

How to Find Reliable Myositis Information on the World Wide Web and Elsewhere

***Opinions, Crazy Ideas, Greed, Fraud =
Chaos and Confusion***

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Who am I?

- ***Polymyositis*** and Lupus patient since 2005
- Lupus symptoms were severe and complicated
- Polymyositis symptoms were extreme/life threatening leaving me quadriplegic with a feeding tube
- IVIG saved my life in the nick of time
- Physical, Occupational and Speech therapies restored my strength and function
- Continued exercise restored more strength, returning me to full function and an active life
- Married to my best friend with 4 grown sons and 8 grandchildren

Why am I speaking to you on this topic today?

- Worked in technology for 15 years
- Business and technology consultant for the last 12 years
- ***I want to help you find the best and most reliable information about myositis diseases and how to cope with them***

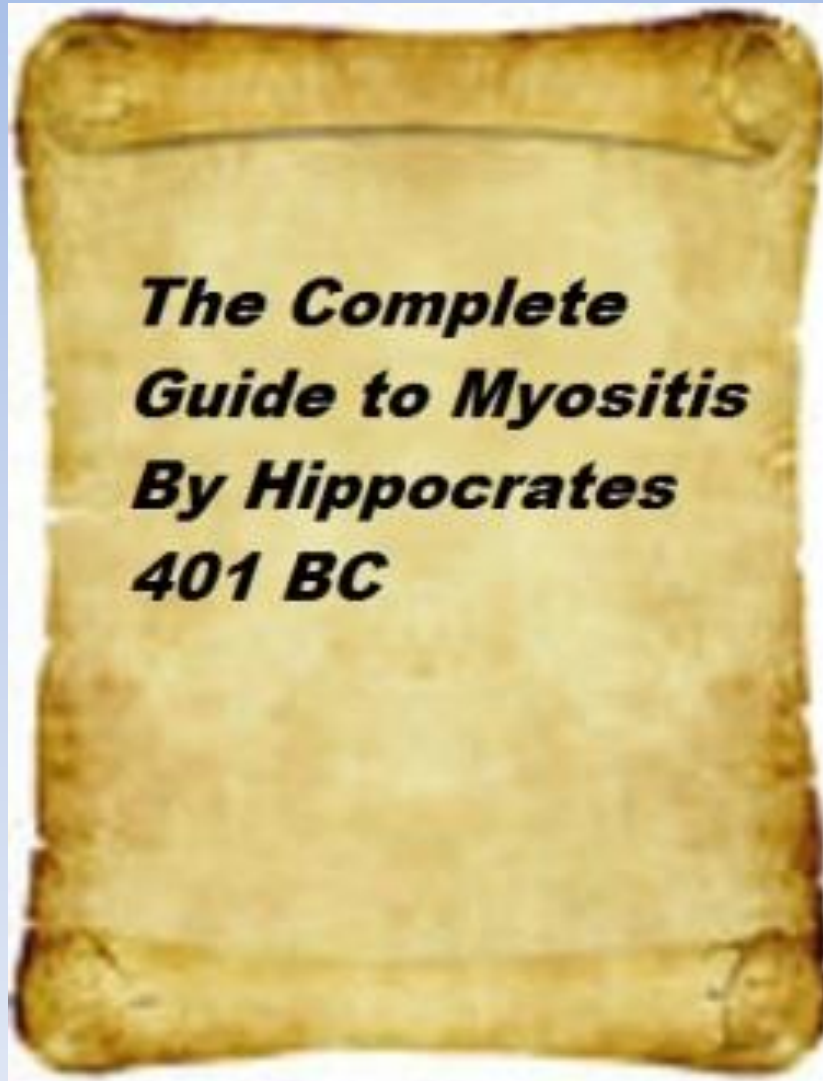
Do you know what this building is?



The Ancient Library of Alexandria, Egypt

- ***2500 years ago*** it was the biggest repository of scientific and general knowledge contained in scrolls kept in the ***Ancient Library of Alexandria, Egypt*** and a second smaller library. Rumored to contain ***500,000-700,000 scrolls***, few had access to discover what was thought to be the collective knowledge of the ancient world. ***Knowledge was scarce and unavailable to most.***
- The library was destroyed by a ***fire*** or fires although scholars do not agree on the facts and dates. Knowledge from the ancients largely disappeared and it took centuries to be partially rediscovered.
- One can only ***speculate*** if that ancient knowledge had been preserved how society and technology might have progressed.

