

LEADERSHIP

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QUESTION: “How do we help our members find good online information and use this in communicating with those in the medical community and others?”

ANSWER: Finding reliable and relevant polio information online can sometimes be a challenge. The difficulty is not a paucity of information but rather the overwhelming number of possibilities to sort through in the search. Sources indicate there are approximately 400 million websites on the Internet. This means the first thing to know is what to look for.

Polio information seems to be offered everywhere, and quality ranges from hard scientific facts described on legitimate websites to opinions and guesses offered on others. It matters that conclusions are backed by properly-conducted studies or recognized authorities in the field. The credentials of the experts we cite also matter. Do we know the difference between an M.D. and a Ph.D.? A psychiatrist and a psychologist? A physiatrist and a podiatrist?

Anecdotal stories related on polio listservs or in chat rooms may be interesting, but they are not a dependable source of polio information. Passing on chat room twaddle in our support groups can actually be dangerous. Of course there is considerable value in discussing personal experiences—this is a main function of support groups. However, it's one thing to inform someone where I bought my comfy shoes. It's quite another to advise that person not to take a certain medication because I, or a polio survivor I know, had a reaction to it. We can all learn to identify and to become reliable resources.

Questions to ask to determine if online information is trustworthy:

- **Has the website been updated frequently?**
Websites often state at the top or bottom of their homepage the last time they updated (and how often they do this). Specific pages or articles that have been updated may also give that revision date.
- **Is the report we're using recent?**
Current material usually tells us more of what we need to know. It might be important to find out if there is a follow up to older reports and if not, why not.
- **If we use a medical article, does it come from a well-known medical research institution, a government medical institution, or a professional medical journal?**
Learning to know the difference may be an ongoing education project for groups. Each source must be evaluated on its merits. An excellent source for one topic may not meet the requirements for another.
- **Are our chosen medical journal articles peer reviewed?**
Journals indicate if they are peer reviewed. It's reassuring to know that professionals in the same field have read and evaluated articles for their scientific and technical quality.

- **Do medical articles represent scientific investigation rather than stories gathered from non-credentialed sources?**

Organized research by skilled professionals yields much more reliable information than reports of individual experiences do.

- **Have all articles been written by individuals qualified by training and expertise to speak on the subject?**

The best person to talk about a subject is an expert in that field. It rarely works to go to a shoe store to buy bread.

- **Are the name and credentials of the author clearly stated?**

It's much easier to judge the worth of an article if we know that the author is a recognized expert on the topic. Anonymous pieces belong at the bottom of the list.

- **Have we been careful to avoid “sponsored” links, which may simply try to sell something rather than offer reliable facts?**

Reviewing pages carefully makes this simple—there is discussion of products being sold on sponsored pages. If a product is linked with a “medical finding,” this may be reason for suspicion.

- **Are product and treatment claims backed up with clinical studies and scientific proof?**

Various types of legitimate research exist. If studies weren't done, a claim may not be as genuine as it purports to be.

Group leaders are always interested in good ways to pass on what's new to members. At the top of the list is being sure that everyone leaves a meeting with dependable facts. This requires leaders to find ways to stay on top of the situation so that factual discussions don't turn into prattle.

Individuals unaware of the difference between an anecdotal tale and significant medical information may not understand the importance of knowing we have the facts right. It might be a good idea to devote a meeting to the art of evaluating material so everyone is on the same page. In the hands of a clever member, such a meeting can be a lot of fun—even exciting!

Mainly we want to avoid those awkward moments when members verbally attack another member or even an invited speaker because the assailants may not be as informed (or as tactful) as they should be. Leaders can help!

One idea is to direct members to appropriate information when the next meeting's topic is announced. The topic committee could hand out a list of excellent websites so members can take a look and be well-informed when the time comes. The committee might also copy the text of a special article (being sure they have permission if it is copyrighted) to give members so they can become familiar with it before the meeting.

It's a good idea to provide this material to invited speakers, as well, if they have been asked to talk on a subject of the group's choosing. If speakers select the topic, perhaps they would be willing to offer the group the same kind information, especially if they are told that the group likes to have a Q&A session with speakers when they finish their talks.

A few tips on asking questions can bring out amazing skills in members interested in the give and take of interactive meetings. How can we get what we're after? Let's say a doctor has described various types of anesthesia used in differing procedures. Does it work best for me to say, "That's just dumb. Everybody knows polio survivors shouldn't be given some of those anesthetics!" Or "Doctor, let me show you this article that says polio survivors are usually better off if they aren't given that particular anesthetic. Would you explain why that's the case?"

Consider Jane, who mentions at a meeting that the pain in her shoulder has been diagnosed as a torn rotator cuff and that she and the doctor are figuring out whether therapy or surgery is the way to go. What happens if another member, Fred, rather than wishing her the best, chimes in with "You'd better have the surgery--my cousin Jack had the same problem, and he couldn't raise a fork to his face today if he hadn't had surgery"? Does Fred understand the implications of surgery for Jane, a paraplegic? Does he know anything about her general condition? Maybe it's better if members don't give advice and, instead, try to stick with their own lives, rather than getting into situations they truly know little about.

Open-minded discussion can be healthy and exhilarating. Everyone learns through energetic participation, which leads to invigorating meetings that members are anxious to return to. Can't beat that!
