

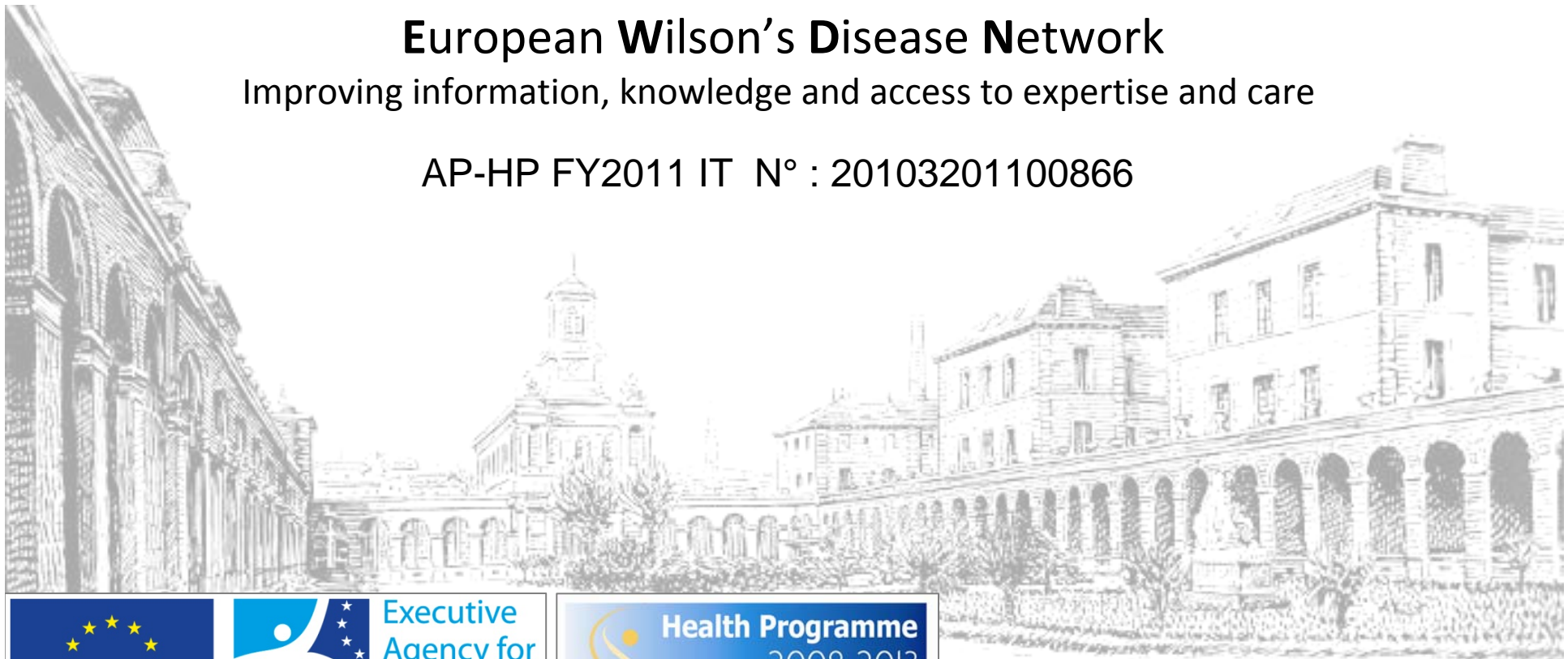
Health Program 2008-2013
Operating Grant 2010



European **Wilson's Disease Network**

Improving information, knowledge and access to expertise and care

AP-HP FY2011 IT N° : 20103201100866



Wilson's disease: a good example for an ERN

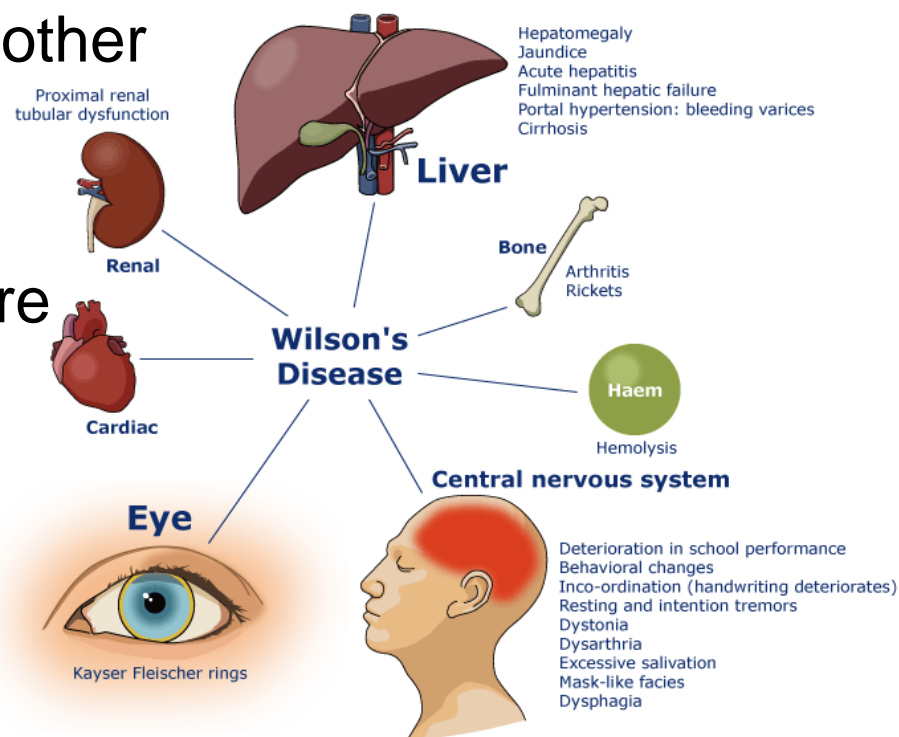
- Orpha905
- An autosomal disorder of copper metabolism
- Presentation is variable with regard to