It might have housed the following scroll!



Do you know what this is?



A Replica of the Gutenberg Press

- The invention of ***moveable type setting*** and the ***printing press*** provided a way to ***mass print books and accelerate the spread of knowledge and to place many books in many libraries***. Although we have been taught that it was invented by Gutenberg in the 15th century printing technology probably started in China in the 11th century and evolved over several centuries.
- The ability to replicate books quickly meant duplicates could be placed in many libraries instead of one.
- ***Knowledge became available to many more seekers.***
- But you still had to ***travel*** to a library.

Do you know what this building is?



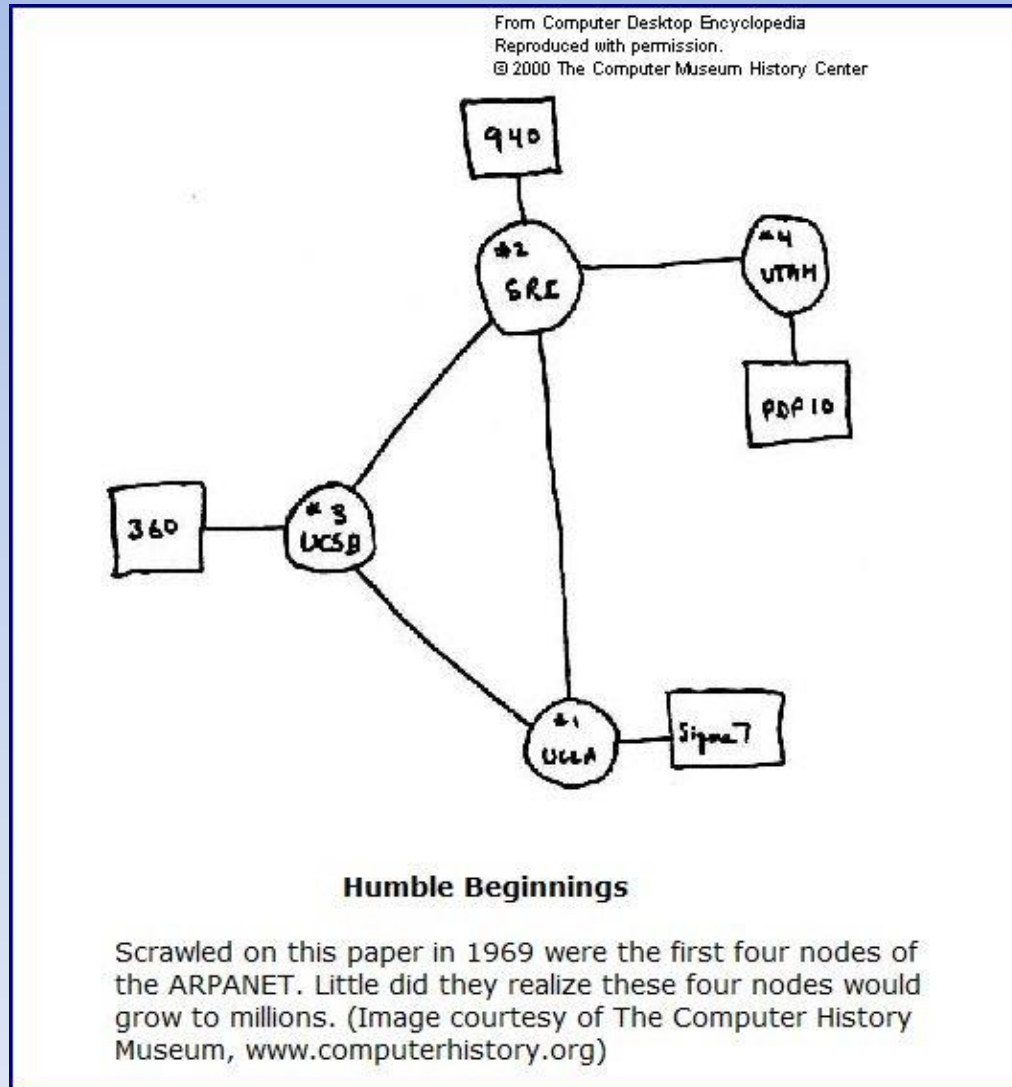
Franklin Public Library, Franklin, Massachusetts

“The ***Franklin Public Library*** (Massachusetts) is considered America's first public library. In 1778, when the town was incorporated, the designated name Exeter was changed to Franklin in honor of Dr. Benjamin Franklin. In return Franklin was asked to donate a bell for the town's church steeple. Acknowledging that "sense" was preferable to "sound", Dr. Franklin responded with an offer of books for the use of the town's residents. When the volumes arrived, a great controversy arose over who should be allowed to use them. ***On November 20th, 1790, those attending Franklin's town meeting voted to lend the books to all Franklin inhabitants free of charge. This vote established the Franklin collection as the first public library in the United States.*** The original Franklin collection is still housed in a book case in the library's Reading Gallery.” Franklin, MA website.

