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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**

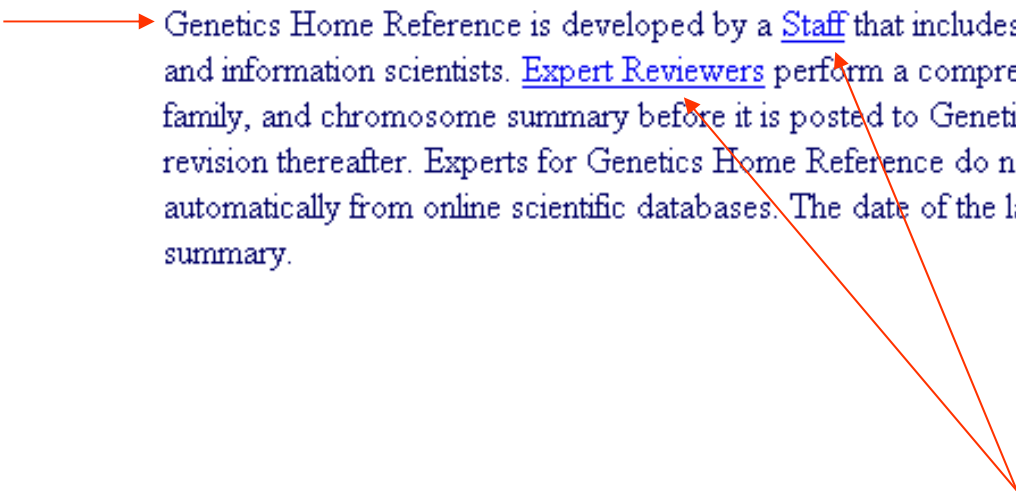


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Indicate the qualifications of the authors

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

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Genetics Home Reference

Your Guide to Understanding Genetic Conditions

A service of the U.S. National Library of Medicine®

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

Handbook

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](#)

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

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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



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Provide details on funding

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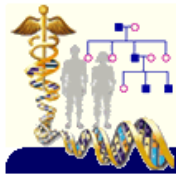
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Published: August 8, 2011

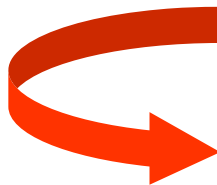
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⇨ Indicates a page outside Genetics Home Reference.

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See [Selection Criteria for Web Links](#).

PDF resources may require a [PDF reader](#).



This site complies with the [HONcode standard](#) for trustworthy health information: [verify here](#).