- Type: hepatic, neurological, other

- Age: 2 to 70s

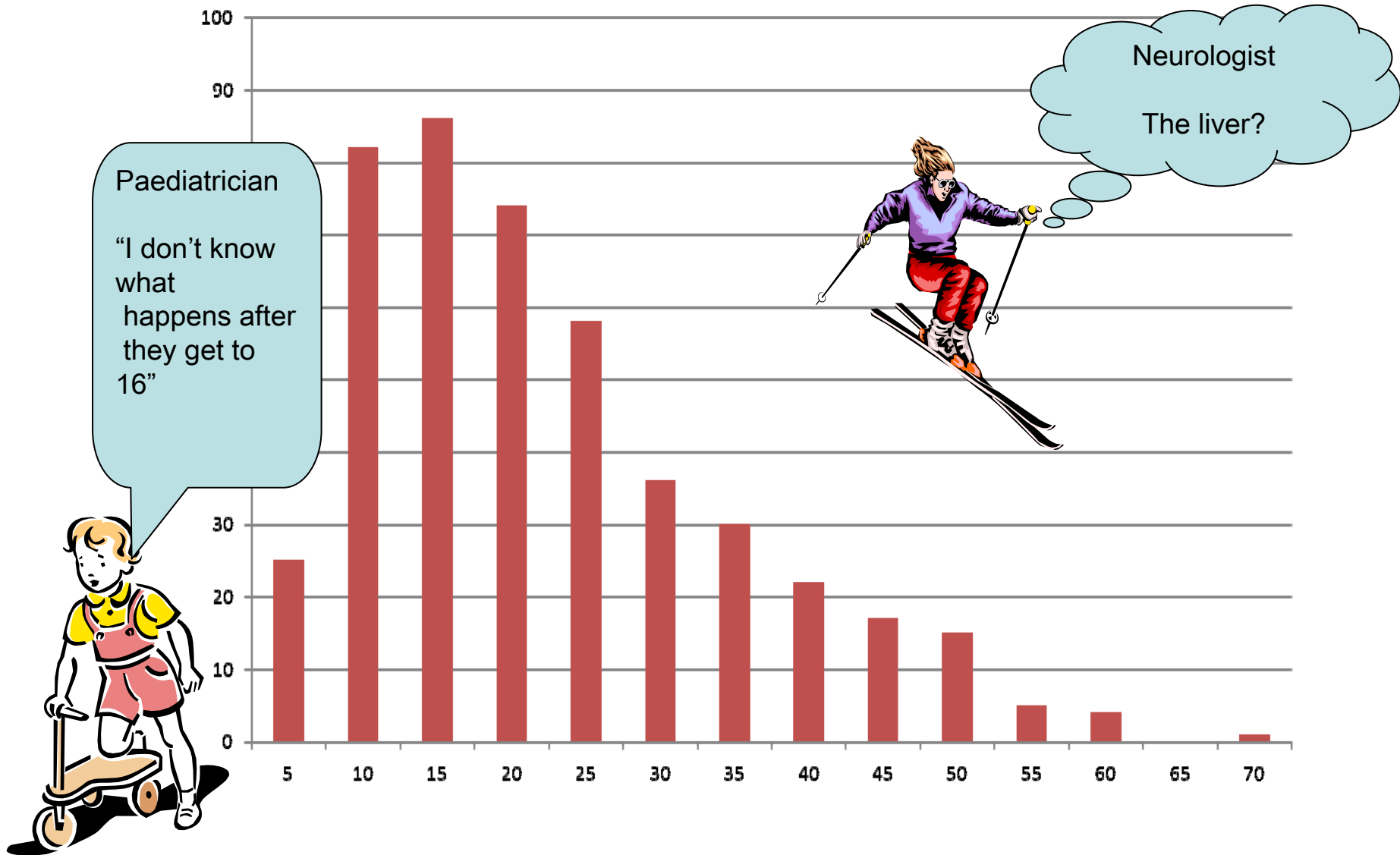
- Severity: eg mild abnormality to fatal liver failure

- Controversies about best treatment
 - Penicillamine, trientine, zinc, or thiomolybdate
- Population screening not yet available



Wilson's disease: a good example for an ERN

2005-7 patients' age distribution



EuroWilson history

ESPGHAN 2001

WORKSHOP

Treatment of WD is variable, uncertain,
& lacks evidence base

ESPGHAN 2002

WORKING PARTY

Can we rationalise and improve treatment
of WD?

