

Alone Together

Cancer Patients and Survivors Find Treatment—and Support—Online.
It Can Make All the Difference

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After her husband was diagnosed with chronic myelogenous leukemia in 1996, Sherri Goldman found it hard to sleep. So one morning at 4 a.m. she sat down in front of their computer, something she had just learned to use. She logged onto an Internet browser and typed the word “leukemia” into the search box.

She didn’t know exactly what she was looking for, but one thing she found was BMT-Talk, an electronic-mail discussion group for people facing bone-marrow transplants to treat diseases such as leukemia, lymphoma and breast cancer.

Sherri sent in a quick note describing what she was going through: Her husband, Allan, a 42-year-old retailing executive, didn’t have a sibling donor for a transplant and hadn’t found an unrelated bone-marrow match. Mr. Goldman was on the drug interferon to keep the cancer in check. The couple with their three children had just moved to Maryland from Pennsylvania.

“I didn’t know a soul,” Mrs. Goldman recalls. “I was gripped with panic and desperate for support.”

The next day, when she logged on again, she was stunned to see about 20 e-mail responses in her “in” box. They ranged from sympathetic and humorous to informative, guiding her to other Internet sites where she could find useful information about Allan’s disease, about interferon, and new studies she should ask her doctor about.

“It saved me spiritually and psychologically,” she says. “I could compare notes with patients around the world, and I have made friends through BMT-Talk that rival lifelong relationships.” Mrs. Goldman says the information she finds online “has made me often more informed than the

oncologists we meet.” Though Allan has responded extremely well to interferon and is in complete remission, she continues to subscribe to BMT-Talk, saying it “has taught me we are not alone in this horrific turn of events we call cancer.”

Along with dozens of other disease-specific mailing lists and cancer-related Web sites, BMT-Talk is part of a growing cyberspace community of former and current patients that offers not only crucial information about treatment, but also moral support at a time when cancer victims and their families need it most.

Some of the online resources are also available by good old-fashioned phone, fax and post, but the Internet has made them accessible at lightning speed to anyone with a computer and a modem. Thanks to the spread of free Internet access at many public libraries, neither lack of a home computer nor computer illiteracy is reason not to take advantage of these resources.

NO SUBSTITUTE

To be sure, caveat emptor applies on the Internet as much as anywhere else. Some of what is out there is useless, confusing, unprofessional, dated, or offered up by someone trying to sell something. And even the best information can’t substitute for one-on-one contact with an experienced physician.

But because there are so many former and current patients behind the Internet’s best cancer resources, much of the homework has already been done for you. Cancer survivors who have already weeded out the good Web sites from the bad provide through their own Web pages direct links to crucial information, and many of them carefully monitor the latest developments. At the very least, these sites allow patients to meet their doctors better informed and better able to ask the crucial questions that could save their lives.

Moreover, much of the information long available only to doctors via medical libraries and government organizations such as the National Institutes of Health is now available to anyone on the Internet. The American Cancer Society, for example, has a Web site with links to online resources. It also instructs patients on how to query their doctors about specific cancers.

That wasn't the case just seven years ago, when this reporter was diagnosed with chronic myelogenous leukemia. I was fortunate to have a well-connected friend, Marilyn Dammerman, a Ph.D. scientist at New York's Rockefeller University. With access to Medline, the online link to the NIH, she was able to search for studies on my disease and come up with statistical information that proved invaluable to me in deciding to have a bone-marrow transplant at the Fred Hutchinson Cancer Research Center in Seattle.

Today, not only is information from Medline available on the Internet, but Fred Hutchinson and most of the nation's other major cancer-treatment centers also have Web sites offering information about doctors, advances in treatment, and how to contact the right experts. Some of these centers are in turn linked with patient-sponsored Web sites and e-mail groups, and they provide guidance while vetting Web sites for accuracy and timeliness.

The University of Pennsylvania's OncoLink service, for example, guides patients to e-mail discussion groups and to sites like Blood and Marrow Transplant Newsletter, the creation of Chicago-area leukemia survivor Susan Stewart. Conversely, Art and GrannyBarb's Leukemia Links—a Web page put together by leukemia survivors Art Flatau of Austin, Texas, and Barbara Lackritz of St. Louis—allows Web surfers to connect directly to OncoLink and other cancer-treatment center Web sites, as well as to medical journals, news articles and survival stories from other patients.