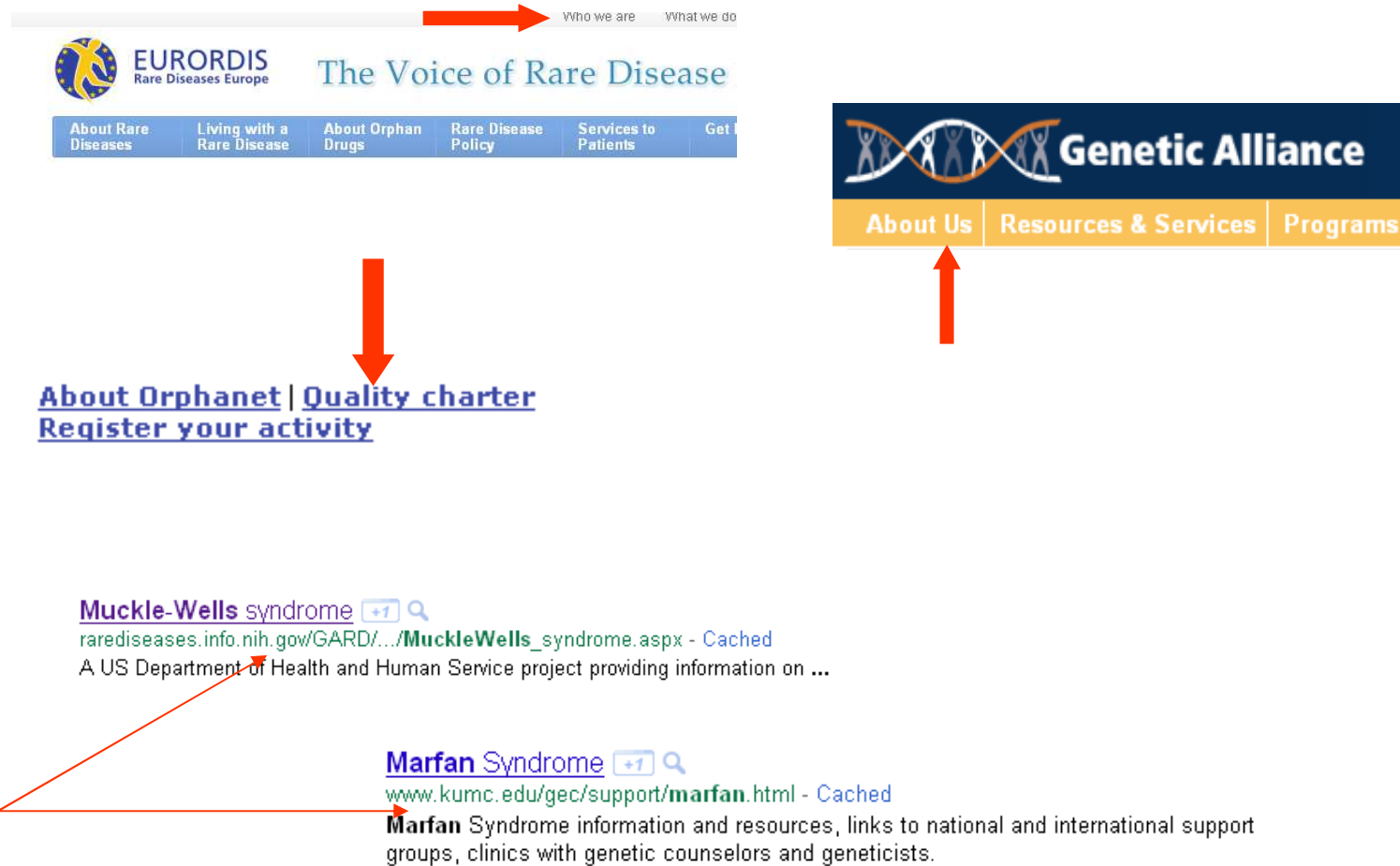
Limitations of HONCode

- **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 ?



 **EURORDIS**
Rare Diseases Europe

The Voice of Rare Disease



About Rare Diseases | Living with a Rare Disease | About Orphan Drugs | Rare Disease Policy | Services to Patients | Get

 **Genetic Alliance**

About Us | Resources & Services | Programs

[About Orphanet](#) | [Quality charter](#)
[Register your activity](#)

[Muckle-Wells syndrome](#)  
rare diseases.info.nih.gov/GARD/.../MuckleWells_syndrome.aspx - Cached
A US Department of Health and Human Service project providing information on ...

[Marfan Syndrome](#)  
www.kumc.edu/gec/support/marfan.html - Cached
Marfan Syndrome information and resources, links to national and international support groups, clinics with genetic counselors and geneticists.

Who pays for the website ?

EURORDIS IS GRATEFUL FOR THE FINANCIAL SUPPORT OF:



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)



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How is the information documented ?

OJR ORPHANET JOURNAL OF RARE DISEASES **IMPACT FACTOR 5.93**

Search for

Home Articles Authors Reviewers About this journal My Orphanet Journal of Rare Diseases

Review **Fabry disease** **Dominique P Germain** **Highly accessed** **Open access**

Correspondence: Dominique P Germain dominique.germain@rpc.aphp.fr **Author Affiliations**

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Division of Medical Genetics, CHU Raymond Poincaré (Assistance Publique - Hôpitaux de Paris), 92380 Garches, France