March 2003

FP6 APPLICATION

Wilson Disease:
Creating a European Clinical Database
and designing randomised controlled
clinical trials.

June 2004

EUROWILSON

Methods, difficulties, results, spin-offs

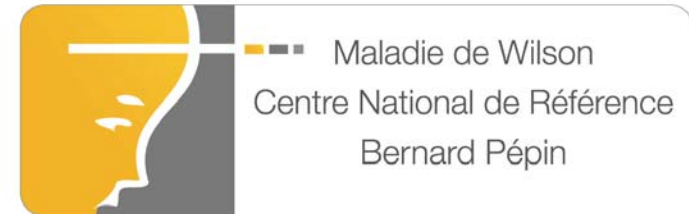
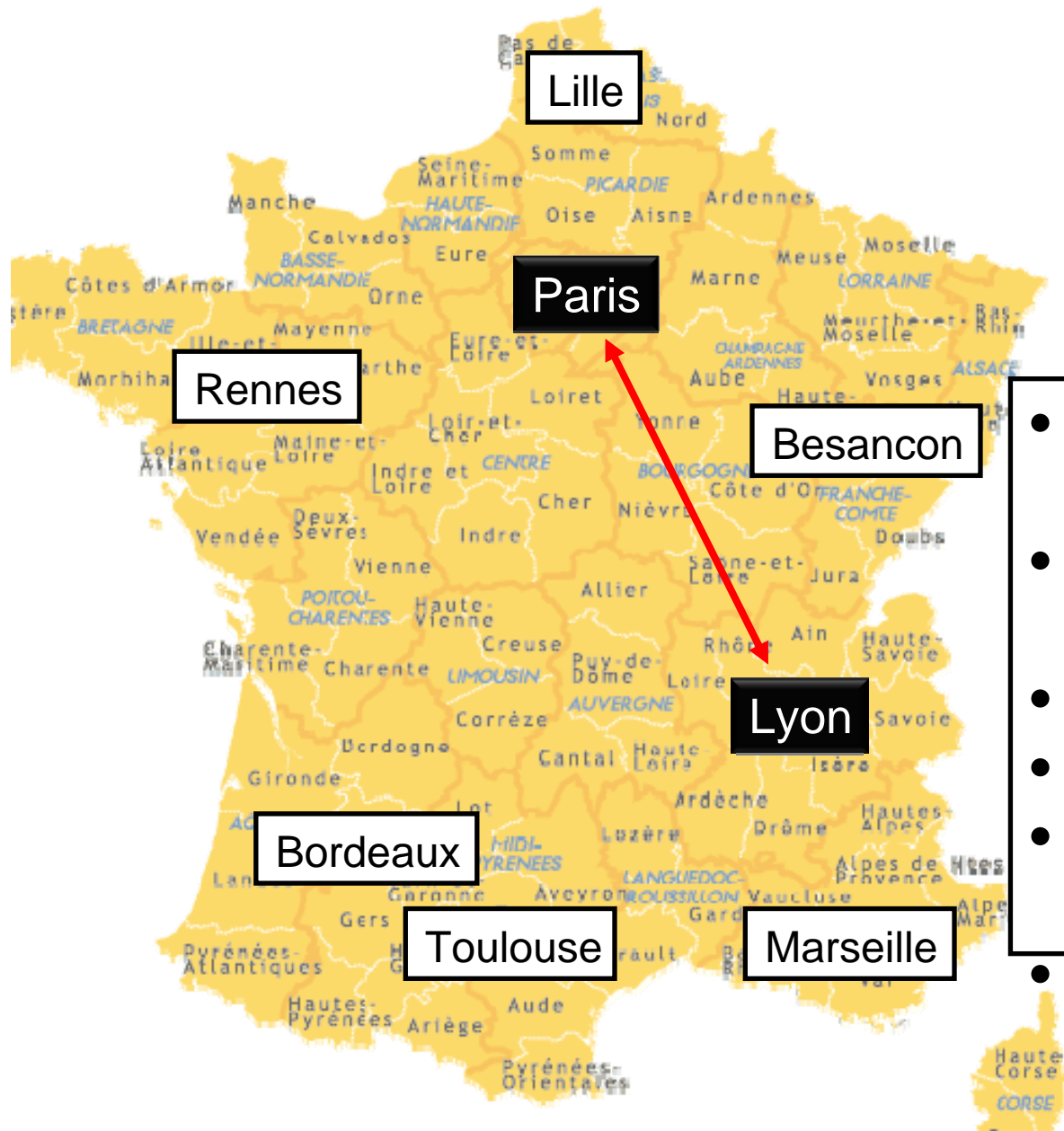
Oct 2008

