www.eurordis.org

Evaluating health information on the Internet

EURORDIS Online Training

David OZIEL
EURORDIS

Part 1
A complex definition for quality

- **The definition of the term**
- **The specificity of health information**
- **The different actors**

The definition of quality

- Content
- Original documents
- Up-to-date information

- Website organization
- Design
- Accessibility

- Search Engine Optimization
- Transparency
- ...

- Quality of a website / Quality of an information

The specificity of Internet health information

- **Internet unregulated**
- **Different levels of information**
- **Sensitivity of health information**

Different actors

- **Websites**
- **Search engines**
- **Internet users**

Initiatives for a better quality

- **Catalogues**
  - Information selected, organized, updated
  - MedlinePlus (National Library of Medicine)

- **Guidelines**
  - Quality criteria
  - Trust it or Trash it

- **Quality labels**
  - Health On the Net (HON)

Part 2
HONCode (from Health On the Net)

Quality labels

- **+ 100** rating tools
  - **Internet Health Coalition**
  - **Discern**
  - **Medcertain**
  - **Netscoring**
  - **HON**
  - **...**

HONCode

- **Health On the Net**
  - Swiss foundation
  - 1996

- **8 000 health websites**

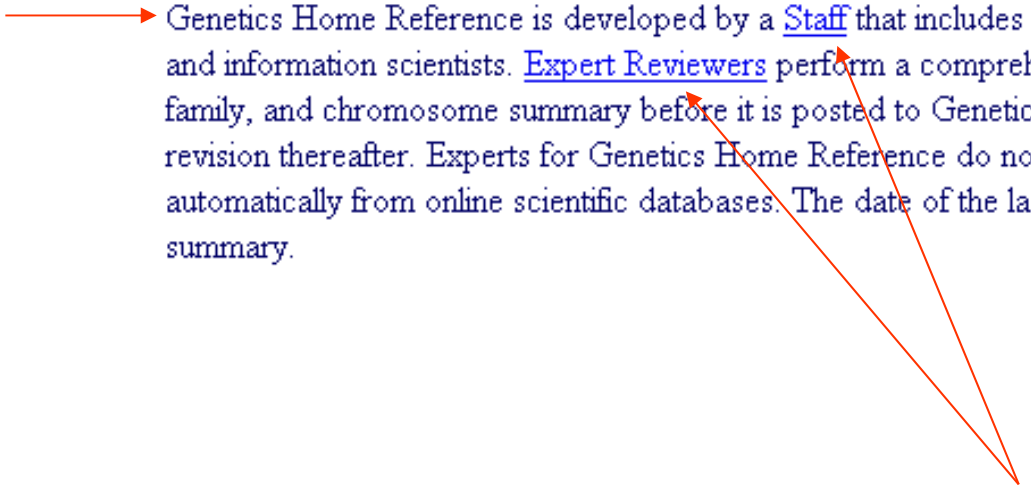
- **Eight principles**

Authority

Indicate the qualifications of the authors

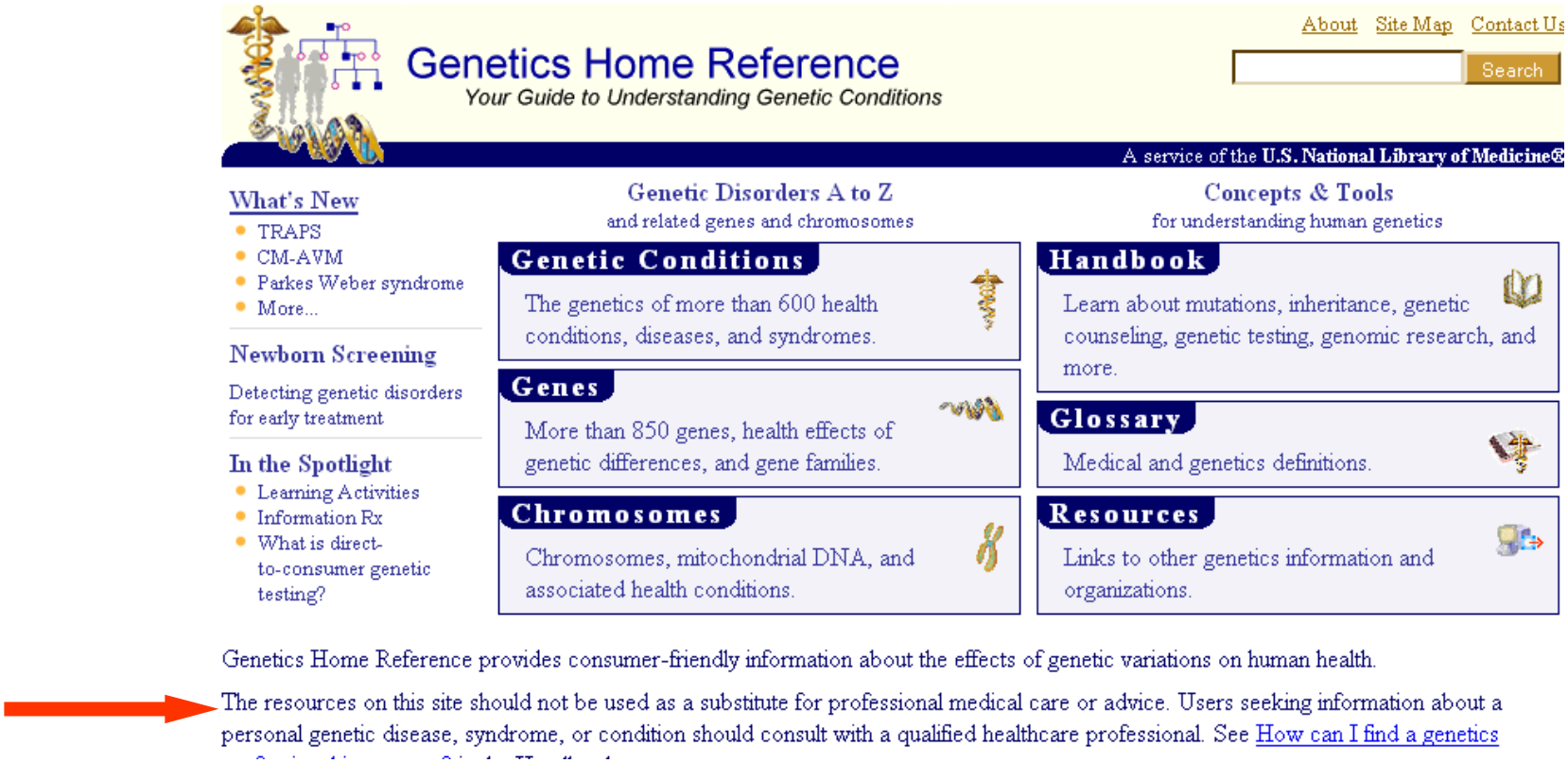
Who develops and reviews the content on Genetics Home Reference?