Things really begin to change

- In **1969** physicists working with the **Defense Department** implemented the internet (network of networks, commonly called a wide area network today). It was first called **ARPANET** and only had a few sites and users but laid the groundwork for what would come later.
- The old system of searching books in libraries had expanded for several centuries and was the only way to search for knowledge until the **World Wide Web** (web) was invented by physicists from **CERN**.
- In **1992** the newly invented World Wide Web application created what is mistakenly called the internet. The World Wide Web is a **software application** running on the internet that we use today. The internet is the **infrastructure** that the WWW runs on. The web has become ubiquitous in science, education, commerce, social discourse, and our lives in general.
- Today, most knowledge, old and new, is **digital** and can be accessed by anyone with a computer and access to web. **Knowledge is literally at our finger tips.**

Hand drawn diagram of Arpanet, 1969.



How did these recent inventions impact storing and finding knowledge?

- Unlike the past you ***do not have to travel to a library***. Virtually ***ALL*** libraries can be accessed from your computer at home. ***Absolutely revolutionary and democratic***.
- Knowledge is increasing on the web exponentially.
- There are ***no web police*** (in the western world) and serious scholars and scientists, quacks, hackers, commercial companies, non profit organizations, government agencies and individuals all contribute to the web daily. ***The American West was never this wild and untamed***.
- Most knowledge that you seek is ***available*** (but not always free) so the ***challenge*** is to find reliable information and avoid ***bogus information*** that could lead you to ***harmful treatments, ineffective magic potions and cures, or worse***.
- The internet is a ***VAST*** network of physical and digital infrastructure (fiber optics and copper cables, satellites, huge data centers with countless computers, routers, switches, storage, back up, and software). It is estimated that 10% of the electric power in the world is used in the technology and information ecosystem. New data centers are constantly being added and all are growing exponentially as more personal data is kept in the “cloud” as storage technology advances to increased capacity.

- The economic engine of the web is **commerce**. The almost free web (except for access fees and proprietary content) we enjoy today is paid for by advertising and websites gathering information and using or selling it to identify potential customers for goods and services. You are constantly being **“tracked” and your internet behavior recorded and analyzed for commercial purposes**. Those annoying ads and pop-ups are part of that system. So are the pop-up ads that appear magically after you visit a particular site to look at something.
- Many **noncommercial websites** that hold medical information we need are created by hospitals, medical schools, advocacy organizations like **TMA**, and government agencies like the **National Institutes of Health**. It is important to **support those private institutions and appreciate that our taxes pay for vital public infrastructure like NIH** and much more.
- About **1 billion websites** today, only 1 in 1991.
- **60 trillion web pages** and growing.
- About **3 billion users** of the web today.
- **Google has 78% of all searches**. 3.5 billion per day, 1.2 trillion per year. When Google was founded in 1998 there were only 10,000 searches per day.

Modern perspectives on storing and disseminating knowledge

“Networked knowledge: Such collaboration is the lifeblood of the internet. Whereas in earlier times libraries and encyclopedias offered their riches to a fortunate few, today all of humanity’s knowledge is online, just a few clicks away from almost anyone.” Northwestern University Economist Dr. Robert Gordon.

“We thought knowledge was scarce, when in fact it was just that our shelves were too small. Our new knowledge is not even a set of works. It is an infrastructure of connection.” Internet Philosopher David Weinberger.

How do you use search engines to find information you need?

- ***Think digital, not library mode.*** The old way of finding information was to physically travel to a library or bookstore. Today, you can “travel” not just to your local library but to every other library in the world using a search engine. A search can be done in seconds or even milliseconds.
- ***Google*** will be the default search engine for this talk.
- Using ***primary search terms*** like polymyositis, dermatomyositis, or inclusion body myositis will produce too many hits. Refine your search by ***adding relevant search terms***: polymyositis and ILD or dysphagia.
- If one search does not produce what you want, ***modify*** it again: polymyositis dysphagia and vital stim. Adding a 2nd or 3rd search term will refine the results. Relevant hits will appear on the first or second page. Each subsequent page becomes less relevant to your search terms.
- Try several different search terms until you find what you seek. ***One small change can be magical.*** Each search engine has proprietary technology and will produce different results.