2011

DG Sanco operating grant

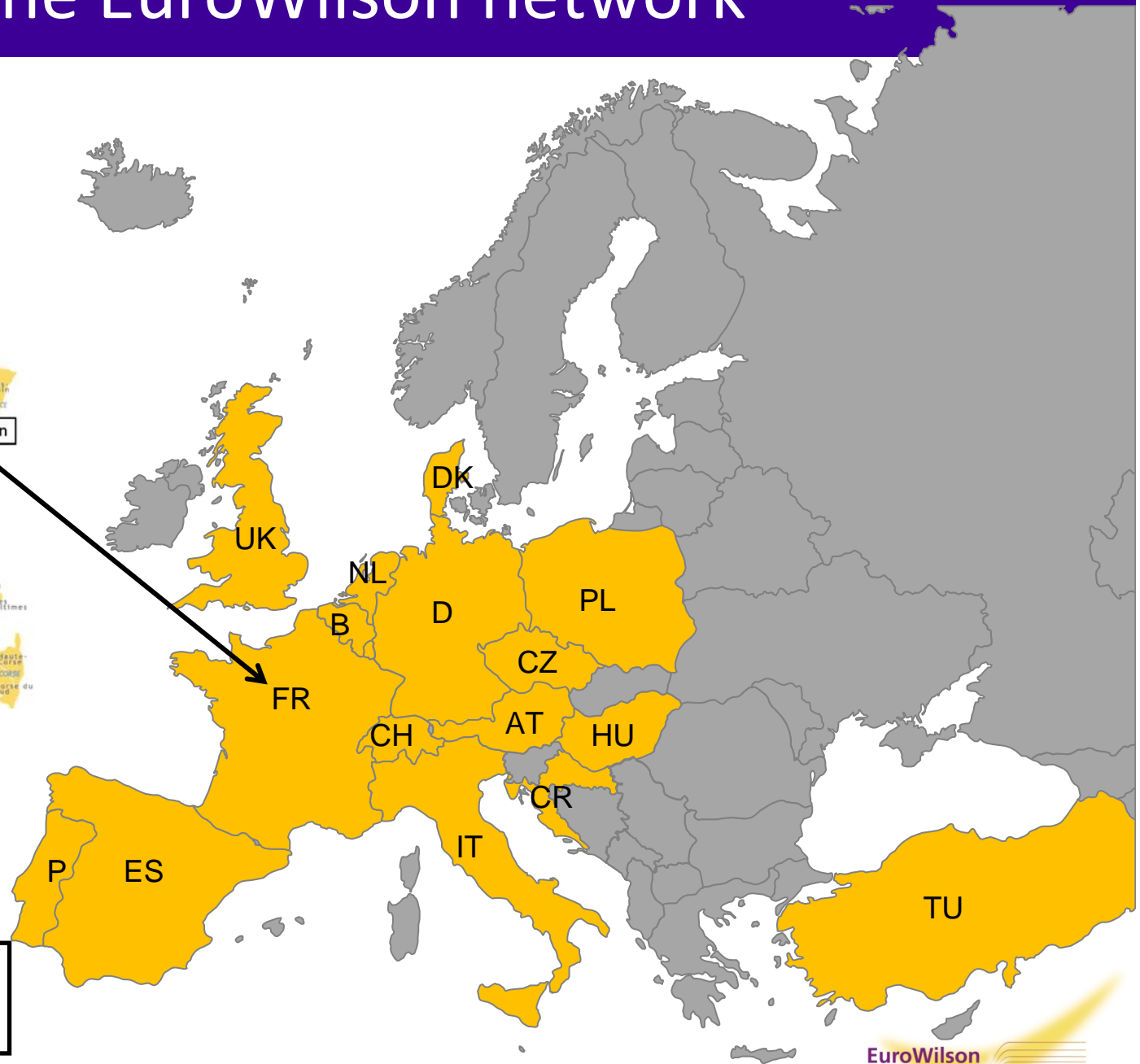
Multi-stakeholder / multi-disciplinary
network of experts and registry

EW coordinating centre in national system



- Formally designated centres of expertise
- Multi-disciplinary approach
- Telemedicine
- Meetings
- Sharing documents and procedures
- French registry