Genetics Home Reference is developed by a Staff that includes genetic counselors, biologists, and computer and information scientists. Expert Reviewers perform a comprehensive review of each condition, gene, gene family, and chromosome summary before it is posted to Genetics Home Reference, and with each substantial revision thereafter. Experts for Genetics Home Reference do not review gene information that was extracted automatically from online scientific databases. The date of the last comprehensive review is noted in each summary.



Complementarity

Information should support, not replace, the doctor-patient relationship

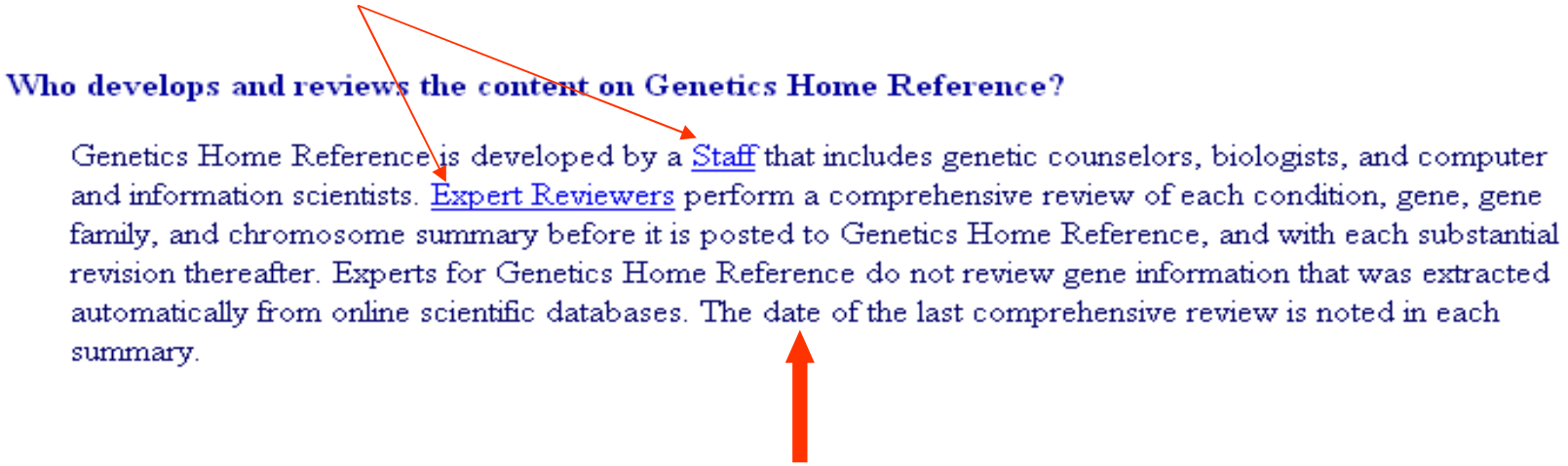


Privacy

Respect the privacy and confidentiality of personal data submitted to the site by the visitor

Attribution

Cite the source(s) of published information and its date

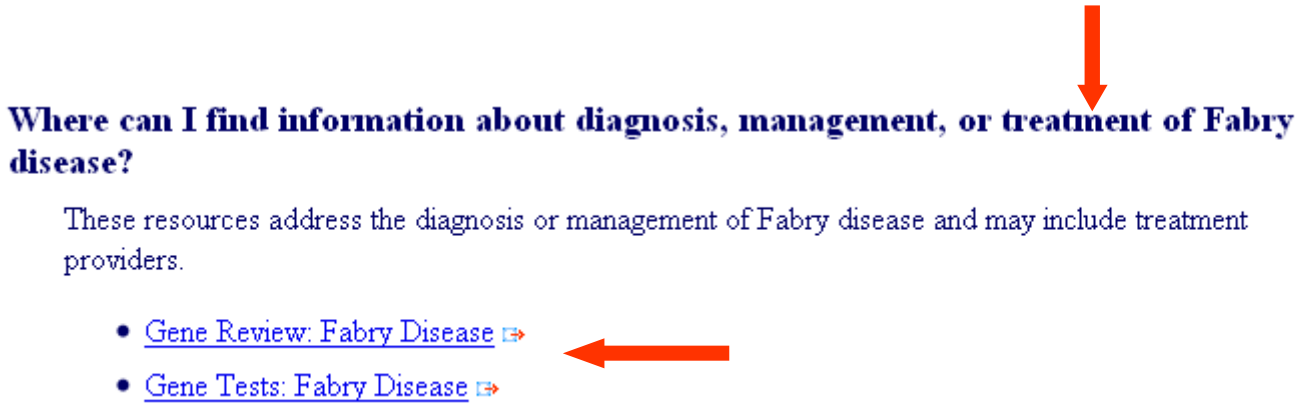


Who develops and reviews the content on Genetics Home Reference?

Genetics Home Reference is developed by a Staff that includes genetic counselors, biologists, and computer and information scientists. Expert Reviewers perform a comprehensive review of each condition, gene, gene family, and chromosome summary before it is posted to Genetics Home Reference, and with each substantial revision thereafter. Experts for Genetics Home Reference do not review gene information that was extracted automatically from online scientific databases. The date of the last comprehensive review is noted in each summary.

