Today's Presenters

Betha Gutsche
WebJunction Program Manager, OCLC

Monika Sengul-Jones
Doctoral Candidate at UC San Diego and former OCLC Wikipedian-in-Residence

Liz Waltman
Outreach, Education and Communications Coordinator, Southeastern/Atlantic Region, National Network of Libraries of Medicine

Why Wikipedia Matters for Health and Medical Information

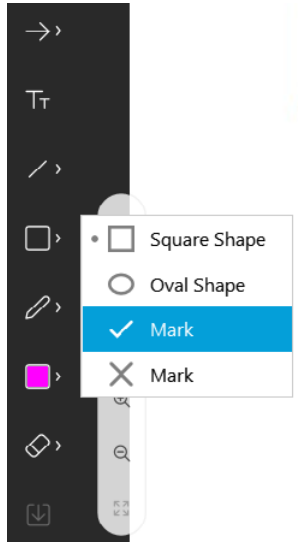
Wednesday, August 14 2019

Topics for Today

- Welcome and warm-up
- Finding the intersection of Wikipedia, libraries, and health information
- The inner workings of Wikipedia
- NNLM and public libraries
- Upcoming course: Wikipedia + Libraries: Health and Medical Information

Annotation Tools

1. Mouse over slide to find **small pill menu** at far left
2. Select top **squiggle icon** to open annotation tool panel
3. Select **square** icon
4. Select **check mark**
5. Click on slide **to practice**



What is your experience with Wikipedia?

- ❑ I look up information for patrons on Wikipedia
- ❑ I use Wikipedia to teach information literacy
- ❑ I help patrons find health and medical information on Wikipedia
- ❑ I have edited one or more Wikipedia articles

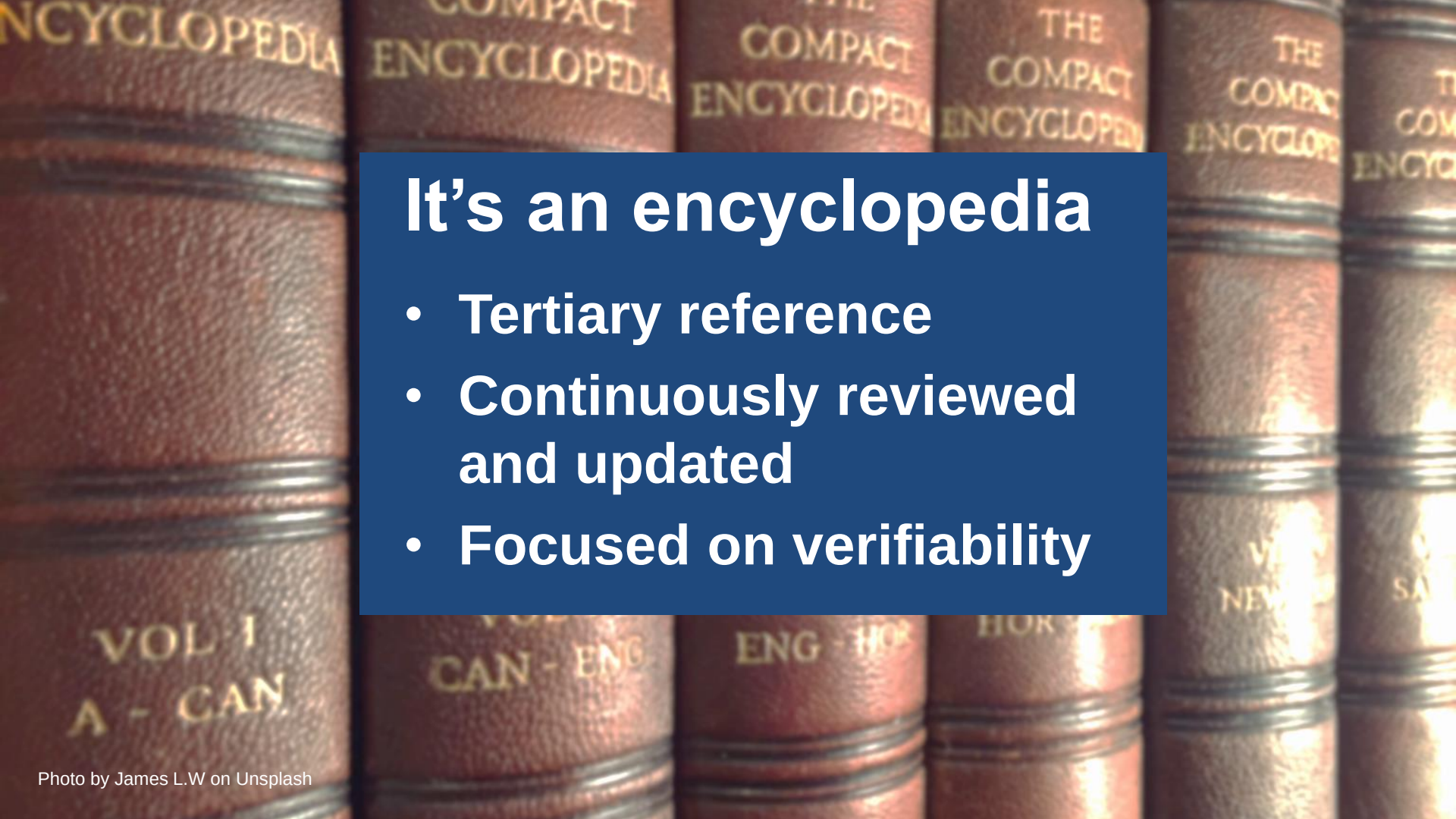
FINDING THE INTERSECTION OF WIKIPEDIA, LIBRARIES, AND HEALTH INFORMATION

What do we know about Wikipedia?