The EuroWilson network



60 Centres
16 European countries

Aim and objectives of the EW network

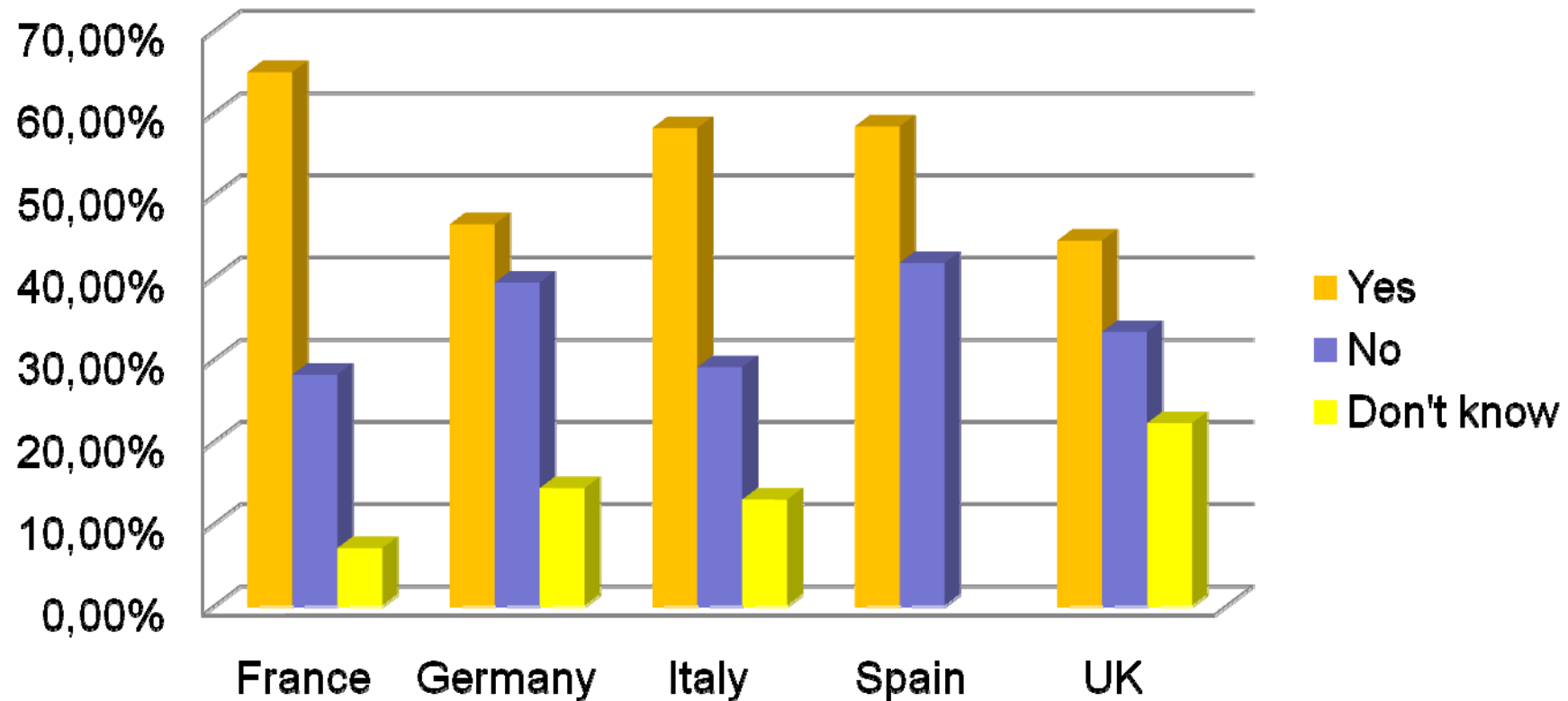
The general objective of EW is to develop the EU WD multi-disciplinary network and its registry and ultimately to provide EU patients and their families with up-to-date information, optimised management and equal access to expert advice, diagnosis and care.

1. Improve information and services to patients
2. Increase knowledge and exchange of experience of WD
3. Improve access and quality of biochemical and genetic testing

Variation between MS in access to information and care

Results of on-going survey to WD patients in 5 countries

Upon receiving your diagnosis, were you provided with adequate sources of information to understand your disease?