Justifiability

Any information on a specific treatment will be supported by the source of information



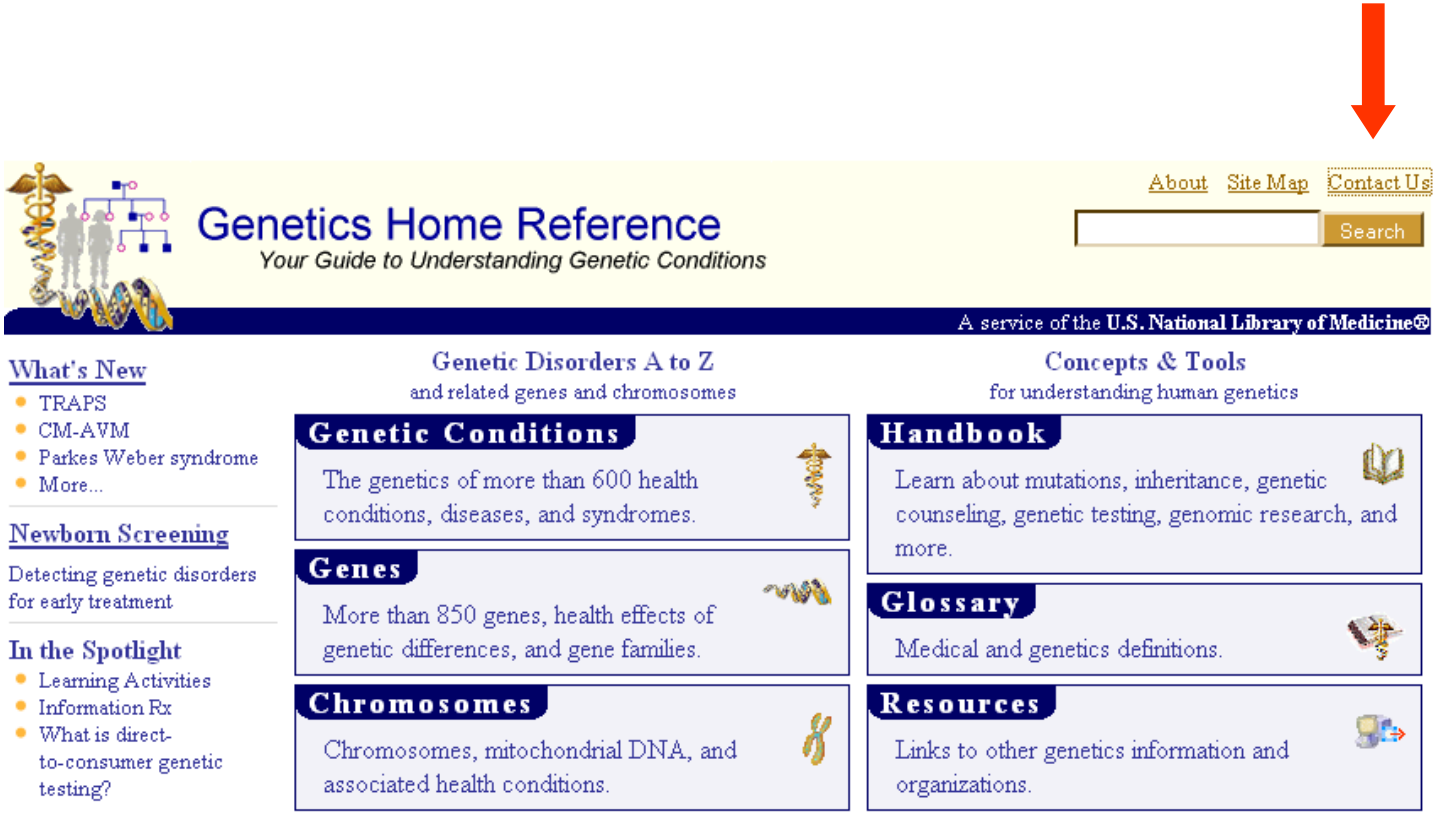
Where can I find information about diagnosis, management, or treatment of Fabry disease?

These resources address the diagnosis or management of Fabry disease and may include treatment providers.

- Gene Review: Fabry Disease
- Gene Tests: Fabry Disease

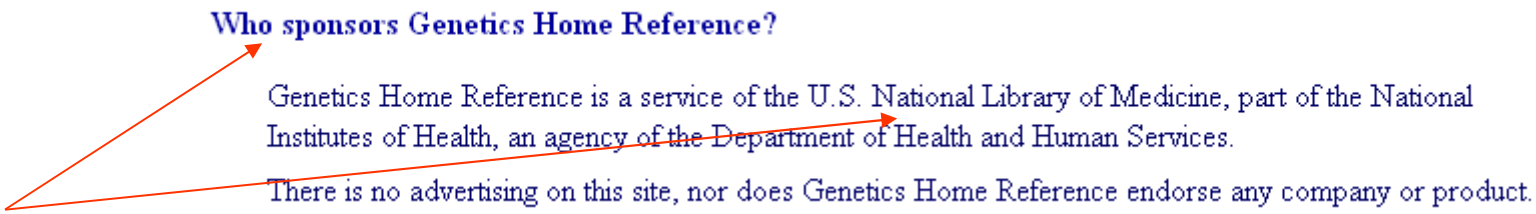
Transparency

Possibility to contact the webmaster for more complete information



Financial disclosure

Provide details on funding



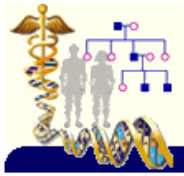
Advertising policy

Clearly distinguish advertising from editorial content

Who sponsors Genetics Home Reference?

Genetics Home Reference is a service of the U.S. National Library of Medicine, part of the National Institutes of Health, an agency of the Department of Health and Human Services.

There is no advertising on this site, nor does Genetics Home Reference endorse any company or product.



Genetics Home Reference

Your Guide to Understanding Genetic Conditions

What's New

- TRAPS
- CM-AVM
- Parkes Weber syndrome
- More...

Newborn Screening

Detecting genetic disorders for early treatment

In the Spotlight

- Learning Activities
- Information Rx
- What is direct-to-consumer genetic testing?

Genetic Disorders A to Z

and related genes and chromosomes

Genetic Conditions

The genetics of more than 600 health conditions, diseases, and syndromes.

Genes

More than 850 genes, health effects of genetic differences, and gene families.