It’s immensely popular

- 5th most visited website
- Half billion visitors per month
- 21% daily Internet traffic
- 200 million pageviews per day

Image by Pete Linforth from Pixabay



It’s an encyclopedia

- Tertiary reference
- Continuously reviewed and updated
- Focused on verifiability

Photo by James L.W on Unsplash

And it’s a community

- Open to all
- Free to use
- No owners; crowd-sourced funding
- Community norms, not rules

How do libraries fit in?

Kansas City Jazz Wikipedia Edit-a-thon-2, Clint Ashlock, CC BY-SA 4.0;

Mission Alignment

WIKIPEDIA
The Free Encyclopedia

“Imagine a world in which every single human being can freely share in the sum of all knowledge. That's our commitment.”

- Wikimedia Foundation vision

Wikipedian + librarian = Wikibrarian!

- Use in informational literacy training
- Advise faculty, school administrators
- Guide students and researchers
- Host editathons
- Add local knowledge
- Participate in #1lib1ref events
- Join Wikimedia projects

Photo courtesy of Allison Frick.

“Now I consider myself a [Wikipedia] convert. I am pushing its value to help students be critical consumers of information.”

– Denise Davis, Morton-James Public Library

What about health and medical information?

Photo by rawpixel on Pixabay

Wikipedia has health & medical articles

- 223,784 articles in 281 languages
- 34,500 English-language articles
- 4.67 billion pageviews
- 1.5M references

80%

of adult internet users looked online for health information

(Pew 2013)

What are internet users looking up?

- 63% disease or medical problem
- 47% medical treatment or procedure
- 44% diet, nutrition, vitamins
- 36% exercise or fitness
- 24% prescription or over-the-counter drugs
- 28% alternative treatments
- 25% health insurance
- 21% depression, anxiety, or stress; doctor or hospital

Health professionals use Wikipedia

- Single leading source of medical information for patients and health care professionals
- 50%+ of physicians use as health information source
- 94% of medical students, 70% of early career doctors, and at least 35% of pharmacists use it
- Evidence suggests that science articles referenced in Wikipedia receive more citations

From James M. Heilman and Andrew G. West, *J. Med Internet Res.* 2015 Mar; 17(3): e62. doi: 10.2196/jmir.4069

Intersection

Armed with knowledge of its inner workings, **library staff** join the Wikipedia community to **strengthen Wikipedia** as a **health information resource** for all.