Nb of replies

62

70

39

13

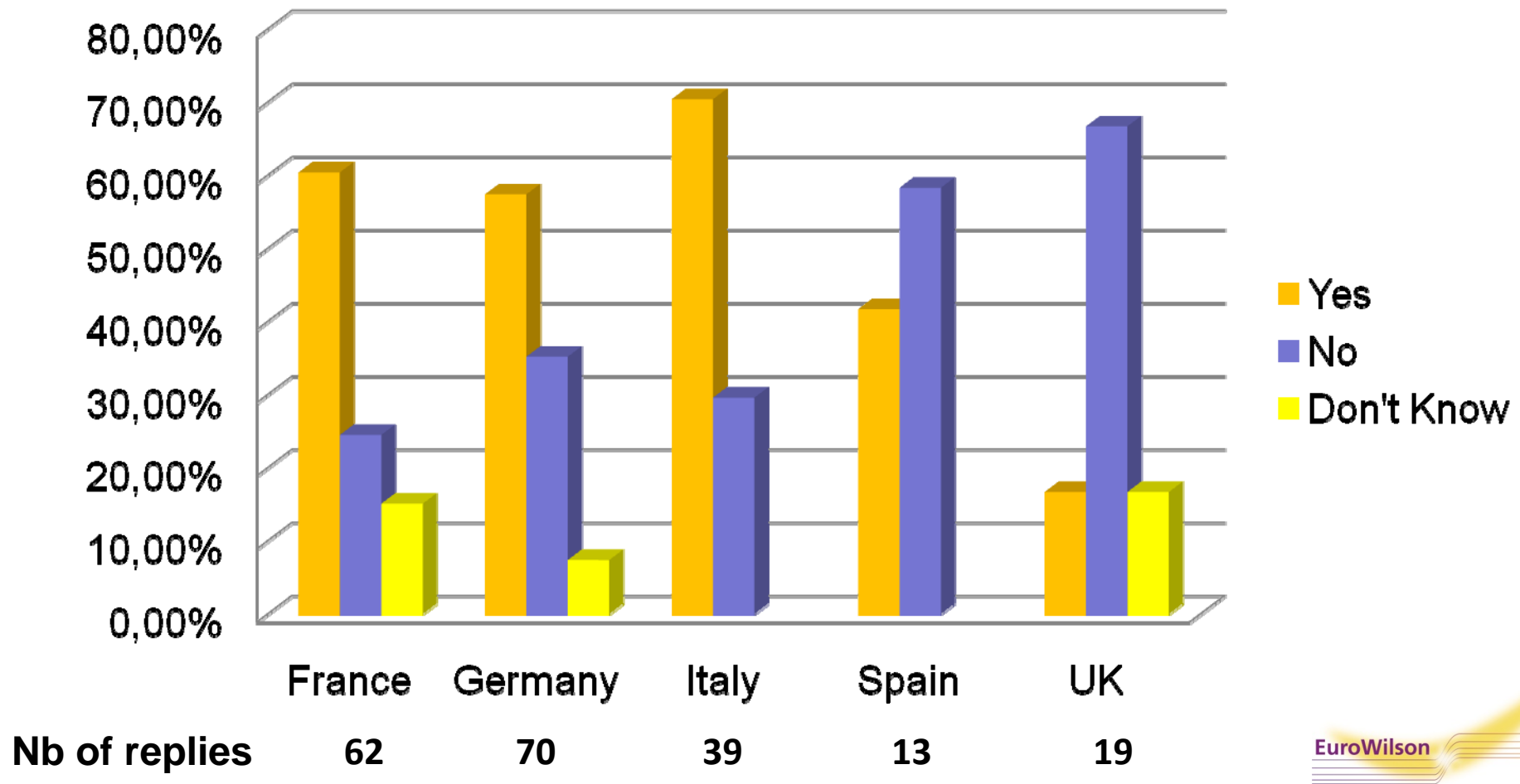
19



Variation between MS in access to information and care

Results of on-going survey to WD patients in 5 countries

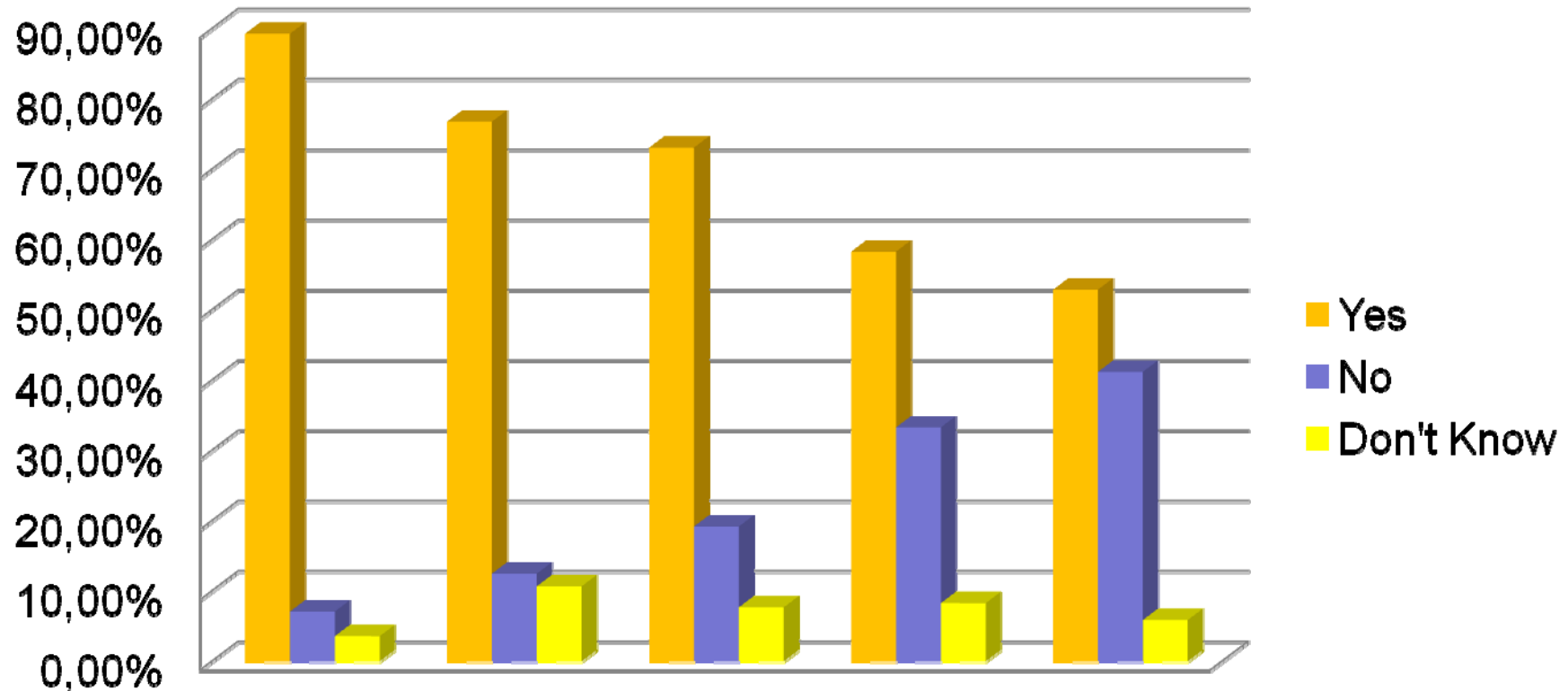
Have you or your family been offered genetic counseling?