Chromosomes

Chromosomes, mitochondrial DNA, and associated health conditions.

Concepts & Tools

for understanding human genetics

Learn about mutations, inheritance, genetic counseling, genetic testing, genomic research, and more.

Glossary

Medical and genetics definitions.

Resources

Links to other genetics information and organizations.

Genetics Home Reference provides consumer-friendly information about the effects of genetic variations on human health.

The resources on this site should not be used as a substitute for professional medical care or advice. Users seeking information about a personal genetic disease, syndrome, or condition should consult with a qualified healthcare professional. See How can I find a genetics professional in my area? in the Handbook.

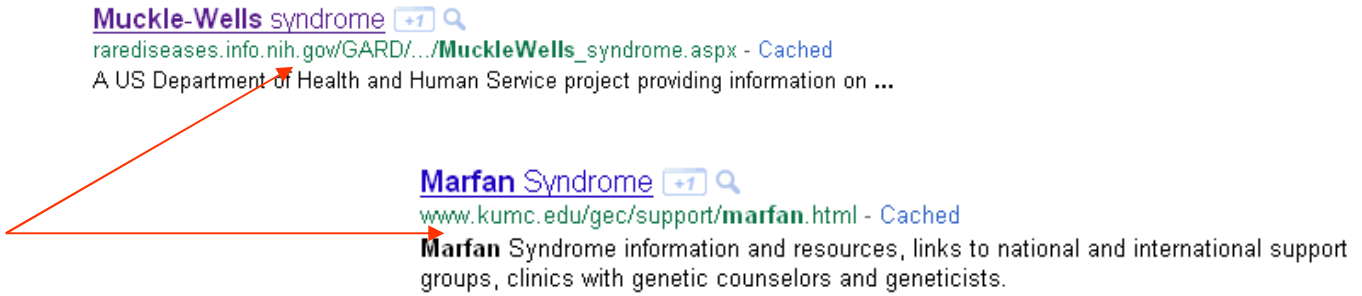
Published: August 8, 2011

Limitations of HONCode

- **Content not evaluated**
- **Ever-changing electronic documents**
- **Quality seals *vs* user's critical judgment**
  - Educated consumers
  - A set of quality criteria

Part 3
Some quality guidelines for Internet health information

Who runs the website ?



Who pays for the website ?

EURORDIS IS GRATEFUL FOR THE FINANCIAL SUPPORT OF :

AFM

Executive Agency for Health and Consumers

LEEM les entreprises du médicament

geneSkin

a website dedicated to rare genetic skin diseases

Funding

The Geneskin project and this website are funded by the European Commission (DG Research - http://www.cordis.europa.eu.int - grant No LSHM-CT-2005-512117)