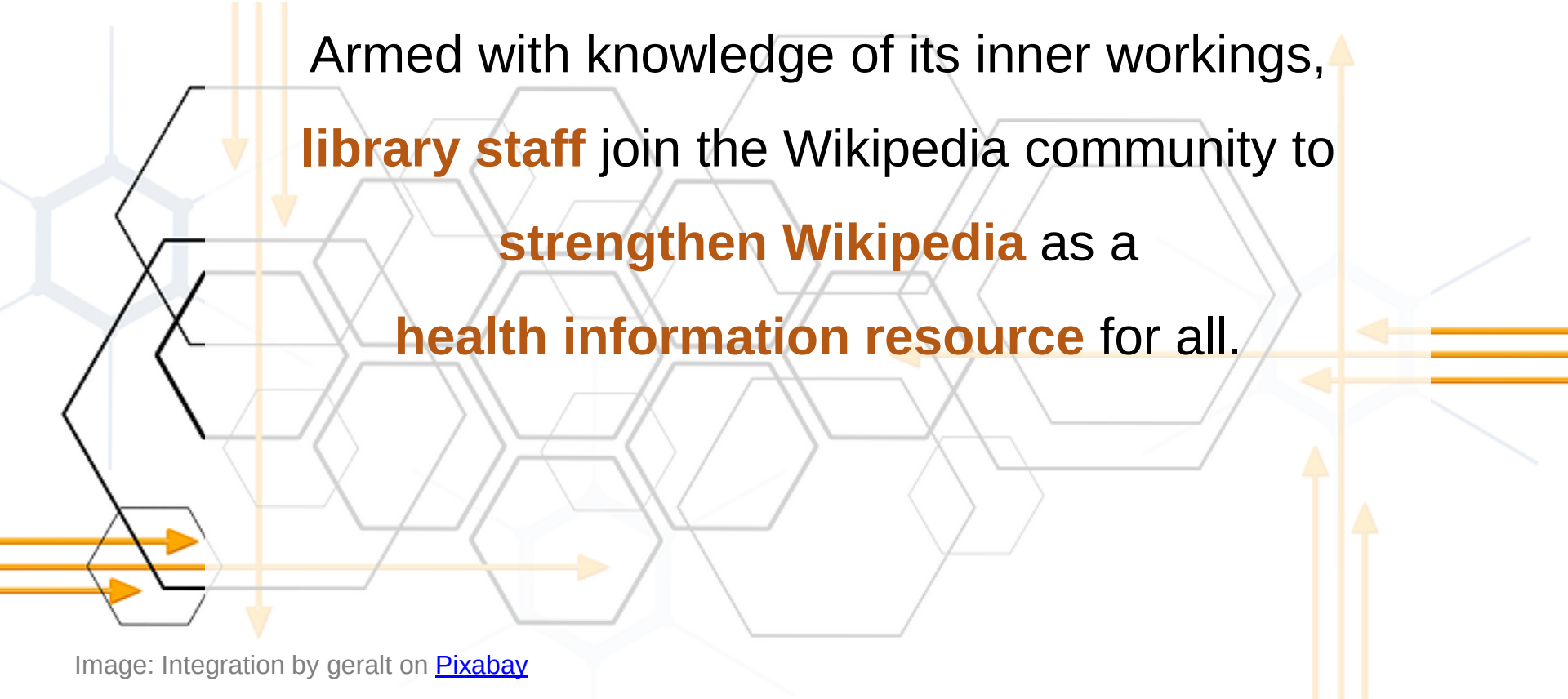


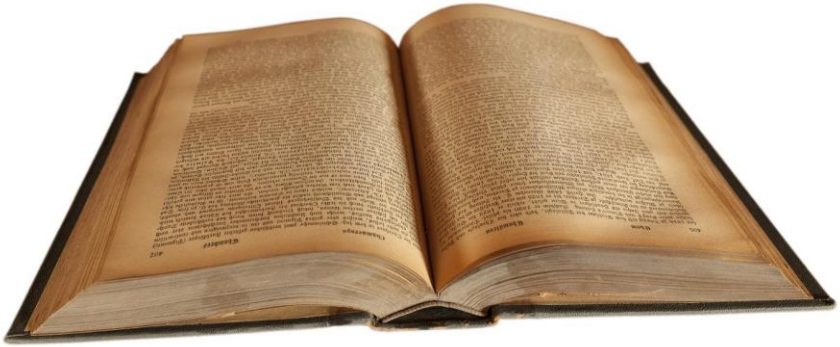
Image: Integration by geralt on Pixabay

THE INNER WORKINGS OF WIKIPEDIA

Why learn about the inner workings of Wikipedia?

How reliable is Wikipedia?

?



“Encyclopedia” by GrauerWolf, CC-0

?

=

?

?

?

What signs of reliability do you look for?

Signs of reliability on Wikipedia

- Stability of articles
- Neutral point of view (no undue weight)
- Claims cited using verifiable secondary sources

Core content policies of Wikipedia

Who edits Wikipedia?

No one person authors Wikipedia articles

117,000 active users make edits every month

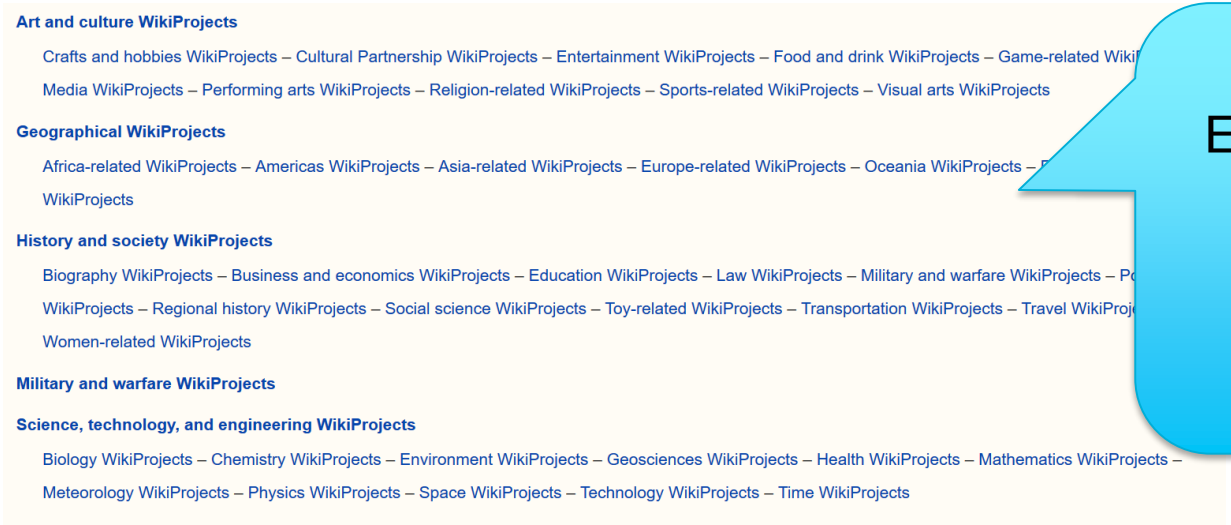
My dog wearing a hat reading "Wikipedia Editor" (Aug 2013). User: Smallbones CC BY-SA 3.0

The BIG volunteer community working together to edit!

