaign has helped us develop large number of resources for future use
- ➢ Built stronger connections to aligned organisations
- ➢ Established ongoing relationships with journalists
- ➢ 20-30% increase in website traffic during social media campaign

Canadian
HEMOCHROMATOSIS
SOCIETY
Société canadienne de l'hémochromatose

Focus on Raising Awareness
Multimedia and grassroot activities

Communities

- A 4 month multi-media campaign utilizing Facebook, Google and YouTube successfully combined awareness, information and direct actions which promoted the benefits of screening and early detection to targeted audiences in the provinces of British Columbia and Nova Scotia, including healthcare professionals and individuals with a Northern European and Celtic ancestry.
- **275,000+** unique individuals in our Facebook audience
- **Hundreds** of shares, comments and reactions gave strong indication that an interested and engaged audience was reached and that the campaign messages were spread to other provinces
- **14,800+** visits from Facebook to our Self-Assessment page on our website, with visitors spending an average of three minutes checking their risk for hemochromatosis.
- **10,000+** visitors from Facebook spent time reading five new case histories on our website, along with symptom and testing information.
- **27,000** visits came through to our website from Google search and display ads.
- **7,000** visits to our website were attributed to health professionals
- **300,000+** views of our 30 second videos on YouTube,
- Ottawa Information Session, using Facebook Live for the first time ever in CHS history to provide greater access for Facebook users wanting to learn more about hemochromatosis

Canadian HEMOCHROMATOSIS SOCIETY
Société canadienne de l'hémochromatose

Focus on Raising Awareness
Multimedia and grassroot activities

Governments

- Hemochromatosis on the Hill event on Parliament Hill with co-host Senator David Wells, promoting awareness amongst MPs, Senators and their constituents

Communities

- Ottawa Irons for Iron Golf Event, which helped to raise awareness and $11,530
- Awareness presentation to Rotary Club of Winnipeg West
- Radio interviews in Atlantic Canada and with campus-based stations
- Interview for Global News online article "What is the 'Celtic Curse?' Hemochromatosis Explained"
- Calgary Information Session with panel of 5 hemochromatosis sufferers