Variation between MS in access to information and care

Results of on-going survey to WD patients in 5 countries

Do you have access to a national expert or specialised centre for this disease?



Nb of replies

62

70



39

13

19



Wilson's disease for younger people

Print  Send to a friend 

0 1 2 3 4 **5** 6 7 8 9 10 11 12 13 14 15 16 17 18 19

5. Am I different from everybody else ?



We are all different. Some of us are tall and some short, some clever at school work, and some clever at other things. A person with Wilson's disease just has a medical problem needing treatment.



Download booklet

- 0. Wilson's disease for younger people
- 1. Why has it got such a funny name?
- 2. What is Wilson's disease?
- 3. How did I get Wilson's disease?
- 4. Is it catching?
- 5. Am I different from everybody else?**
- 6. What does my liver do?
- 7. If my liver gets worse, will it hurt?
- 8. Why do some people with Wilson's disease eyes go yellow?
- 9. Why do I have to keep taking medicines?
- 10. How long will I have to keep on

en if I take my
y?
en if I stop taking
e doctor look at
cial light?
people with
ve a tremor or
doctor look at my
doctor keep doing
...?

- 18. Do other people need to know?
- 19. Do my friends need to know?



Wilson's disease for younger people

Wilson's disease for patients and families

www.eurowilson.org

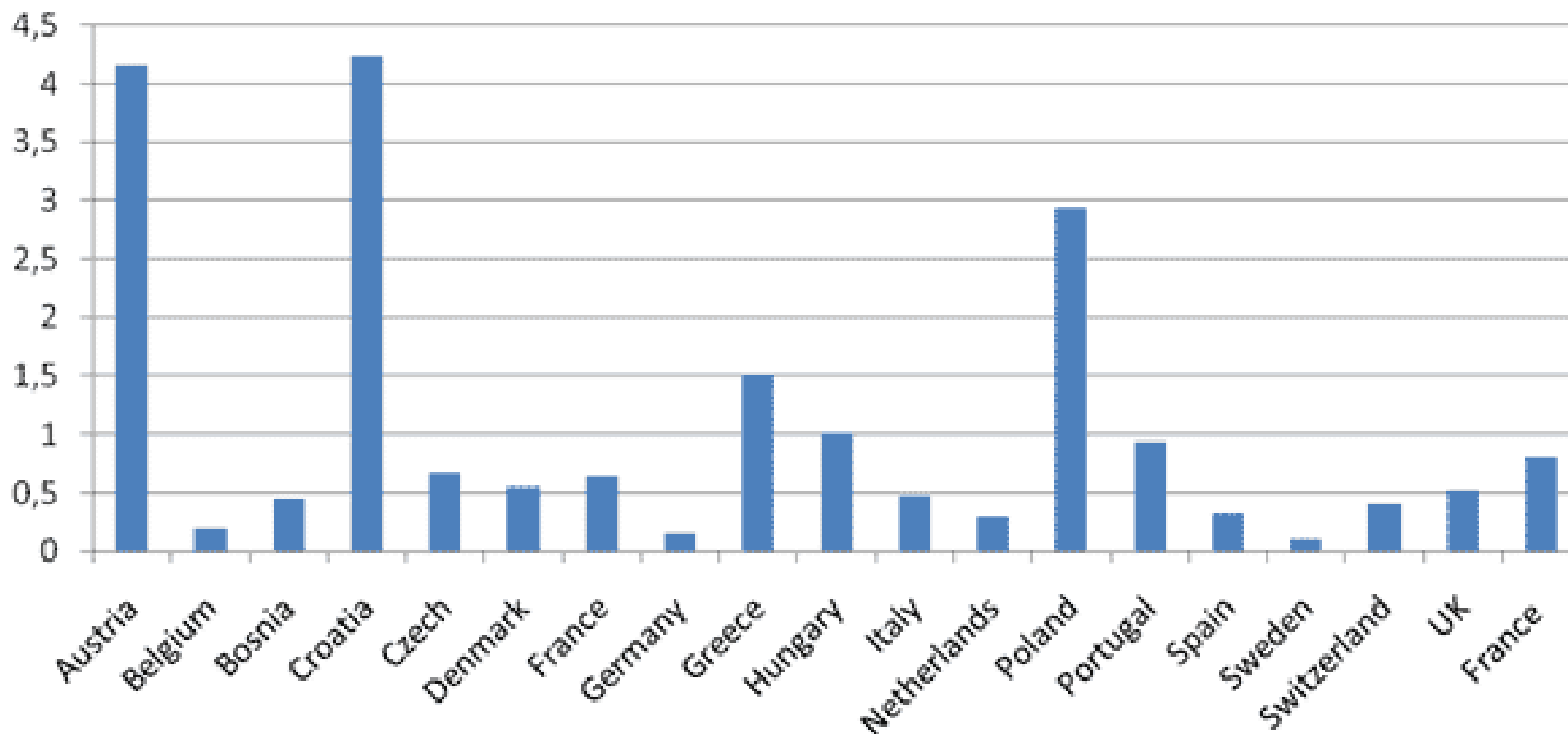
- Recommendations, for example, dietary
- Network of patient organisations