WikiConference USA, Washington D.C. Group photo 32. 2015 User: Geraldshields11, CC BY-SA 4.0

WikiProjects

A **WikiProject** is a group of contributors who want to work together as a team to improve Wikipedia.



Art and culture WikiProjects

Crafts and hobbies WikiProjects – Cultural Partnership WikiProjects – Entertainment WikiProjects – Food and drink WikiProjects – Game-related Wiki

Media WikiProjects – Performing arts WikiProjects – Religion-related WikiProjects – Sports-related WikiProjects – Visual arts WikiProjects

Geographical WikiProjects

Africa-related WikiProjects – Americas WikiProjects – Asia-related WikiProjects – Europe-related WikiProjects – Oceania WikiProjects –

WikiProjects

History and society WikiProjects

Biography WikiProjects – Business and economics WikiProjects – Education WikiProjects – Law WikiProjects – Military and warfare WikiProjects – P

WikiProjects – Regional history WikiProjects – Social science WikiProjects – Toy-related WikiProjects – Transportation WikiProjects – Travel WikiProj

Women-related WikiProjects

Military and warfare WikiProjects

Science, technology, and engineering WikiProjects

Biology WikiProjects – Chemistry WikiProjects – Environment WikiProjects – Geosciences WikiProjects – Health WikiProjects – Mathematics WikiProjects –

Meteorology WikiProjects – Physics WikiProjects – Space WikiProjects – Technology WikiProjects – Time WikiProjects

English Wikipedia currently has over **2,000** WikiProjects

WikiProject Medicine

WikiProject Medicine

Welcome to **WikiProject Medicine**! We discuss, collaborate, and debate anything and everything relating to medicine and health on Wikipedia on our **discussion page**.
Everyone is welcome to join!

WikiProject Medicine editors, including John Byrne, Rich Farmbrough and Sydney Poore at Wikimania 2014. Credit: Chris McKenna (WMF)

Policies and guidelines

WikiProject Medicine has rigorous policies and guidelines that complement those of Wikipedia

NNLM AND PUBLIC LIBRARIES

National Network of Libraries of Medicine

Eight Regional Medical Libraries (RML)

NNLM offers:

- Funding opportunities
- Training
- Educational materials
- Community outreach

Membership

NNLM members provide health professionals and the general public with health information resources and services

- Membership is FREE!
- Institutional, not individual
- Receive access to funding opportunities, training, and educational materials

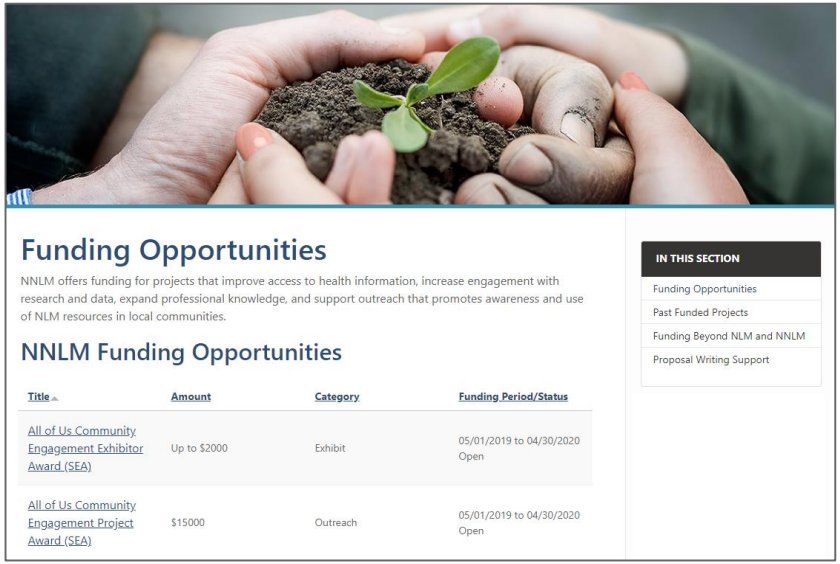
Funding Opportunities

May 1 - April 30

Awards ranging from $1,500 to $19,000

Available awards include:

- Professional Development
- Health Information Outreach
- Exhibitor Award
- Technology Improvement



Training Opportunities

All courses offered by NNLM are FREE!

Ability to claim MLA CE credit

NNLM offers a variety of learning formats:

- Webinars
- On Demand
- Asynchronous
- In-person

Consumer Health Information Specialization

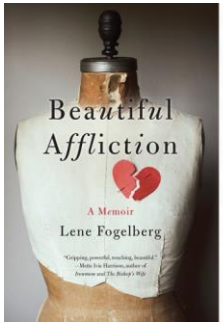
Specialization offered through MLA

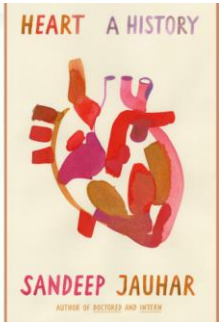
Organized around eight core competencies

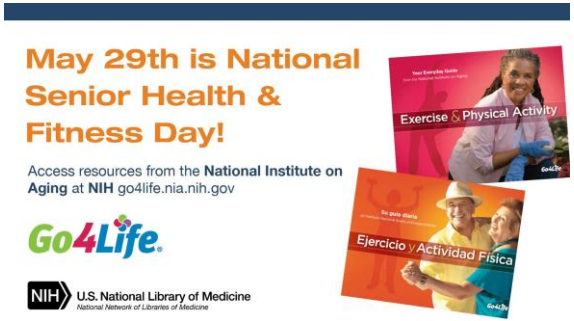
Available classes include:

- Rural health resources
- Multicultural health information
- Opioid crisis
- K-12 health information

Health Programming Materials







#CiteNLM

The National Library of Medicine is actively engaged in reaching a major strategic goal to “reach more people in more ways through enhanced dissemination and engagement pathways.”