At the heart of the patient-developed resources is a deeply felt desire by those who have fought cancer to light the path for others. Boulder, Colo., computer programmer Steve Dunn, diagnosed in 1989 with metastatic kidney cancer at the age of 32, was initially given a dismal prognosis and told there was no standard treatment. Realizing “if I wanted the right treatment it was up to me to find it,” he enlisted friends and family in a blitz of research, investigating clinical trials and interrogating experts. His search led him to an experimental therapy with high-dose Interleukin-2, combined with interferon. Today, he is disease-free.

EAGER TO HELP

Mr. Dunn was eager to help others, and with a college biology degree he was better equipped than most to do so. He started by developing a community course to help patients find clinical trials, doing much of his research on the Internet before

it occurred to him to put his findings on a Web site. In 1996, he established the online CancerGuide, laying out details of his own quest for the right treatment and guiding browsers to reliable sources of information on a wide range of cancers.

Mr. Dunn cautions site visitors that there are pros and cons to researching one's own disease and treatment. Yes, it is “empowering,” providing an antidote to despair while enabling patients to make more-informed decisions. But it can be intimidating and dangerous: Patients might confront some dismal statistics, or, worse, misconstrue data and make a life-threatening decision. And doctors sometimes offer a chilly reception to patients who come in armed with statistics and medical-journal articles.

But in the end, Mr. Dunn believes, Internet research is worthwhile for many people. Even specialists in a field may not have read the latest papers on it. When Mr. Dunn was initially diagnosed, he found in a medical library a paper on his disease and new clinical trials that his doctor didn't know about. Today, many medical papers or abstracts summarizing them are available on the Internet, through such publications as the New England Journal of Medicine's online edition.

“Some doctors do feel threatened by people researching their own care,” Mr. Dunn says. But, he adds, that attitude should diminish as a new generation of Internet-savvy doctors comes into the profession.

Mrs. Lackritz—aka GrannyBarb—urges patients to stand up to doctors who resist discussing certain information. Diagnosed with chronic lymphocytic leukemia at the age of 50 in 1989, the speech pathologist and onetime alderwoman initially researched her disease at the Washington University Medical Library. In 1992, knowing little about computers, she went online for the first time, navigating her way through the Web to some useful sites, including BMT-Talk. She then decided to put her own story online and develop her own Web page. Through some of the cancer-discussion groups, she met Mr. Flatau, a computer scientist, now 38, who also had a Web site. They decided to merge the two and post all the useful links they had discovered.

Last year, at Boston's Dana-Farber Cancer Institute, through a venture with Brigham and Women's Hospital, Mrs. Lackritz underwent an autologous bone-marrow transplant, one that uses the patient's own marrow. Like Mr. Dunn of CancerGuide, she outlines on her site the entire saga of her several years' battle for survival. Now cancer-free, she admits that putting her life on the line, so to speak, has its drawbacks.

“I'm giving up my medical privacy,” she says. “But if it helps one person not to go into a panic when they hear they have cancer, and not go into a panic when they communicate with their doctor, and have the chutzpah to say, ‘This is my life and I'm going to do something about it,’ then it's worth it.”

A SECOND OPINION

Among the most comprehensive online sources for cancer support and information is the Association of Cancer Online Resources, or ACOR, founded by Gilles Frydman, a French entrepreneur. After his wife was diagnosed with breast cancer, Mr. Frydman used a breast-cancer mailing list to do research that led him to the conclusion that their physician was recommending far too radical a course of treatment. The Frydmans sought a second opinion, and in the end they rejected the first doctor's advice. Impressed with how helpful the mailing group's information was, Mr. Frydman began trying to create an archive of previous e-mail traffic.

"The information on the mailing lists was so good it was a crime not to archive it," he says.

Mr. Frydman noticed that other cancer mailing lists such as BMT-Talk, Cancer-L and a brain-tumor list were scattered over various servers run by universities and other nonprofit institutions. "I spent a year trying to convince other nonprofits we should put all the resources under one roof" and create a single "clearinghouse" for e-mail lists relating to different cancers, Mr. Frydman says. L-Soft, International Inc., a Landover, Md., company that develops and licenses ListServ software for managing electronic mailing lists, agreed to donate its services to ACOR, which now includes 96 mailing lists and delivers one million e-mail messages a week, covering everything from breast cancer to such rare diseases as leiomyosarcoma. (Acor's site includes a waiver that says it tries to ensure the "integrity and accurateness" of information but makes no guarantees.)

Because bone-marrow transplantation and newer techniques are being used against a growing number of diseases—from leukemia and lymphoma to breast and ovarian cancer—sites devoted to these issues provide an interesting window into the world of Internet medical information and support. And of the many cancer survivors who devote themselves to helping others by providing resources and help—both online and off—leukemia survivors Susan Stewart and Laurel Simmons are model cyberspace practitioners. Here's a look at how they did it and some of the people they've helped.