Drug Information Online Drugs.com

enter a

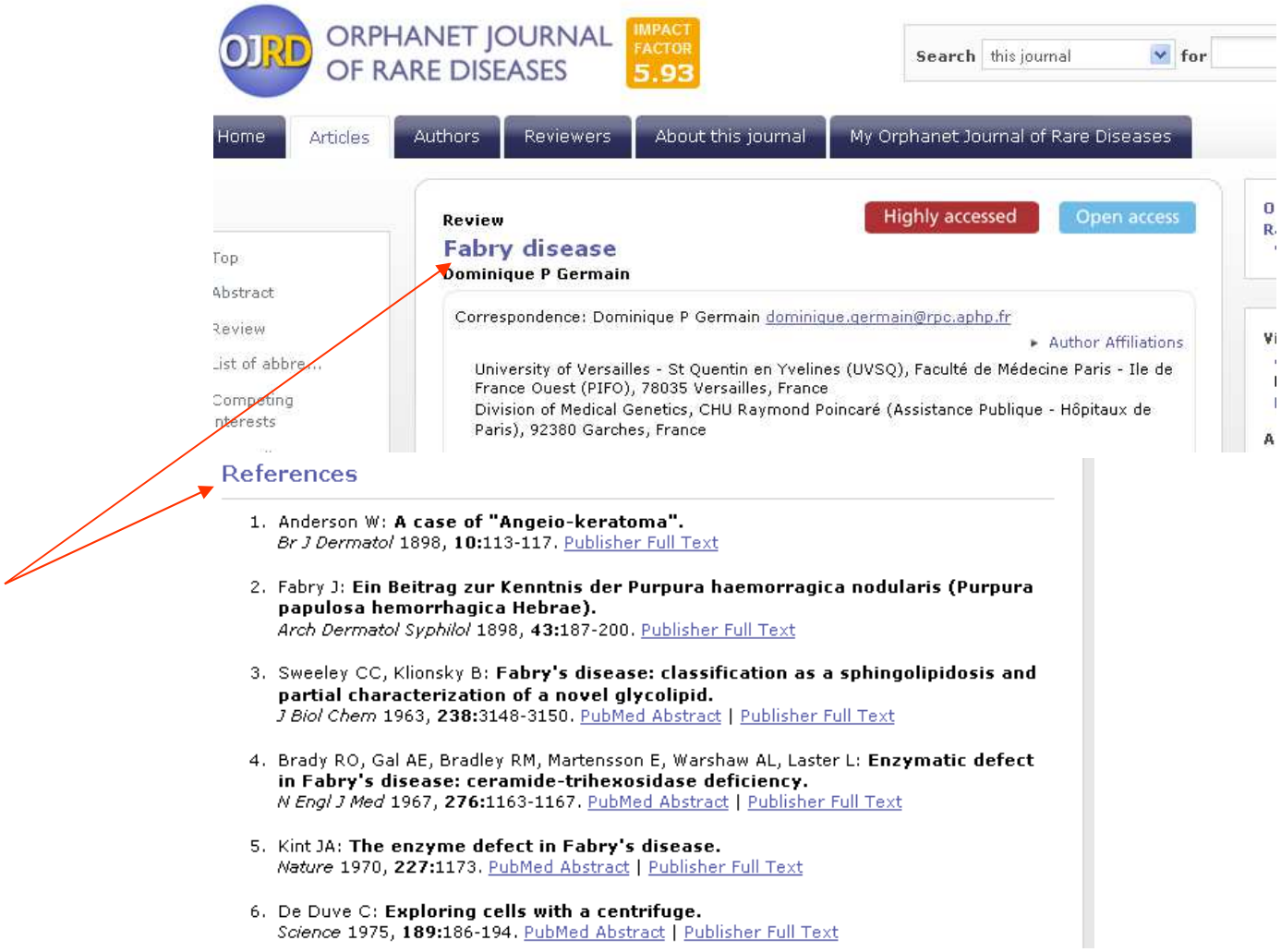
Browse all medica

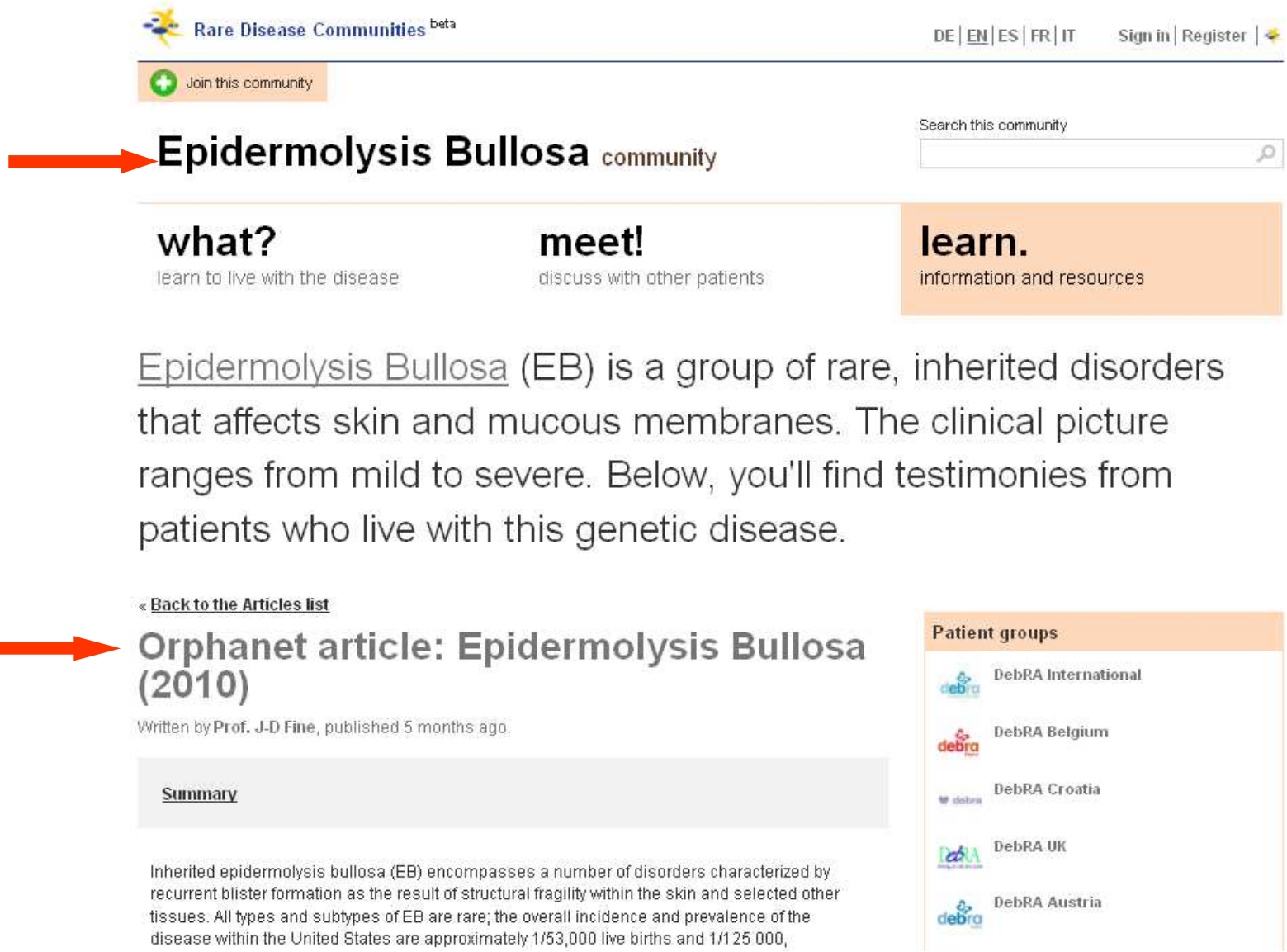
Drugs A to Z | Pill Identifier | Interactions Ch