By holding Wikipedia Edit-a-thons, we can:

- Improve the use of NLM and other open access resources
- Engage NNLM members nationwide
- Make Wikipedia a better, evidence-based resource

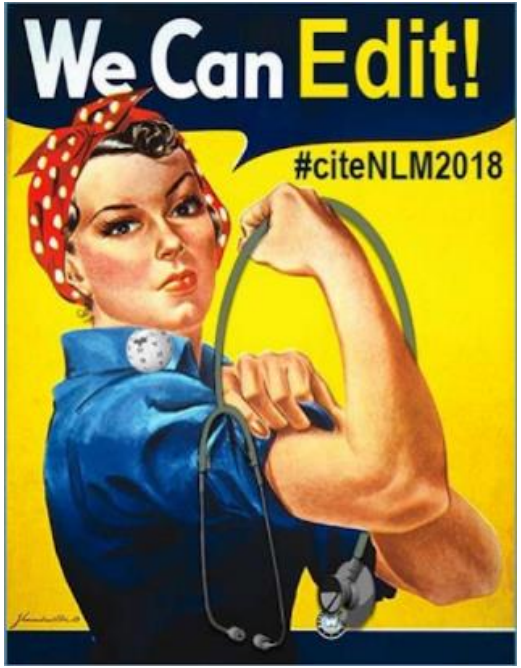
#CiteNLM

Three past events:

- Rare Diseases - Spring 2018
- Women's Health - Fall 2018
- Health Equity - Spring 2019

In total, our 136 editors have:

- Made 1,575 edits
- Edited 357 articles
- Created 25 new articles



#CiteNLM


PubMed


MedlinePlus®
Trusted Health Information for You


Genetics
Home
Reference


NIH
National Institutes
of Health

#CiteNLM

Join us for future #CiteNLM Edit-a-Thons!

- Mental Health - Fall 2019
- Join us for our virtual edit-a-thon on **Wednesday, November 20**
- Host your own event between **October 1 - November 30**

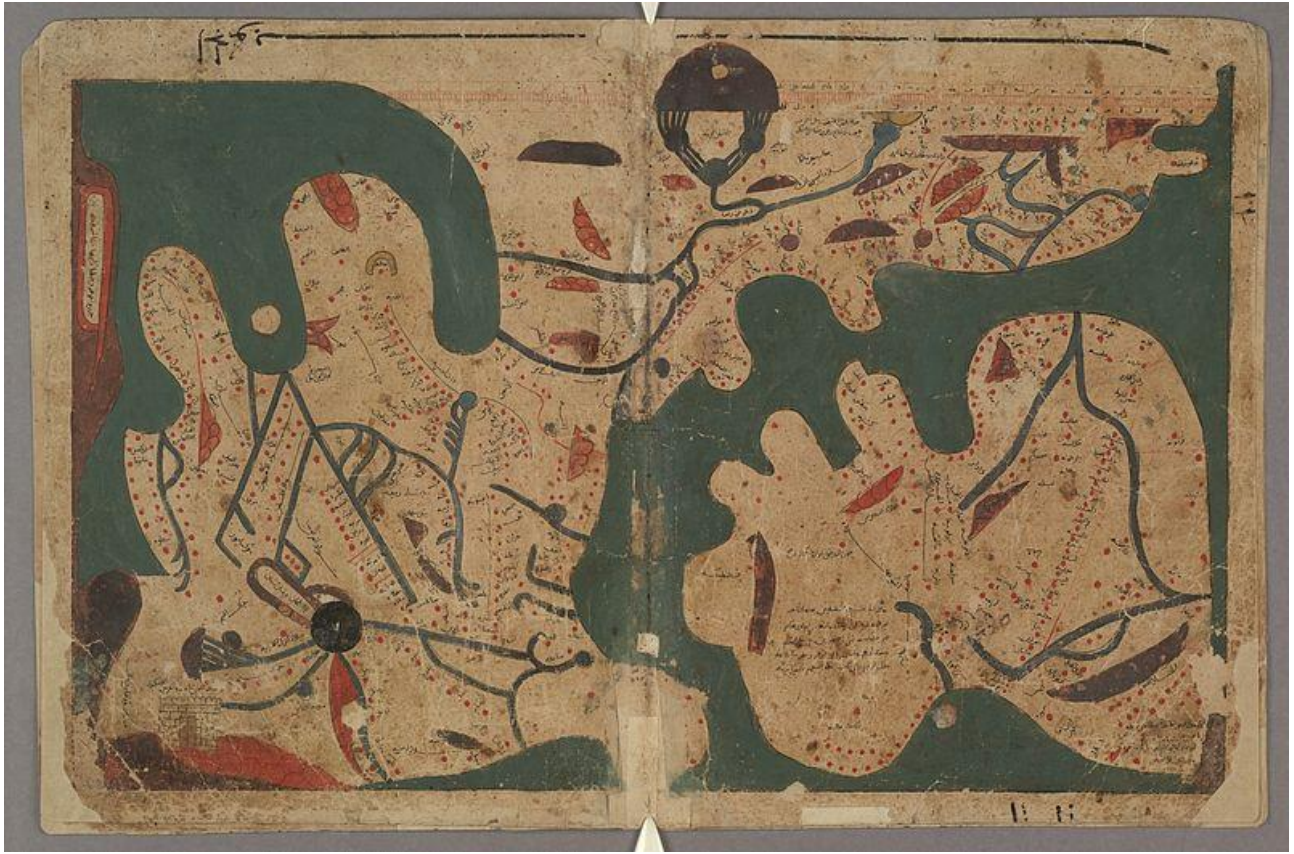
Interested in hosting your own event? Our **Guide for Organizers** is coming soon!

