

International Federation of Human Genetics Societies (IFHGS) and European Reference Networks (ERN)

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International Federation of



Human Genetics Societies

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International Federation of Human Genetics Societies

Founded in 1996, an international collaboration of professional human genetics societies, the IFHGS ensures that an International Congress of Human Genetics will take place every five years and that a credible forum for the sharing of ideas about human genetics is provided.

Plan to attend...

ICHG 2016

April 3-7 2016

Kyoto International Conference Center
Japan

Organised on behalf of the International Federation of Human
Genetics
www.ichg2016.org

Next ICHG in Cape Town in 2021

Why IFHGS?

- The International Federation of Human Genetics Societies was founded in 1996
- Complicated membership: Full members, Corresponding members, Affiliated members and Preliminary members

- The American Society of Human Genetics (ASHG)
- Asia-Pacific Society of Human Genetics (APSHG)
- East Asian Union of Human Genetics Societies (EAUHGS)
- The European Society of Human Genetics (ESHG)
- The Human Genetics Society of Australasia (HGSA)
- Latin American Network of Human Genetics Societies
- African Society of Human Genetics (AfSHG)

Corresponding members

- The webpage lists 48 corresponding members
- The corresponding members can suggest items to the Agenda (if another member supports the suggestions) and they also can endorse possible statements, guidelines etc

The mission in the bylaws

"The purpose of The International Federation of Human Genetics Societies (the Federation) is to **provide a forum** for organized groups dedicated to all aspects of human genetics, including research, clinical practice, and professional and lay education. The Federation will **enable communication** between its member groups and **encourage interaction** between workers in genetics fields and in related sciences and will make itself available **to promote meetings and publications** and other forums which support human genetics research and practice."

So far, the main action has been supporting the
ICHG Conferences.

Could IFHGS do something more?

- Promote genetics in countries with the biggest difficulties relating to access to medical genetic services and to education in medical and human genetics?
 - More fellowships to international congresses?
 - Free video courses?
 - Volunteers to go somewhere to teach/supervise clinics?
 - Affordable student/researcher exchange?

Could IFHGS do something more?

- Ensure that genetics is performed in an ethically sound way?
 - React to misuse of genetics like genetic discrimination?
 - React to inappropriate advertising of genetic services, including DTC?
 - React to possible inhuman experiments?

ESHG and IFHGS

- ESHG has the presidency of IFHGS for years 2015-2017
- ESHG Board was very positive to "doing more" in IFHGS"
 - Three Board members volunteered to think about ideas on how to promote global genetics
 - Feliciano Ramos
 - Zeynep Tümer
 - Angus Clarce



European Reference Networks (ERNs)

- ERNs are created to improve treatment of Rare Diseases and help to implement Cross Border Directive
 - National (officially designated) Centres of Expertise for (groups) of rare diseases
 - For instance CE of Rare Dermatological Diseases in Finland
 - These will join to form ERNs
 - For instance ERN for Rare Dermatological Diseases, coordinated by XX CE

ERNs

- These are EU structures
- The aim is to guarantee the quality of treatment for RD patients relating to cross borders treatment.
- The ERNs will write best practice guidelines, collect cohorts of RD patients, arrange training etc
- It is advisable, that the doctors treating RD in the non-EU countries follow what is happening in the ERNs to benefit from the accumulation of expertise in these networks.