References

1. Anderson W: **A case of "Angeio-keratoma"**. *Br J Dermatol* 1898, **10**:113-117. [Publisher Full Text](#)
2. Fabry J: **Ein Beitrag zur Kenntnis der Purpura haemorrhagica nodularis (Purpura papulosa hemorrhagica Hebrae)**. *Arch Dermatol Syphilol* 1898, **43**:187-200. [Publisher Full Text](#)
3. Sweeley CC, Klionsky B: **Fabry's disease: classification as a sphingolipidosis and partial characterization of a novel glycolipid**. *J Biol Chem* 1963, **238**:3148-3150. [PubMed Abstract](#) | [Publisher Full Text](#)
4. Brady RO, Gal AE, Bradley RM, Martensson E, Warshaw AL, Laster L: **Enzymatic defect in Fabry's disease: ceramide-trihexosidase deficiency**. *N Engl J Med* 1967, **276**:1163-1167. [PubMed Abstract](#) | [Publisher Full Text](#)
5. Kint JA: **The enzyme defect in Fabry's disease**. *Nature* 1970, **227**:1173. [PubMed Abstract](#) | [Publisher Full Text](#)
6. De Duve C: **Exploring cells with a centrifuge**. *Science* 1975, **189**:186-194. [PubMed Abstract](#) | [Publisher Full Text](#)

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 ?

Genetics of Osteogenesis Imperfecta

Author: Horacio Plotkin, MD, FAAP; Chief Editor: Bruce Buehler, MD [more...](#)

Print

Overview

Presentation

DDx

Workup

Treatment

Medication

Follow-up

Author

Horacio Plotkin, MD, FAAP Adjunct Associate Professor of Pediatrics and Orthopedic Surgery, University of Nebraska School of Medicine
Horacio Plotkin, MD, FAAP is a member of the following medical societies: [American Academy of Pediatrics](#) and [American Society of Human Genetics](#)
Disclosure: Genzyme Corporation Salary Management position

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plotkin h osteogenesis imperfecta

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See Osteogenesis Imperfecta in GeneReviews

Osteogenesis imperfecta (OI) is a group of disorders characterized by fractures with minimal or absent trauma, dentinogenesis imperfecta (DI), and, in adult years, hearing loss.

[Management](#) | [Genetic Counseling](#)

All (14)

[Free Full Text \(8\)](#)

[Review \(2\)](#)

Results: 14

[Surgical treatment of osteogenesis imperfecta: current concepts.](#)

1. Esposito P, Plotkin H.
Curr Opin Pediatr. 2008 Feb;20(1):52-7. Review.
PMID: 18197039 [PubMed - indexed for MEDLINE]
[Related citations](#)

[Reliability of the gross motor function measure for children with osteogenesis imperfecta.](#)

2 free full-text articles in Pub Central

[Review](#) Syndromes with congenital [BMC]

The effects of intravenous pamidronate on bone tissue of children and ad [J Clin

How is the information reviewed ?

BROWSE BY SPECIALTY

Medicine		
Allergy and Immunology	Genomic Medicine	Pathology
Anatomy	Hematology	Perioperative Care
Cardiology	Infectious Diseases	Physical Medicine and Rehabilitation
Clinical Procedures	Medical Devices	Psychiatry
Critical Care	Nephrology	Pulmonology
Dermatology	Neurology	Radiology
Emergency Medicine	Obstetrics/Gynecology	Rheumatology
Endocrinology	Oncology	Sports Medicine
Gastroenterology		
Surgery		
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DERMATOLOGY SECTIONS

- › Allergy and Immunology
- › Bacterial Infections
- › Benign Neoplasms
- › Bullous Diseases
- › Connective Tissue Diseases
- › Cosmetics
- › Diseases of Pigmentation
- › Diseases of the Adnexa
- › Diseases of the Dermis
- › Diseases of the Oral Mucosa
- › Diseases of the Subcutaneous Tissue
- › Diseases of the Vessels
- › Environmental
- › Fungal Infections
- › Internal Medicine
- › Lymphoma And Related Processes
- › Malignant Neoplasms
- › Metabolic Diseases
- › Mycobacterial Infections
- › Nails
- › Papulosquamous Diseases
- › Parasitic Infections
- › Pediatric Diseases