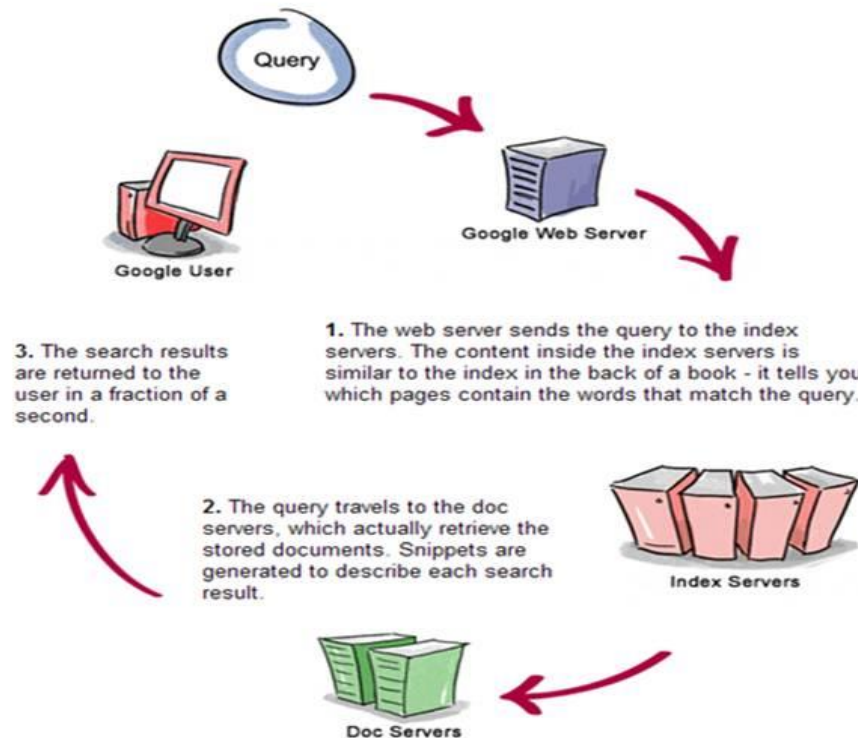
- No need to use the “King’s English” or proper grammar. Even if you spell it wrong it will correct you. Your search engine will *interpret* what your search terms mean. **Google “translates” them to produce relevant results.**
- Google **advanced search** can be accessed by clicking on the gear on the upper right of the Google search home page, then advanced search. Refine your search as needed.
- There are also some **generic search modifiers** under the Google search bar for your current search: web, images, books, news, videos and more.
- Your search engine will *“learn”* from your searches and refine results based on past searches and sites you visit so try to do your heavy research from one computer for best results.
- **Paradoxically, it is often more effective to use Google instead of searching on a specific site.** Their search engines are often not as powerful or intuitive as Google.
- The best general search engines are Google, Bing, and Yahoo but there are many others.

What happens in a web search request?

Life of a Google Query

Life of a Google Query

The life span of a Google query normally lasts less than half a second, yet involves a number of different steps that must be completed before results can be delivered to a person seeking information.



How can you work through the chaos of the internet to find reliable information?

Following are some suggestions from McGraw-Hill Companies on ***how to judge the reliability of internet information***. Ask the following:

- Who is the author or sponsor of the page?
- Are there obvious reasons for bias?
- Is contact information provided?
- Is this page a “zombie?”
- What is the purpose of the page?
- How well organized is the page?
- Is the information on the page primary or secondary?
- Can you verify the information?
- If you are worried that the information may lack credibility, try starting with a source you know is reputable.

Additional suggestions from the *Medical Library Association* (MLA) to evaluate sites and content:

- Who is sponsoring the website?
- How often is the site updated?
- Does the site present facts and not opinion?
- Who is the intended audience?

MLA further suggests going to their translation site: **What did my Doctor say?** MLA also evaluates medical sites and offers advice to get started.

www.mlanet.org/resources/userguide.html

What are some reliable sites?