Thanks #CiteNLM!

WIKIPEDIA + LIBRARIES: HEALTH AND MEDICAL INFORMATION

THE COURSE

Learning the inner workings of Wikipedia is like …



Map of the world, from *Book of Curiosities*, late 12 or early 13th century.
Source: Bodleian Library, University of Oxford, via Wikimedia Commons

Course will build digital information literacy skills in …

Kansas City Jazz Wikipedia Edit-a-thon-2, Clint Ashlock, CC BY-SA 4.0.

- Evaluation
- Assessment
- Citations

Topics ...

- History
- Guidelines
- Page analyses
- Editing
- Activism

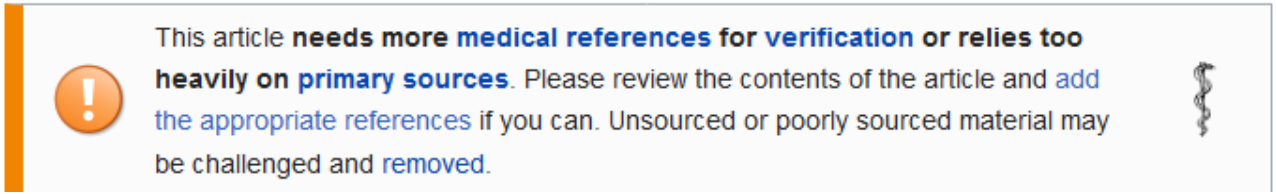
Signs and signals to evaluate articles

1. Assessment class
2. Templates
3. Breadth and readability
4. Reference diversity
5. Stability
6. Authority of contributors

Signs and signals to evaluate articles

1. Assessment class
2. Templates
3. Breadth and readability
4. Reference diversity
5. Stability
6. Authority of contributors

Class	Criteria
FA	Featured article
A	A-Class
GA	Good article
B	B-class
C	C-class
Start	Start
Stub	Stub



Signs and signals to evaluate articles

1. Assessment class
2. Templates
3. Breadth and readability
4. Reference diversity
5. Stability
6. Authority of contributors

Huntington's disease

From Wikipedia, the free encyclopedia

Huntington's disease (**HD**), also known as **Huntington's chorea**, is an inherited disorder that results in the death of brain cells.[4] The earliest symptoms are often subtle problems with mood or mental abilities.[1] A general lack of coordination and an unsteady gait often follow.[2] As the disease advances, uncoordinated, jerky body movements become more apparent.[1] Physical abilities gradually worsen until coordinated movement becomes difficult and the person is unable to talk.[1][2] Mental abilities generally decline into dementia.[3] The specific symptoms vary somewhat between people.[1] Symptoms usually begin between 30 and 50 years of age, but can start at any age.[4][3] The disease may develop earlier in life in each successive generation.[1] About eight percent of cases start before the age of 20 years and typically present with symptoms more similar to Parkinson's disease.[3] People with HD often underestimate the degree of their problems.[1]

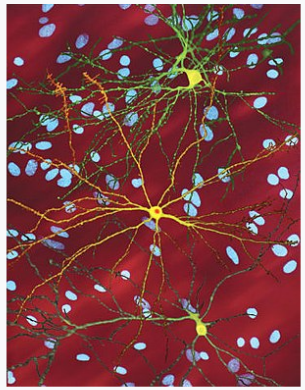
HD is typically inherited, although up to 10% of cases are due to a new mutation.[1] The disease is caused by an autosomal dominant mutation in either of an individual's two copies of a gene called *Huntingtin*.[4] This means a child of an affected person typically has a 50% chance of inheriting the disease.[4] The *Huntingtin* gene provides the genetic information for a protein that is also called "huntingtin".[1] Expansion of CAG (cytosine-adenine-guanine) triplet repeats in the gene coding for the Huntingtin protein results in an abnormal protein, which gradually damages cells in the brain, through mechanisms that are not fully understood.[4] Diagnosis is by genetic testing, which can be carried out at any time, regardless of whether or not symptoms are present.[5] This fact raises several ethical debates: the age at which an individual is considered mature enough to choose testing; whether parents have the right to have their children tested; and managing confidentiality and disclosure of test results.[2]