Dermatology Articles

Sort: Alphabetically | by Section

ALLERGY AND IMMUNOLOGY

- Acquired Angioedema
- Allergic Contact Dermatitis
- Angioedema
- Atopic Dermatitis
- Atopic Dermatitis in Emergency Medicine
- Bruton Agammaglobulinemia
- Cholinergic Urticaria
- Chronic Urticaria
- Common Variable Immunodeficiency
- Complement Receptor Deficiency
- Contact Urticaria Syndrome
- Dermatologic Manifestations of Graft Versus Host Disease
- Dermatologic Manifestations of Hereditary Angioedema
- Dermatologic Manifestations of Hypereosinophilic Syndrome
- Dermatologic Manifestations of Job Syndrome
- Dermatologic Manifestations of Severe Combined Immunodeficiency
- Dermographism Urticaria
- Drug Eruptions
- Drug-Induced Photosensitivity
- Exfoliative Dermatitis
- Fixed Drug Eruptions
- Id Reaction (Autoeczematization)
- Irritant Contact Dermatitis
- Papular Urticaria
- Pressure Urticaria
- Protein Contact Dermatitis
- Schnitzler Syndrome
- Solar Urticaria

BACTERIAL INFECTIONS

- Acrodermatitis Chronica Atrophicans

Articles in...

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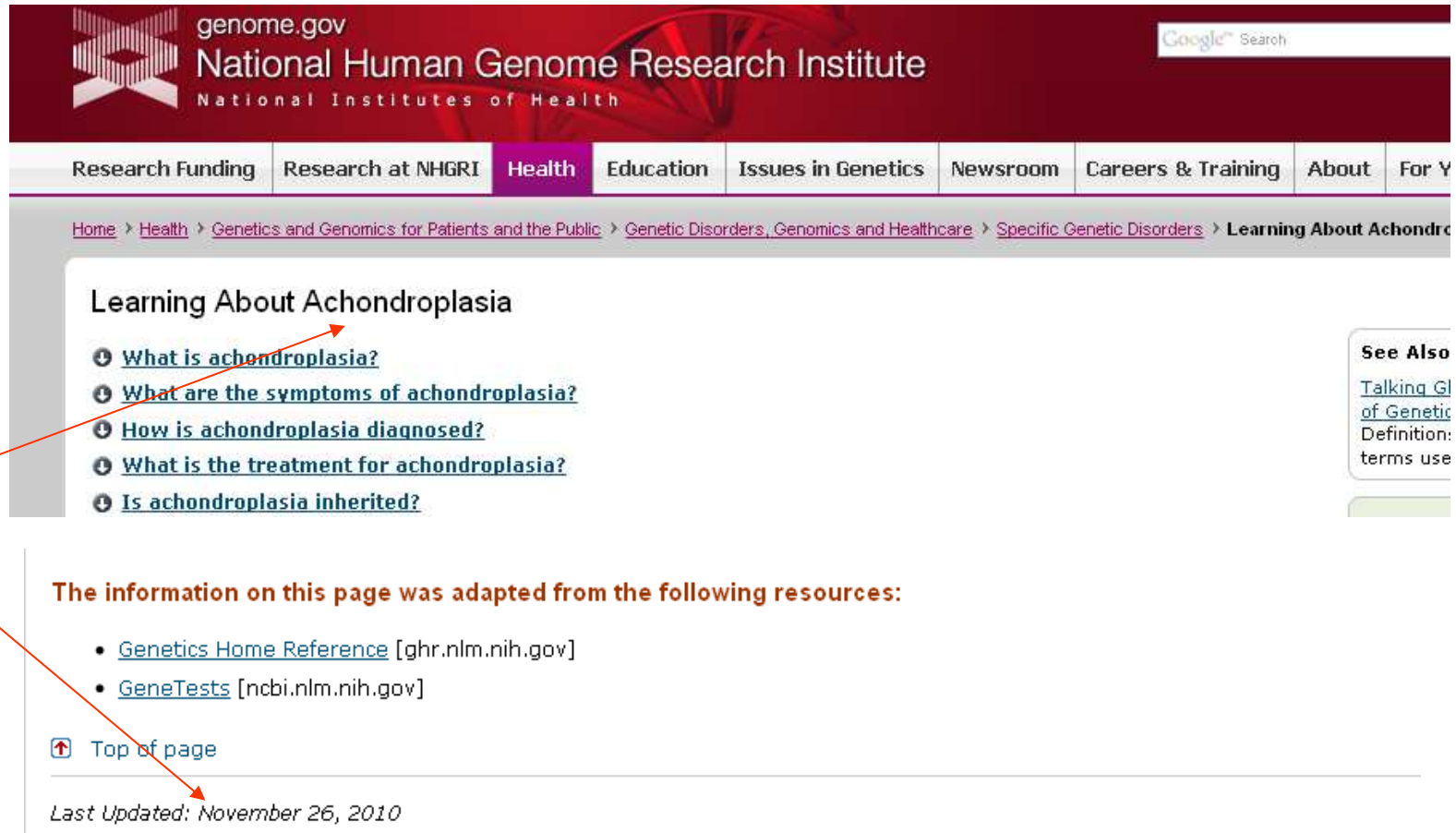
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Home > Health > Genetics and Genomics for Patients and the Public > Genetic Disorders, Genomics and Healthcare > Specific Genetic Disorders > Learning About Achondro