Drugs by Condition | Side Effects | Dosage | Pregnancy | New Drugs

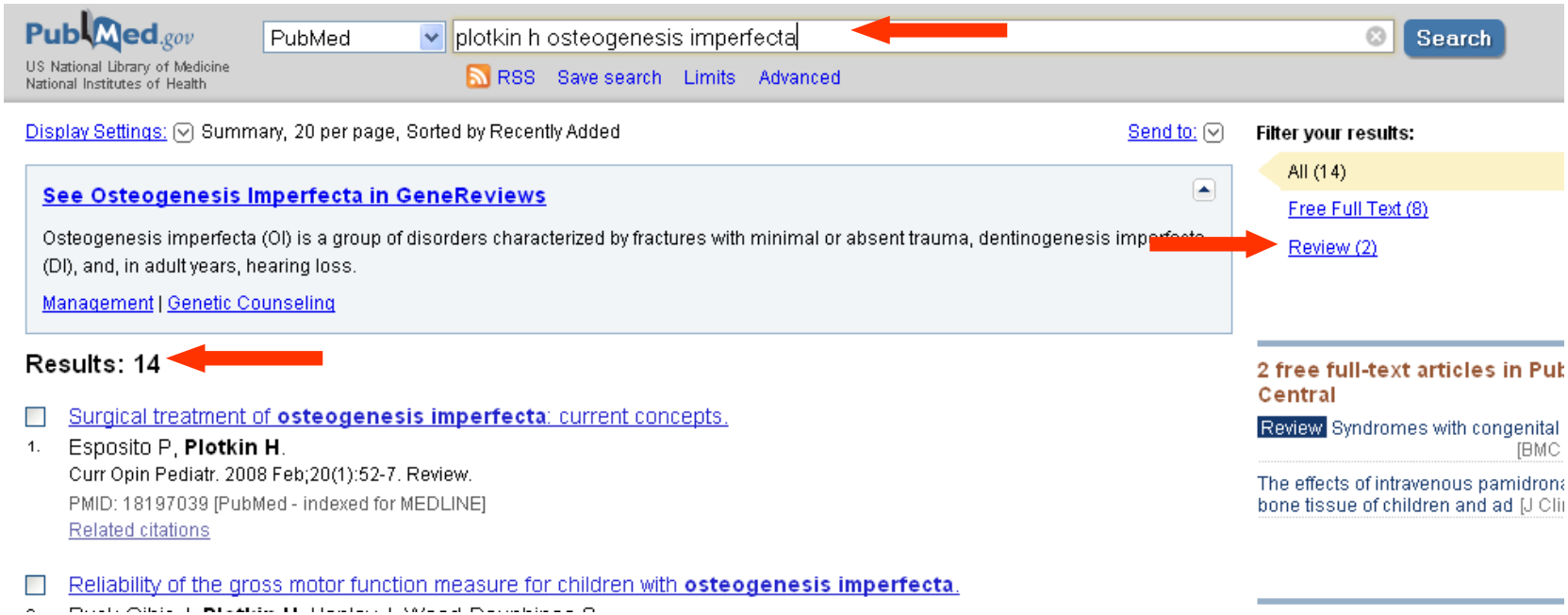
Drugs.com is NOT affiliated with any pharmaceutical companies. The only funding we receive from pharmaceutical companies is by way of advertisements that appear on the Drugs.com website. This advertising in no way affects the content of the drug information we supply.

How is the information documented ?

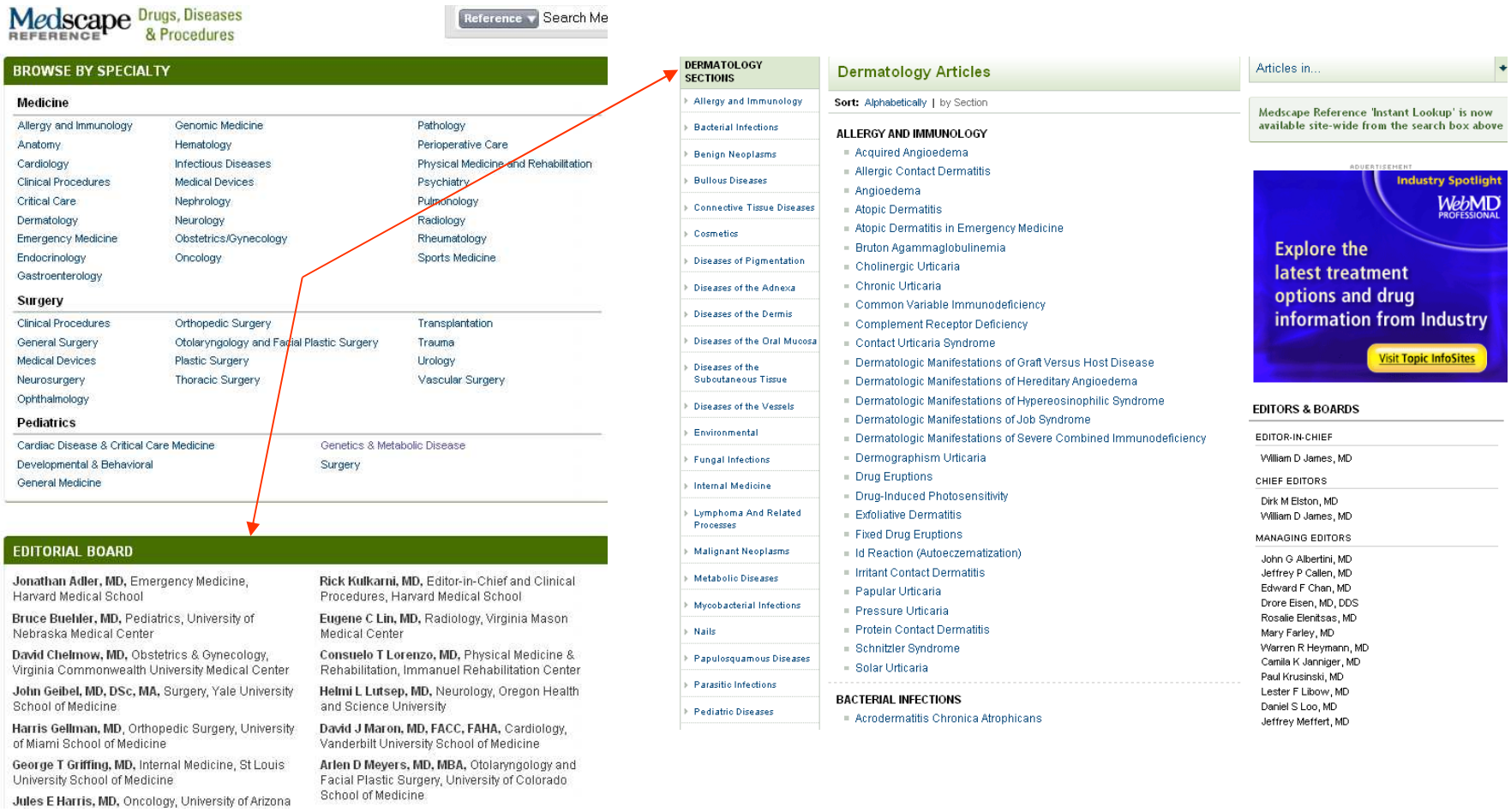



Rare Disease Communities beta
DE | EN | ES | FR | IT
Sign in | Register
Join this community
Epidermolysis Bullosa community
Search this community
what?
learn to live with the disease
meet!
discuss with other patients
learn.
information and resources
Epidermolysis Bullosa (EB) is a group of rare, inherited disorders that affects skin and mucous membranes. The clinical picture ranges from mild to severe. Below, you'll find testimonies from patients who live with this genetic disease.
« Back to the Articles list
Orphanet article: Epidermolysis Bullosa (2010)
Written by Prof. J-D Fine, published 5 months ago.
Summary
Inherited epidermolysis bullosa (EB) encompasses a number of disorders characterized by recurrent blister formation as the result of structural fragility within the skin and selected other tissues. All types and subtypes of EB are rare; the overall incidence and prevalence of the disease within the United States are approximately 1/53,000 live births and 1/125 000,
Patient groups
DebRA International
DebRA Belgium
DebRA Croatia
DebRA UK
DebRA Austria