Improving information and services to patients

- List of centres of expertise on the website
- Recommendations that labs diagnosing WD attach information about EuroWilson to the treating clinician
- Network meetings to support centres and share knowledge and experience
- Platform for telemedicine

Increase knowledge: follow-up of registry cohort

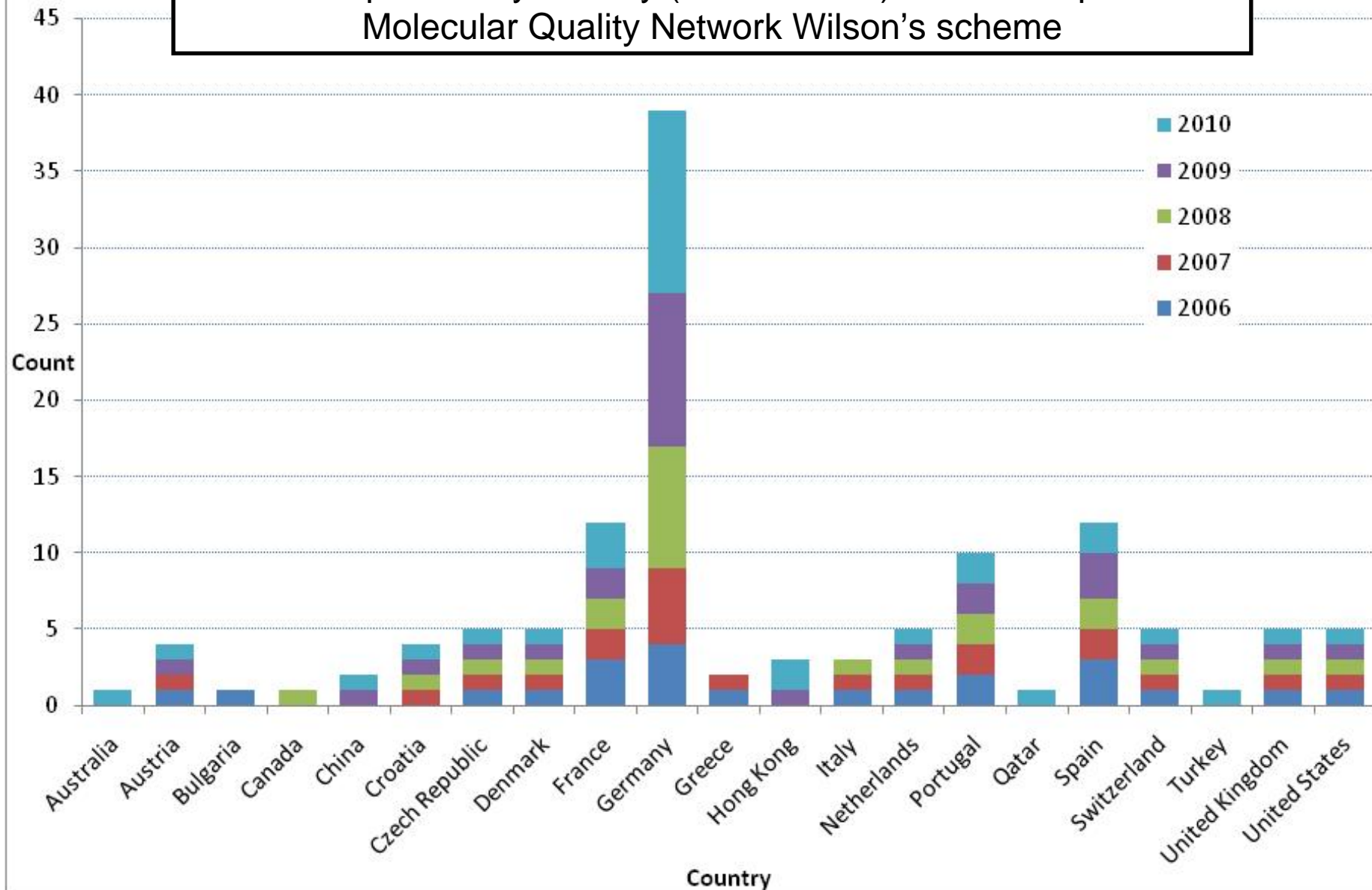
Average incidence/million population



Source: EuroWilson registry

Ensuring quality of diagnostic testing: EMQN scheme

Participations by country (2006 – 2010) to the European Molecular Quality Network Wilson's scheme



The future

- Continue to exchange best practice, guidelines, recommendations, telemedicine
- Long term funding of EuroWilson
- Education → earlier diagnosis
- Therapeutic development application to the 7FP for RCT
- Basic research
 - Modifier genes
 - Disease mechanisms
- Generalisable lessons