There is no cure for HD.[4] Full-time care is required in the later stages of the disease.[2] Treatments can relieve some symptoms and in some improve quality of life.[3] The best evidence for treatment of the movement problems is with tetrabenazine.[3] HD affects about 4 to 15 in 100,000 people of European descent.[1][3] It is rare among Japanese, while the occurrence rate in Africa is unknown.[3] The disease affects men and women equally.[3] Complications such as pneumonia, heart disease, and physical injury from falls reduce life expectancy.[3] Suicide is the cause of death in about 9% of cases.[3] Death typically occurs fifteen to twenty years from when the disease was first detected.[4]

The first likely description of the disease was in 1841 by Charles Oscar Waters.[7] The condition was described in further detail in 1872 by the physician George Huntington, after whom it is named.[7] The genetic basis was discovered in 1993 by an international collaborative effort led by the Hereditary Disease Foundation.[8][9] Research and support organizations began forming in the late 1960s to increase public awareness, to provide support for individuals and their families, and to promote research.[9][10] Current research directions include determining the exact mechanism of the disease, improving animal models to aid with research, testing of medications to treat symptoms or slow the progression of the disease, and studying procedures such as stem cell therapy with the goal of repairing damage caused by the disease.[8]

Huntington's disease

Other names	Huntington's chorea, Saint Vitus' dance



An edited microscopic image of medium spiny neurons (yellow) with nuclear inclusions (orange), which occur as part of the disease process, image width 360 µm

Specialty	Neurology
Symptoms	Problems with mood, mental abilities, coordination, jerky body movements[1][2]
Complications	Pneumonia, heart disease, physical injury from falls, suicide[3]
Usual onset	30–50 years old[4]
Duration	Long term[4]
Causes	Genetic (inherited or new mutation)[4]
Diagnostic method	Genetic testing[5]
Differential diagnosis	Sydenham's chorea, benign hereditary chorea, lupus, paraneoplastic syndrome, Wilson's disease[6]
Treatment	Supportive care[2]
Medication	Tetrabenazine[3]

References [edit]

