With 27 interactive community forums, Better Health, formerly the Better Health & Medical Network, receives almost 2 million new entries each month. And, its support groups are booming, too, with 500 regularly scheduled meetings a month. Founder Elin Silveous shares her experience and explores the virtues and drawbacks of this high-tech approach to health care.
A Virtual Pioneer

Over the past two years, there has been an information explosion through online electronic services such as the World Wide Web and commercial services such as America Online. In the forefront of this movement is Elin Silveous, a virtual pioneer in harnessing the power of online media to support health decisions of people everywhere. Co-Senior Editor George Pfeiffer, FAWHP, and Silveous discuss the potential of online services.

George Pfeiffer: You were one of the first proponents and developers of consumer health-oriented online media, specifically through your association with America Online. How did you start the Better Health & Medical Network, and how did it grow?

Elin Silveous: I launched the Better Health & Medical Network on AOL in the spring of '93, when AOL had 250,000 members. Today, the service is available on AOL and the World Wide Web. AOL reaches more than 12 million households, and there are more than 20 million more logging onto the Web.

From the very first day on AOL, my partner and husband, Allen Douma, M.D., and I set out to build the nation's most active, supportive online community for informed health-care decision making, empowerment and people helping people. That was our publicly stated mission then and remains our mission now.

Conceptualizing, developing and growing the online forum was the culmination of several years of experience in health-care publishing and marketing, health promotion and managed-care communications — coupled with my personal diagnosis of multiple sclerosis. Following the diagnosis, I went online to look for information and support. I tried several different sources, and it quickly became clear that information was nonexistent, difficult to find or very expensive. The same was true for online mutual support groups via message boards and chat rooms.

So I did a competitive analysis of the online services at the time — AOL, Delphi, Genie, CompuServe, Prodigy. The Better Health & Medical Network grew from that analysis, and AOL was our choice to distribute it.

As technology changed and developed, the Better Health & Medical Network changed too. We were the first to provide consumers access to MEDLINE in an easy-to-use, low-cost manner. We built and managed sites for five large national voluntary health organizations, as well as managed-care organizations.

The Better Health & Medical Network is among the most visited health-care communities on AOL and the Web. We offer more than 500 live, regularly scheduled online mutual support groups each month, in addition to ask-the-expert programming.

In May 1997, the company that Allen and I founded — Health ResponseAbility Systems (publishers of the Better Health & Medical Network) — merged with iVillage Inc. Allen and I are still actively involved in the online health community and are consultants to iVillage and other companies. He and I are also in the process of establishing a foundation to facilitate the use of online technology to empower people, particularly the elderly and individuals with disabilities.
Pfeiffer: What are the major benefits of the World Wide Web in disseminating health information?

Silveous: Online technology — whether through the open communities of the Internet and the World Wide Web or closed communities such as AOL or CompuServe — has tremendous potential to empower people and help them become more informed health-care consumers.

The technology breaks down barriers to communication, such as lack of local resources or transportation. It’s available 24 hours a day and provides people with a broad and deep range of information, from medical self-care to managing a chronic condition. It also gives people access to more timely and sometimes personalized information, such as news.

From their homes, employees — as well as health-care professionals — can access things such as the latest clinical trials (from the National Cancer Institute’s Web site at http://www.nci.nih.gov/), medical journals, the National Library of Medicine’s MEDLINE (http://www.ncbi.nlm.nih.gov/PubMed/), experts’ opinions and answers to questions on topics ranging from children’s health to women’s health.

It also permits consumers to get information directly from national voluntary health organizations such as the American Diabetes Association, the American Running and Fitness Association, or the American Medical Association.

Very importantly, a big advantage of the technology is that people online can talk with other people, via message boards, chat rooms and private e-mail. The opportunity for an individual to log on and connect with another person who understands his or her emotional or physical challenges is a very powerful resource. And millions of people are doing it daily across the Internet and around world, since the Internet spans the globe.

Our research shows that participation in online health communities decreases unnecessary visits to the physician, as well as the emergency room. Both represent significant costs not only to consumers, but employers as well.

Pfeiffer: Who do you think benefits the most from online technology?

Silveous: Forty-one percent of respondents to a survey conducted on the efficacy of the Better Health & Medical Network indicated it was a very valuable source of networking with others whose health or disability interests were similar to theirs.

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Pfeiffer: And what are the drawbacks to online services?

Silveous: Some of the benefits are also drawbacks. I mentioned the volumes of information that health-care consumers can access. But there’s too much information, and it’s often tough for people to figure out where to start. We’ll see this drawback decrease as search engines add context to content and community, as one service has already done.
Also, there is a lot of misinformation online. Because Web sites can archive so much information, it can be out-of-date or inappropriate. This drawback will be eliminated, too, as more personalized needs- and interest-assessment tools are implemented.

Another source of misinformation is individuals who promote their agendas because it is easy and inexpensive to publish on the Web. Their agendas may be driven by personal experience that doesn’t apply to others or because they are selling products related to their information.

In terms of getting online, hardware costs, such as for a computer and monitor, are still a barrier for people, especially lower-income families and the elderly. Lack of knowledge about computers and online services is also a barrier. Both of these will become less so as more programs are developed to help older individuals and lower-income families gain access via their local communities or third parties.

The technology has the potential of creating a disparity between those who have access to information and those who don’t. That’s just one of the reasons why accessibility is so very important.