Health professionals

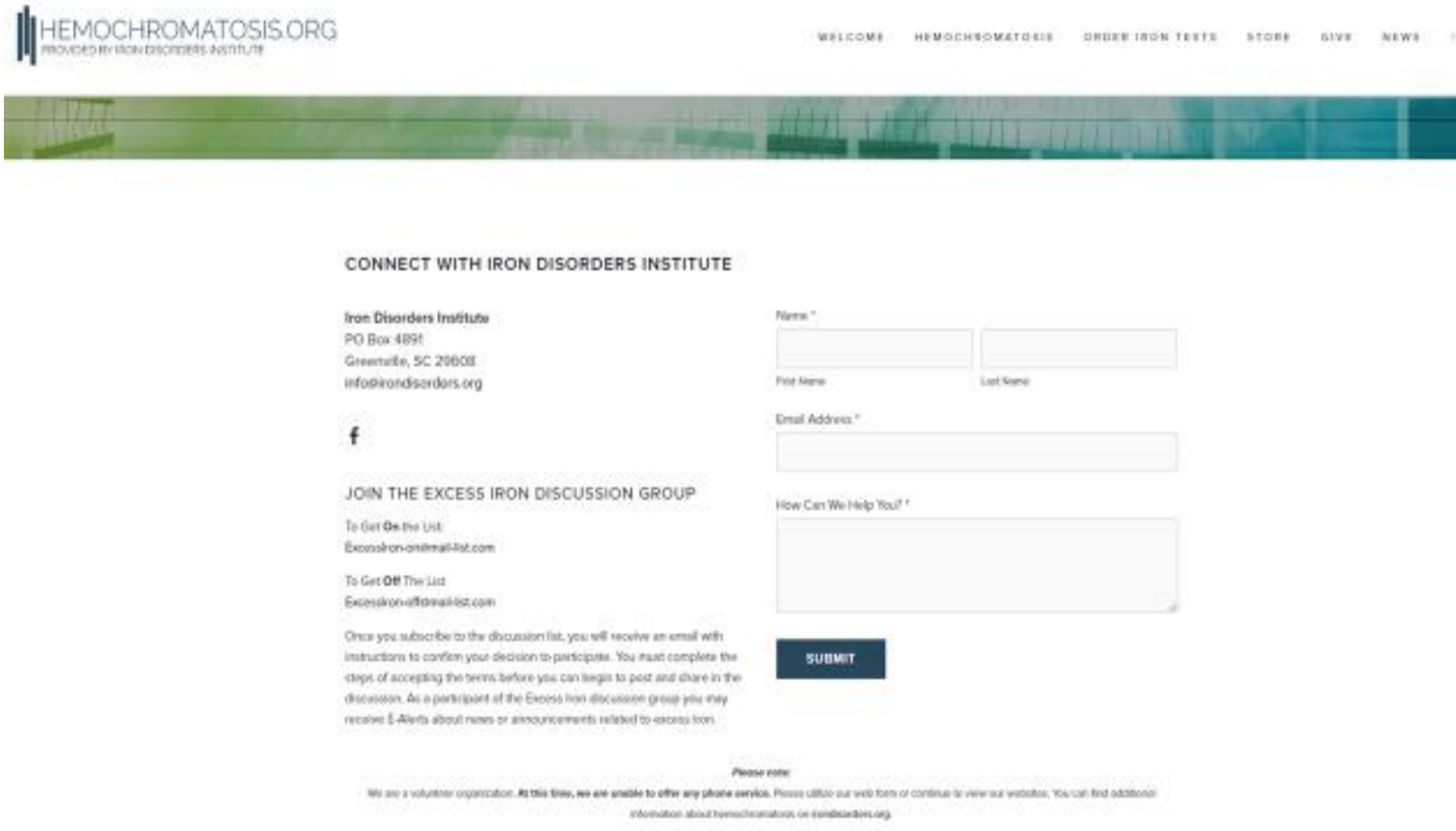
- Awareness and information booth at Ottawa Health and Wellness Expo
- Awareness at Canadian Blood Services blood donor clinic in Quispasmis, NB
- Awareness booth at the Family Medicine Forum in Toronto to connect with 3,500 attending family physicians

NZ
www.leukaemia.org.nz

- HI's newest member
- https://www.leukaemia.org.nz/information/about-blood-cancers/haemochromatosis

- Treatment managed by NZ Blood Service until maintenance reached when patient is referred back to their general practitioner
- https://www.nzblood.co.nz/clinical-information/transfusion-medicine/information-for-health-professionals/venesection-and-haemochromatosis