Search reliable sites like:

- The Myositis Association: www.myositis.org
- National Institutes of health: www.nih.gov
- National Institute of Arthritis and Musculoskeletal and Skin Diseases: www.niams.nih.gov
- Johns Hopkins Myositis Center: www.hopkinsmyositis.org
- Clinical Trials, NIH: www.clinicaltrials.gov
- JAMA Neurology (Journal of the AMA): www.jamanetwork.com/journal
- Muscular Dystrophy Association: www.mdausa.org
- American College of Rheumatology (The Rheumatologist Magazine): www.rheumatology.org/publications/tr/index.asp

Search reputable e-medical sites such as:

www.medicinenet.com

www.emedicine.com

Search sites of Major Medical Institutions like Mayo Clinic, Northwestern Memorial Hospital, The Cleveland Clinic and Johns Hopkins to name a few.

Subscribe to free email services like MedlinePlus (NIH) or Science Daily and receive emails in your area of interest. Select your area(s) of interest and receive the latest articles and research with links to additional information. “***MedlinePlus*** is the National Institutes of Health's site for patients and their families and friends. Produced by the National Library of Medicine, it brings you information about diseases, conditions, and wellness issues in language you can understand. MedlinePlus offers reliable, up-to-date health information, anytime, anywhere, for free.”

www.nlm.nih.gov/medlineplus/
www.sciencedaily.com/

TIP: Professional articles are sometimes free and available in PDF format. Most sites require registration. Some require a subscription fee or an individual payment for an article (can be expensive). TMA will often have important myositis articles posted which can be accessed from the home page under “Explore Research.” ***Check TMA before paying.***

What is Pub Med and why should you use it?

Search Pub Med for medical articles (Wikipedia citations as of 7/28/2014).

- *“PubMed comprises more than **24 million** citations for biomedical literature from MEDLINE, life science journals, and online books. Citations may include links to full-text content from PubMed Central and publisher web sites.”*
- *Records go back to 1966, selectively to 1865, and very selectively to 1809 with about 500,000 articles added annually.*
- *13.1 million articles are listed with their abstracts. 14.2 million articles have links to full-text versions (3.8 million free).*
- *A vast resource of medical information in the **National Library of Medicine (NLM) at the National Institutes of Health.***
- ***Register** as a user to access this vast library. Registration is **free.***
www.ncbi.nlm.nih.gov/pubmed

How can you use PubMed and what resources are available to help new users?

- Go to the PubMed site and **register** as a user
- Under **“Using PubMed”** there are resources for using the site:
 - PubMed Quick Start Guide
 - Full Text Articles information
 - PubMed FAQs
 - PubMed Tutorials
- **YouTube** instructional videos for many topics
- Other resources for advanced users
- **My NCBI** (National Center for Biotechnology Information) provides tools to save your searches, filter search results, set up email updates, and more.

What can you do if an article is not free?

- Try accessing through your local, ***public library***
- Go directly to the ***publisher or author***
- Try accessing through your ***local medical library***
- Go to ***TMA***
- Do a ***Google*** search to see if available on another site for free

TIP: use Google to find a free version of an article from an alternate site.

What resources does TMA have?

- Go to the ***TMA Home Page*** at www.myositis.org and ***explore all the resources offered***
- “Learn about Myositis”
- “Your Myositis Community”
- “For Health Professionals”
- “Explore Research”
- “Get involved”

Should you use the TMA community forums?

Post your questions to get answers from your ***peers***. Many have the knowledge and experience you seek and cannot get from your doctor or researchers. ***Doctors are NOT Myositis Patients and do not have the real life experiences we have.*** However, remember that most posters are not medical professionals and ***good and bad information is posted.*** Usually, knowledgeable posters will challenge or correct inappropriate information that is not supported by science or best medical practices.

Join a TMA KIT group if there is one in your community

Should you join Facebook groups created for myositis patients?

There are many groups administered by myositis patients or caregivers. Some are open groups where any FB member can read and post on the page. Others are closed and only FB members who are accepted by the administrators can read and post. Keep in mind that ***FB “owns” any information you post.*** FB can be very useful but it can also be the “wildest of the west” on the web.

Some final thoughts

Be ***skeptical*** of the following:

- Any site that is ***selling*** something
- Alternative/complementary/homeopathic medicine, diets, supplements, and treatments as ***primary*** treatments
- ***Anecdotal stories*** of success with no medical studies to back them up
- Doctors or others who claim to have a ***wonder treatment*** that the medical community ignores

Thank you for coming to this session

Questions?

Presented by ***Bill Simeral***

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(Note there is an underscore between my first and last name)

September 2014

***A PDF copy of this presentation is posted on the
TMA site for downloading***