Learning About Achondroplasia

- What is achondroplasia?
- What are the symptoms of achondroplasia?
- How is achondroplasia diagnosed?
- What is the treatment for achondroplasia?
- Is achondroplasia inherited?

See Also
[Talking Gl of Genetic Definition: terms use](#)

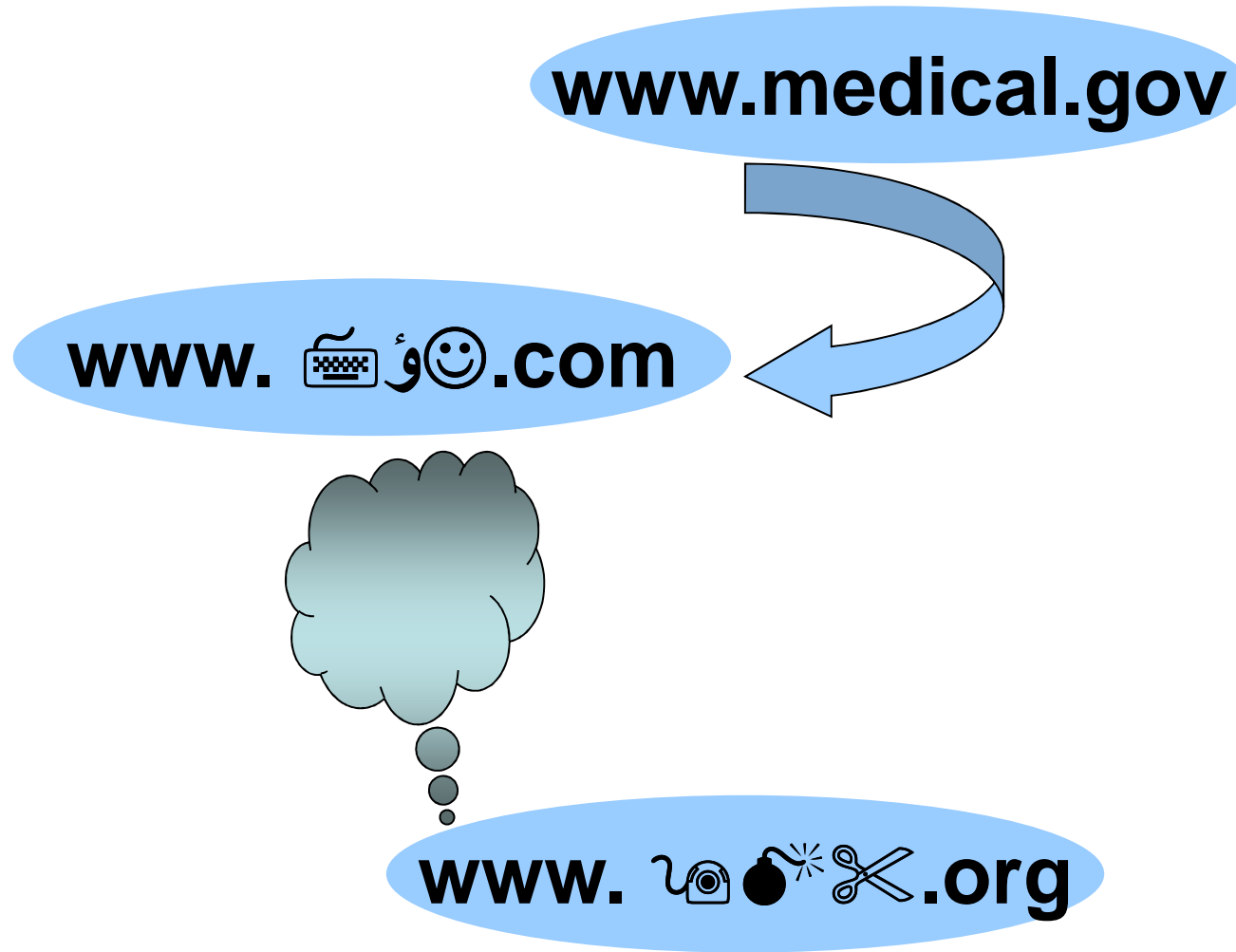
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- [Genetics Home Reference](#) [ghr.nlm.nih.gov]
- [GeneTests](#) [ncbi.nlm.nih.gov]