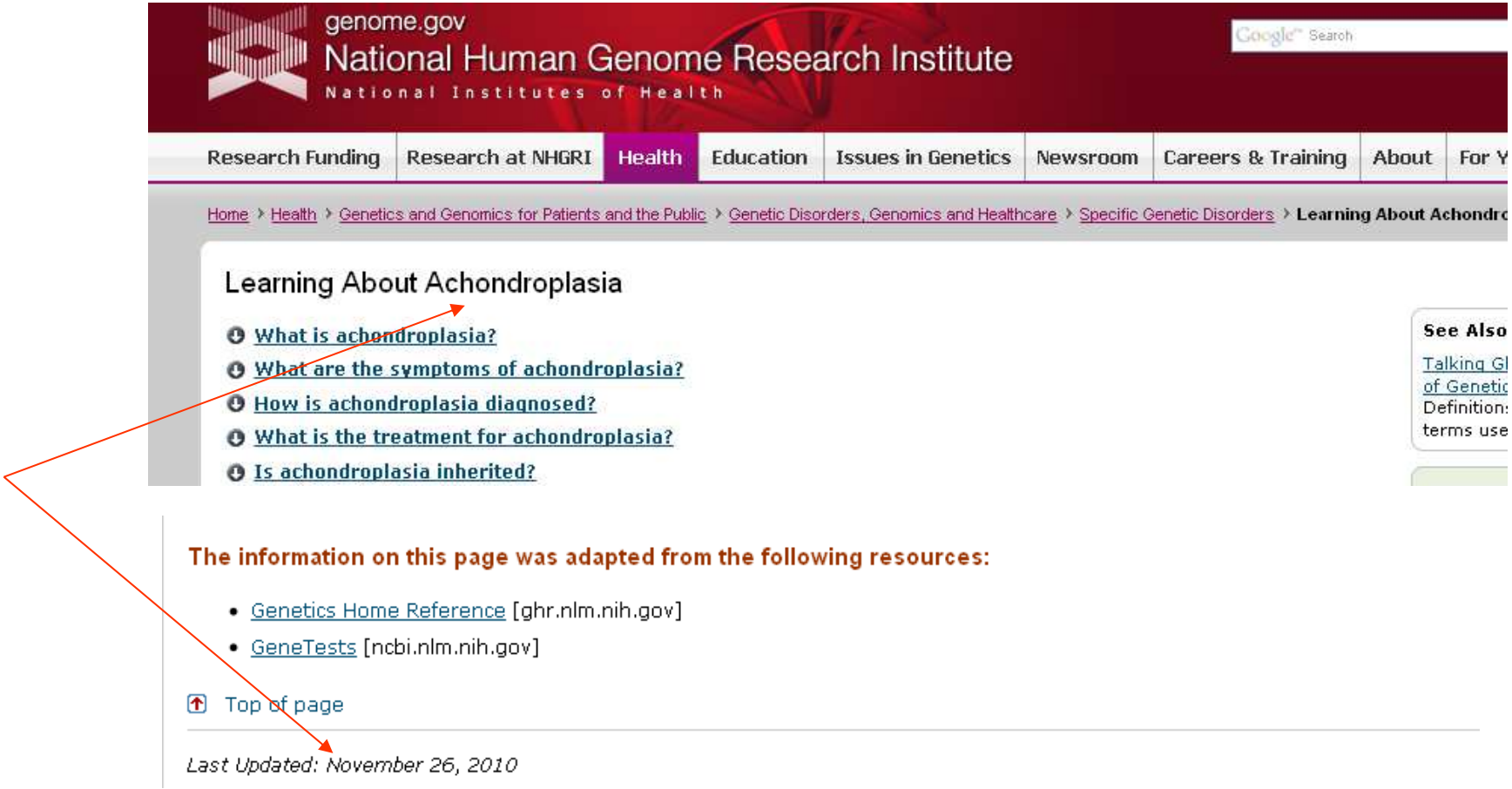
What are the qualifications of the authors ?