But, almost everyone in small towns will be able to log on at the library. Retirees will be able to log on from the mobile home clubhouse. And kids in the inner city will be able to get online at school or church. My dream is that no one dealing with a health issue or concern feels alone — that, someday, anyone will be able to log on from a location, and they won’t have to be able to afford a computer.

**Pfeiffer**: Related to the issues of credibility and medical quackery, how does the average consumer make an informed health decision when researching health information on the Internet?

**Silveous**: Misinformation has always been available, whether from tabloids, books or over the backyard fence. Consumers should know not to believe everything they see, hear or download from the Web. They should check the source of the information, as well as multiple resources, including their personal health-care professionals.

The good news is that when information is accessed in the context of an active online health community, there is a lot of self-regulation. And, concerns about this issue will increase awareness of its importance off-line and greater efforts will take place to improve and educate people on how to be more informed consumers, no matter what the source of the information.

**Pfeiffer**: What about the issue of security and confidentiality of health information?

**Silveous**: There’s been a great deal of discussion about the need to protect patients’ medical information when it is communicated via the Internet. This will certainly continue to be a major focus of people who encrypt and protect information. But perhaps what many people don’t realize is that medical information has been transferred electronically for years without major problems.

Concerns about confidentiality of health information may be especially important for intranets in which all traffic can be easily tracked. But, currently, all corporate e-mail can be, and there is already a lot of access by human-resources personnel to health benefits info. The same level of privacy must be maintained as for all other personal medical info.

And the use of anonymous screen names or e-mail addresses can allow people on the Internet to communicate more personal information without others knowing who they are.

**Pfeiffer**: What is the future of this technology as it reaches more people?

**Silveous**: Although a small percentage of people over the age of 60 now have online access, they are logging on at a faster rate than any other age group. Over the course of the next few years, use of the Internet by this age group will explode, as it becomes simpler and less expensive for people to connect online.

In the meantime, encouraging them to go to the library or providing company-sponsored kiosks will be a good thing.

For older individuals and caregivers too, the opportunity to connect with others in a mutual support group or communicate with family members via e-mail will be the difference between a life of isolation and a life with meaning.

That’s why my husband and I are starting a foundation to bring this technology to people with limited access.

**Pfeiffer**: How can companies use this technology for employees with disabilities?

**Silveous**: For employees with disabilities, staying connected via online may mean the difference between short-term disability and long-term disability. Also, the ability for employees with disabilities to work from home —
sometimes or all the time — is a powerful productivity tool that some companies are overlooking. Most people with disabilities want to work and contribute to society. Flexible work hours and flexible work-from-home policies enable them to do so, while increasing the effectiveness of corporate health, disease- and demand-management efforts.

Over the next few years, we’ll see an explosion in the development of assistive technologies and devices to help this growing audience log on. Speech software will make it physically easier for older folks with arthritis or joint problems. Ergonomic home-office chairs will be more comfortable for people with back problems or osteoporosis. Software that permits consumers to increase the size of type at work-from-home offices, labs, pharmacies and hospitals will be connected. And a majority of the doctors will have their own Web sites where patients and health professionals will communicate electronically.

Speaking about disabilities, many progressive companies are already using the Internet as a recruiting tool for prospective employees with — or without — disabilities.

For individuals with disabilities, the Internet is a valuable source of information and software for assistive technology and devices.

As the nation continues to age, it will be increasingly important for companies to keep a keen eye on how to adapt policies and procedures to accommodate work-from-home or assistive-technology needs.

**Pfeiffer: Where do you think the Internet is moving to technologically, and how will it help people better manage their health?**

**Silveous:** Five to 10 years from now, almost everyone will have online access. They’ll be logging on from home, office, school, hospital, libraries and local public health departments. International Data Corp. predicts that 23 percent of U.S. households will be online by the end of the year. In 1996, only 13 percent were online — that’s almost double in two years.

In the coming years, we’ll see a significant increase in patient-provider communications. Physicians will communicate with patients via e-mail, and consumers will have access to providers’ intranets. The use of telemedicine will be greater. All doctors’ offices, labs, pharmacies and hospitals will be connected. And a majority of the doctors will have their own Web sites where patients and health professionals will communicate electronically.

We’ll also see increased research on consumer health-care behavior, and clinicians will log on to attract participation in clinical trials.

We’ll see a gradual replacement of some public or open corporate Web sites with intranet sites over the next year. Almost every business — especially those with more than 50 employees — will have its own intranet so that employees and retirees can access health and employee benefits-related information. Or, some companies will have both. Intranets will be used to communicate private information to employees, and vice versa. The open Internet or Web sites will be used to inform consumers and prospective employees about the company and its products and services.

We’ll see more retail online pharmacies and extensions of mail-order pharmacies to online. Pharmaceutical manufacturers will play an increasing role in medication compliance.

Online banking and commerce will increase. And we’ll experience even more sophisticated technologies to target consumers’ health needs and interests. Needs- or interest-assessment instruments will be used to generate highly personalized, customized experiences for consumers.

There will be greater use of streaming audio and video to help employees become more informed, empowered consumers. The software will be better. The speeds faster. The hardware costs cheaper.

We’ll see companies adapting their human-resources policy manuals to accommodate work-from-home needs of people with caregiving demands — either for their children or an aging parent or a spouse with a disability — as well as for individuals with disabilities.

We’ll experience panmedia. Online will blend with television, radio, CDs, newspapers and magazines. International borders will blend, too. We’ll be an international online community achieving individual results. In health, those results will be enhanced health, well-being and quality of life.