IRON DISORDERS INSTITUTE
Advancing cures for Iron-Out-of-Balance™



CONNECT WITH IRON DISORDERS INSTITUTE

Iron Disorders Institute
PO Box 4891
Greenville, SC 29608
info@irondisorders.org

JOIN THE EXCESS IRON DISCUSSION GROUP

To Get **On** the List
ExcessIron-on@mail-list.com

To Get **Off** The List
ExcessIron-off@mail-list.com

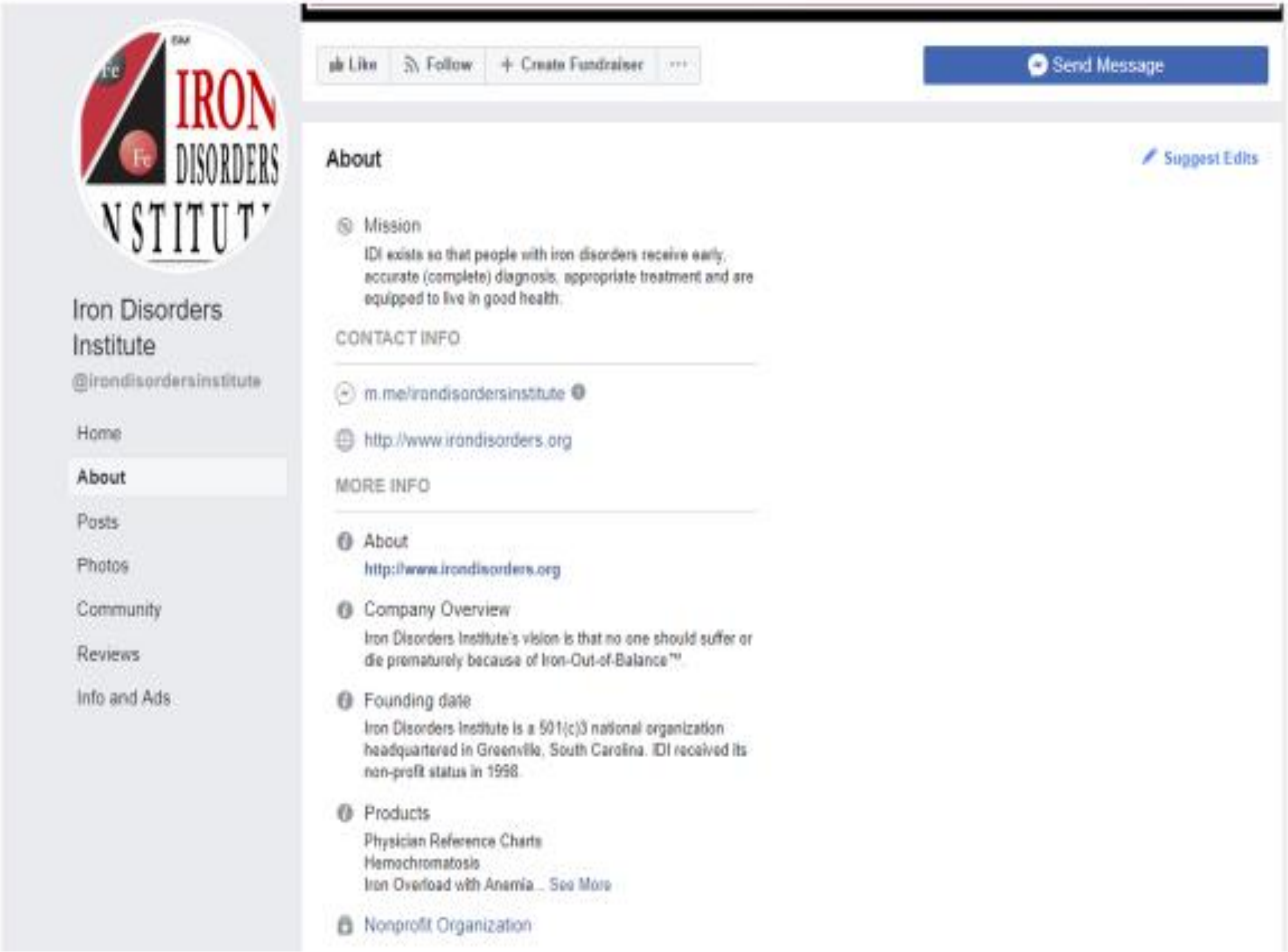
Once you subscribe to the discussion list, you will receive an email with instructions to confirm your decision to participate. You must complete the steps of accepting the terms before you can begin to post and share in the discussion. As a participant of the Excess Iron discussion group you may receive E-Alerts about news or announcements related to excess iron.

Please note:

We are a volunteer organization. **At this time, we are unable to offer any phone service.** Please utilize our web form or continue to view our websites. You can find additional information about hemochromatosis on **irondisorders.org**.

IRON DISORDERS INSTITUTE

Advancing care for Iron-Out-of-Balance™



Iron Disorders Institute

@irondisordersinstitute

About

Mission

IDI exists so that people with iron disorders receive early, accurate (complete) diagnosis, appropriate treatment and are equipped to live in good health.

CONTACT INFO

m.me/irondisordersinstitute

http://www.irondisorders.org

MORE INFO

About

http://www.irondisorders.org

Company Overview

Iron Disorders Institute's vision is that no one should suffer or die prematurely because of Iron-Out-of-Balance™.

Founding date

Iron Disorders Institute is a 501(c)3 national organization headquartered in Greenville, South Carolina. IDI received its non-profit status in 1998.

Products

Physician Reference Charts
Hemochromatosis
Iron Overload with Anemia... See More

Nonprofit Organization

A worldwide Network so active!