1. ^ a b c d e f g h i j k Dayalu P, Albin RL (February 2015). "Huntington disease: pathogenesis and treatment". *Neurologic Clinics*. **33** (1): 101–14. doi:10.1016/j.ncl.2014.09.003. PMID 25432725.
2. ^ a b c d e f Caron NS, Wright GE, Hayden MR (2014). Adam MP, Ardinger HH, Pagon RA, Wallace SE, Bean LJ, Stephens K, Amemiya A (eds.). "Huntington Disease". *GeneReviews*. PMID 20301482.
3. ^ a b c d e f g h i j k l Frank S (January 2014). "Treatment of Huntington's disease". *Neurotherapeutics*. **11** (1): 153–60. doi:10.1007/s13311-013-0244-z. PMC 3899480. PMID 24366610.
4. ^ a b c d e f g h i j k "Huntington's Disease Information Page: National Institute of Neurological Disorders and Stroke (NINDS)". *NINDS*. 28 January 2016. Archived from the original on 27 July 2016. Retrieved 19 July 2016.
5. ^ a b Durr A, Gargiulo M, Feingold J (November 2012). "The presymptomatic phase of Huntington disease". *Revue Neurologique*. **168** (11): 806–8. doi:10.1016/j.neurol.2012.07.003. PMID 22902173.
6. ^ Ferri, Fred F. (2010). *Ferri's differential diagnosis : a practical guide to the differential diagnosis of symptoms, signs, and clinical disorders* (2nd ed.). Philadelphia, PA: Elsevier/Mosby. p. Chapter H. ISBN 978-0323076999.
7. ^ a b Vale TC, Cardoso F (2015). "Chorea: A Journey through History". *Tremor and Other Hyperkinetic Movements*. **5**. doi:10.7916/D8WM1C98. PMC 4454991. PMID 26056609.
8. ^ a b "Learning About Huntington's Disease". *www.genome.gov*. Archived from the original on 4 July 2016. Retrieved 19 July 2016.
9. ^ a b c d "History of the HDF". Hereditary Disease Foundation. Archived from the original on 19 November 2015. Retrieved 18 November 2015.
10. ^ a b "Huntington's Disease Society of America – Our History". Huntington's Disease Society of America. 2008. Archived from the original on 9 April 2015. Retrieved 17 March 2009.
11. ^ a b c d van Duijn E, Kingma EM, van der Mast RC (2007). "Psychopathology in verified Huntington's disease gene carriers". *The Journal of Neuropsychiatry and Clinical Neurosciences*. **19** (4): 441–8. doi:10.1176/appi.neuropsych.19.4.441. PMID 18070848.
12. ^ a b c d e f g h i j k l m n o p q r s t u v w x y z aa ab ac ad ae af ag ah ai aj ak al am an ao ap aq ar as at au av aw ax ay az ba bb bc bd be bf bg bh bi bj bk bl bm bn bo bp bq br bs bt Walker FO (January 2007). "Huntington's disease". *Lancet*. **369** (9557): 218–28. doi:10.1016/S0140-6736(07)60111-1. PMID 17240289.
13. ^ a b c "Huntington Disease". *genereviews bookshelf*. University of Washington. 19 July 2007. Archived from the original on 10 February 2009. Retrieved 12 March 2009.
14. ^ Hammond K, Tatum B (26 June 2010). "The Behavioral Symptoms of Huntington's Disease". Huntington's Outreach Project for Education, at Stanford. Archived from the original on 8 August 2014. Retrieved 4 August 2014.
15. ^ a b Kremer B (2002). "Clinical neurology of Huntington's disease". In Bates G, Harper P, Jones L (eds.). *Huntington's Disease – Third Edition*. Oxford: Oxford University Press. pp. 28–53. ISBN 978-0-19-851060-4.
16. ^ Wagle AC, Wagle SA, Marková IS, Berrios GE (2000). "Psychiatric Morbidity in Huntington's disease". *Neurology, Psychiatry and Brain*
67. ^ Simonin C, Duru C, Salleron J, Hincker P, Charles P, Delval A, Youssov K, Burnouf S, Azulay JP, Verny C, Scherer C, Tranchant C, Goizet C, Debruxelles S, Defebvre L, Sablonnière B, Romon-Rousseaux M, Buée L, Destée A, Godefroy O, Dürr A, Landwehrmeyer B, Bachoud-Levi AC, Richard F, Blum D, Krystkowiak P (October 2013). "Association between caffeine intake and age at onset in Huntington's disease". *Neurobiology of Disease*. **58**: 179–82. doi:10.1016/j.nbd.2013.05.013. PMID 23732677.
68. ^ "EBM: Levels of Evidence". Essential Evidence Plus. Archived from the original on 2 March 2012. Retrieved 23 February 2012.
69. ^ Panagiotakis PH, DiSario JA, Hilden K, Ogara M, Fang JC (2008). "DPEJ tube placement prevents aspiration pneumonia in high-risk patients". *Nutrition in Clinical Practice*. **23** (2): 172–5. doi:10.1177/0884533608314537. PMID 18390785.
70. ^ a b "EHDN Physiotherapy Guidance Document" (PDF). European HD Network Physiotherapy Working Group. Archived (PDF) from the original on 4 March 2016. Retrieved 15 November 2015.
71. ^ Quin L, Busee M (February 2012). "Development of physiotherapy guidance and treatment-based classifications for people with Huntington's disease". *Neurodegenerative Disease Management*. **2** (1): 21–31. doi:10.2217/nmt.11.86.
72. ^ Khalil H, Quinn L, van Deursen R, Martin R, Rosser A, Busse M (January 2012). "Adherence to use of a home-based exercise DVD in people with Huntington disease: participants' perspectives". *Physical Therapy*. **92** (1): 69–82. doi:10.2522/ptj.20100438. PMID 21960468.
73. ^ Travers E, Jones K, Nicol J (2007). "Palliative care provision in Huntington's disease". *International Journal of Palliative Nursing*. **13** (3).
74. ^ "FDA Approves First Drug for Treatment of Chorea in Huntington's Disease". U.S. Food and Drug Administration. 15 August 2008. Archived from the original on 21 August 2008. Retrieved 10 August 2008.
75. ^ Harper P (2002). "Genetic counselling and presymptomatic testing". In Bates G, Harper P, Jones L (eds.). *Huntington's Disease – Third Edition*. Oxford: Oxford University Press. pp. 198–242. ISBN 978-0-19-851060-4.
76. ^ Harper PS (June 1999). "Huntington's disease: a clinical, genetic and molecular model for polyglutamine repeat disorders". *Philosophical Transactions of the Royal Society of London. Series B, Biological Sciences*. **354** (1386): 957–61. doi:10.1098/rstb.1999.0446. PMC 1692597. PMID 10434293.
77. ^ Andrew SE, Goldberg YP, Kremer B, Telenius H, Theilmann J, Adam S, Starr E, Squitieri F, Lin B, Kalchman MA (August 1993). "The relationship between trinucleotide (CAG) repeat length and clinical features of Huntington's disease". *Nature Genetics*. **4** (4): 398–403. doi:10.1038/ng0893-398. PMID 8401589.
78. ^ Crauford D, Snowden J (2002). "Neuropyschological and neuropsychiatric aspects of Huntington's disease". In Bates G, Harper P, Jones L (eds.). *Huntington's Disease – Third Edition*. Oxford: Oxford University Press. pp. 62–87. ISBN 978-0-19-851060-4.
79. ^ Di Maio L, Squitieri F, Napolitano G, Campanella G, Trofatter JA, Conneally PM (April 1993). "Suicide risk in Huntington's disease". *Journal of Medical Genetics*. **30** (4): 293–5. doi:10.1136/jmg.30.4.293. PMC 1016335. PMID 8487273.

Signs and signals to evaluate articles

1. Assessment class
2. Templates
3. Breadth and readability
4. Reference diversity
5. Stability
6. Authority of contributors

When

- October 8 – November 1
- Four live weekly sessions, beginning Tuesday, October 8
- Readings, activities and discussions in between sessions

How to enroll

- Go to oc.lc/wikihealth
- Limited to 100 public library staff
- It’s FREE!
- See course FAQ for other information

thank you