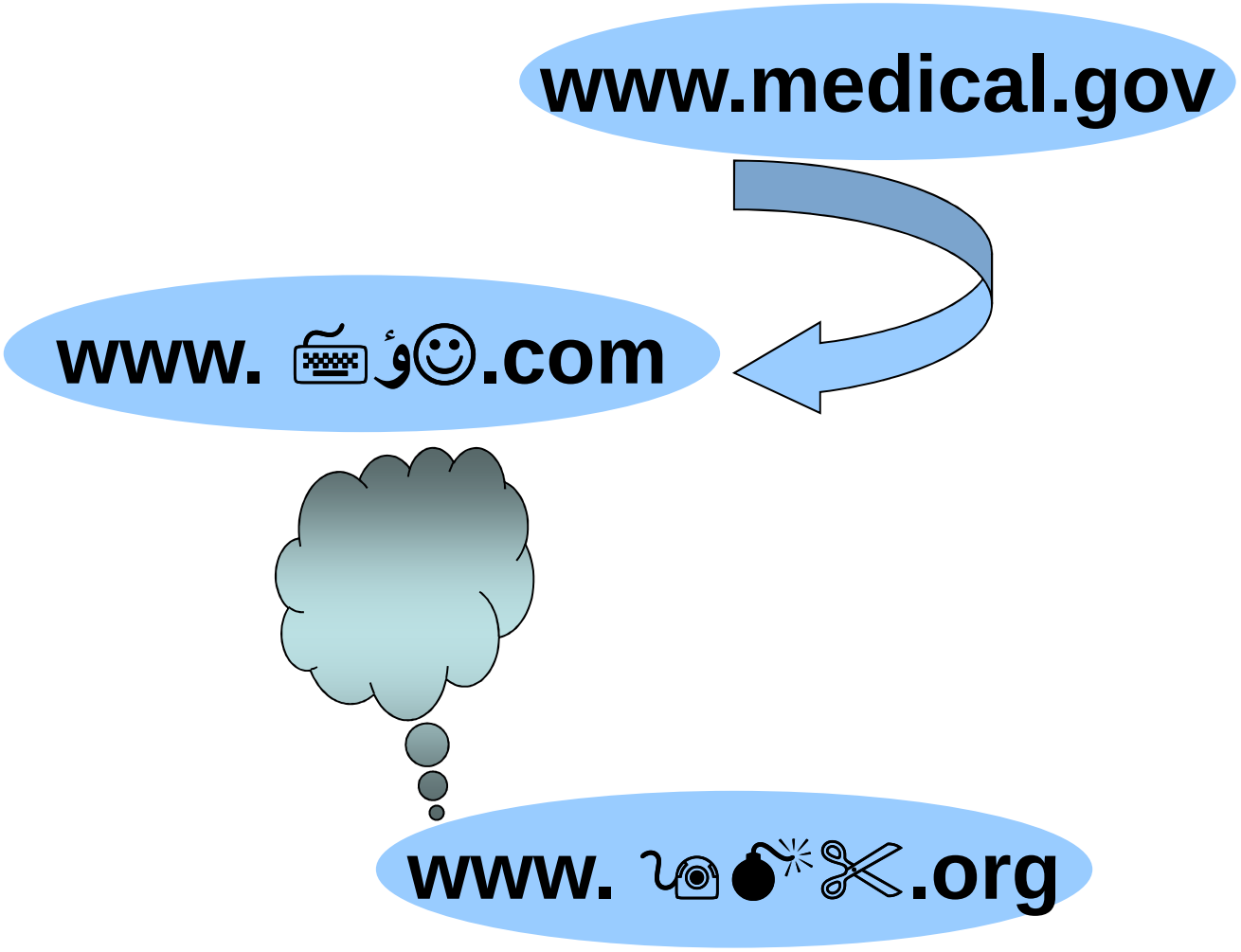
How is the information reviewed ?



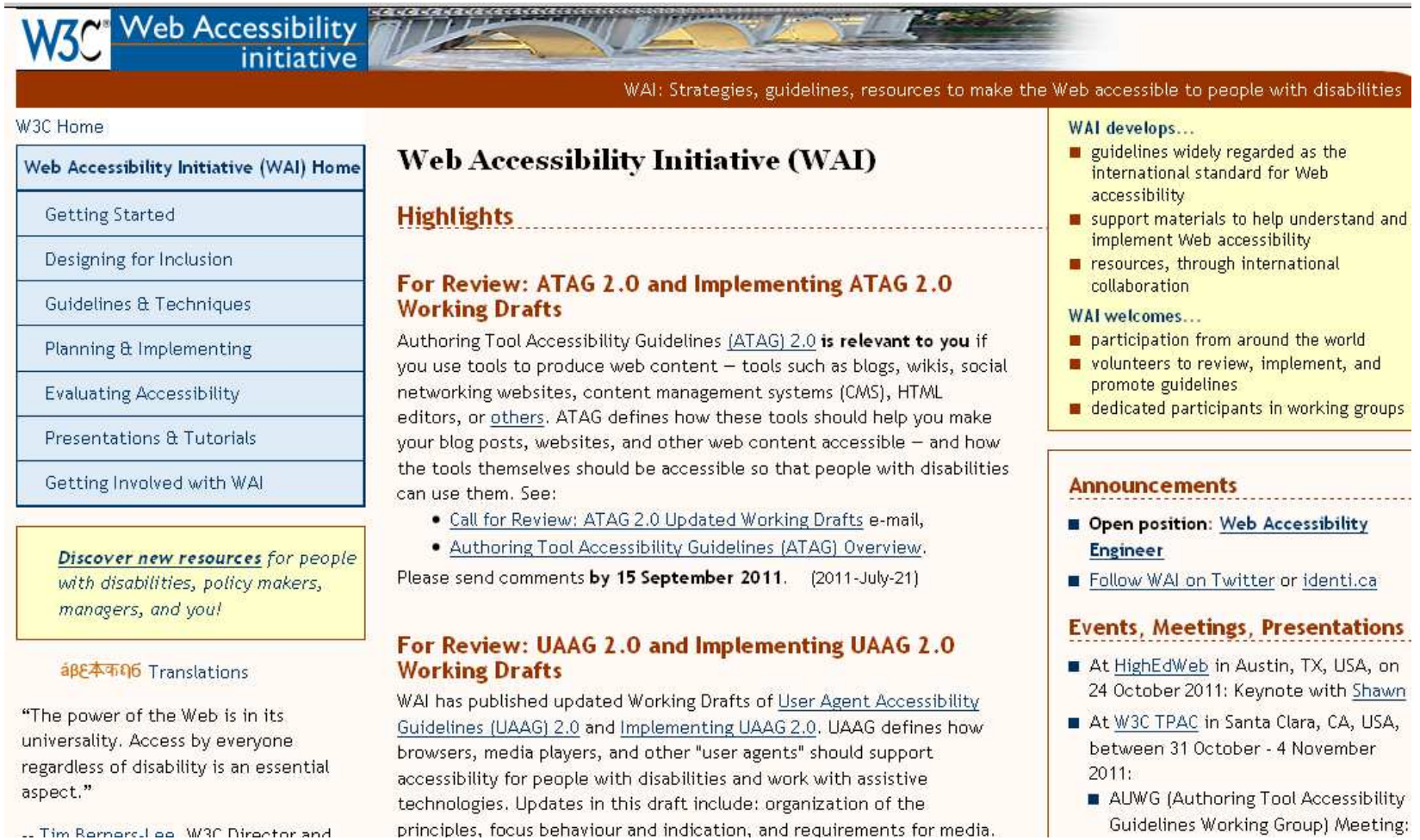
How is the information updated ?



Be cautious with hyperlinks



Accessibility



Other criteria

- **Information**
  - Complete, exhaustive
  - Readable
  - Useful

- **Websites**
  - Organization
  - Search engine optimization
  - Design

- ***Users'critical judgment***