[Top of page](#)

Last Updated: November 26, 2010

Be cautious with hyperlinks



Accessibility

W3C Home

Web Accessibility Initiative (WAI) Home

Getting Started

Designing for Inclusion

Guidelines & Techniques

Planning & Implementing

Evaluating Accessibility

Presentations & Tutorials

Getting Involved with WAI

Discover new resources for people with disabilities, policy makers, managers, and you!

अनुवाद Translations

“The power of the Web is in its universality. Access by everyone regardless of disability is an essential aspect.”

-- Tim Berners-Lee, W3C Director and

Web Accessibility Initiative (WAI)

Highlights

For Review: ATAG 2.0 and Implementing ATAG 2.0 Working Drafts

Authoring Tool Accessibility Guidelines ([ATAG](#)) 2.0 is relevant to you if you use tools to produce web content – tools such as blogs, wikis, social networking websites, content management systems (CMS), HTML editors, or others. ATAG defines how these tools should help you make your blog posts, websites, and other web content accessible – and how the tools themselves should be accessible so that people with disabilities can use them. See:

- [Call for Review: ATAG 2.0 Updated Working Drafts](#) e-mail,
- [Authoring Tool Accessibility Guidelines \(ATAG\) Overview](#).

Please send comments **by 15 September 2011**. (2011-July-21)

For Review: UAAG 2.0 and Implementing UAAG 2.0 Working Drafts

WAI has published updated Working Drafts of [User Agent Accessibility Guidelines \(UAAG\)](#) 2.0 and [Implementing UAAG 2.0](#). UAAG defines how browsers, media players, and other "user agents" should support accessibility for people with disabilities and work with assistive technologies. Updates in this draft include: organization of the principles, focus behaviour and indication, and requirements for media.

WAI develops...

- guidelines widely regarded as the international standard for Web accessibility
- support materials to help understand and implement Web accessibility
- resources, through international collaboration

WAI welcomes...

- participation from around the world
- volunteers to review, implement, and promote guidelines
- dedicated participants in working groups

Announcements

- **Open position:** [Web Accessibility Engineer](#)
- [Follow WAI on Twitter](#) or [identi.ca](#)

Events, Meetings, Presentations

- At [HighEdWeb](#) in Austin, TX, USA, on 24 October 2011: Keynote with [Shawn](#)
- At [W3C TPAC](#) in Santa Clara, CA, USA, between 31 October - 4 November 2011:
 - [ALWG \(Authoring Tool Accessibility Guidelines Working Group\) Meeting](#):

Other criteria

- **Information**

- Complete, exhaustive
- Readable
- Useful

- **Websites**

- Organization
- Search engine optimization
- Design

- ***Users' critical judgment***