SUSAN STEWART'S BMT NEWSLETTER

For Susan Stewart, the idea of starting the Blood and Marrow Transplant Newsletter began after she struggled through her own battle with acute myelogenous leukemia in 1987. As she faced chemotherapy and a transplant, she was frustrated in her efforts to find information that would explain in lay terms what she was up against. "There was nothing in written form I could use," she says. "I went through it blind."

As a former director of a Chicago-area watchdog group that challenged utility-rate increases, she had writing experience. So she began compiling data from transplant experts for a quarterly newsletter and a companion handbook on the "nuts

and bolts" of a bone-marrow transplant, which she published herself and offered free to anyone who asked for it.

After initially paying for everything out of her own pocket, Ms. Stewart raised some money from pharmaceutical companies to help fund her nonprofit newsletter group and cover the costs of printing and shipping. But those donations were cut back as the companies trimmed costs. Some home-health-care concerns also provided contributions, but Ms. Stewart balked when they sought editorial control. At present her financial support comes mostly from large cancer centers and institutions that take bulk subscriptions for their staffs and provide the materials to their patients. Ms. Stewart also gets money from foundations, and from fund-raising appeals to subscribers who get the newsletter free of charge.

The Internet has broadly expanded the reach of BMT Newsletter (which has no relation to BMT-Talk). In the three months through July, the site had 6,246 visitors, compared with fewer than 500 in its first month, September 1997. Site visitors can download and print the entire handbook on transplants, as they can the newsletter and its archives. "The Internet has made it so much easier for people who need it to get the information more quickly," Ms. Stewart says. BMT Newsletter also offers a patient-to-survivor e-mail link, which Ms. Stewart says makes it easier for those "who are afraid they might break down and cry if they were talking on the phone to someone."

Ms. Stewart still prints about 15,000 copies of each quarterly newsletter—up from 700 originally—and tries to fill requests for back issues. When Kathy Peck's 2 1/2-year-old son was diagnosed with three blood-related cancers at once, the New Jersey mother called Ms. Stewart, who agreed to send all the back issues. "I read them all in one night and went and threw up," says Mrs. Peck. But she says the information prepared her to deal better with her son's treatment. Though he has been cancer-free for several years, she still reads the newsletter and urges her local cancer-care center to provide it to others facing the same kind of crisis.

Likewise, Edmonds, Okla., attorney Jane Eulberg relied on the BMT Newsletter when her longtime companion, plumber Jean Prockish, had a recurrence of breast cancer in 1994. Ms. Prockish was weighing whether to have a bone-marrow transplant—an increasingly common treatment for that disease—when a nurse liaison at their cancer center gave the two a copy of Ms. Stewart's BMT handbook.

ARMED WITH FACTS

"When we read the book for the first time, it scared us very much and Jean was even thinking about not going through with a transplant," Ms. Eulberg says. But being armed with the facts helped her decide to have one. The two

continue to subscribe. "It gives me comfort to know that if there is another recurrence, we have this information at our fingertips," Ms. Eulberg says.

Ms. Stewart also provides an attorney-referral service via phone, e-mail or fax for patients fighting insurance companies over payment for transplants. In May, Laura DuPont, a Chapel Hill, N.C., breast-cancer patient, was about to enter Duke University's medical center for a stem-cell transplant—a procedure that involves not extracting bone marrow but drawing and treating blood cells, in Ms. Stewart's case her own. But then her insurer informed the hospital that the case was up for review. Ten days later it denied coverage for the procedure.

Ms. Stewart put Ms. DuPont in touch with a local attorney who agreed to take on her case, preparing formal appeal letters, and peppering the insurance company with medical data and journal articles about the efficacy of such transplants for breast-cancer patients. In the meantime, fearful about her survival, Ms. DuPont raised \$75,000 from family members to make an admission deposit required by Duke, and went ahead with the procedure. Fortunately, she says, after reviewing her case at her attorney's urging the insurer reversed its denial in July and agreed to pay the entire cost of the procedure.

"I was getting nowhere fast before I made that call to BMT Newsletter," says Ms. DuPont.

Ms. Stewart attends medical seminars on transplantation and relies on an advisory panel of experts from some of the leading transplant centers to vet much of the material and provide help through an "Ask the Doctor" service that she provides through the printed newsletter and online. Ms. Stewart also helps individuals answer specific questions by linking them with specialists or by doing research for them.

For example, after several readers asked whether bone-marrow transplant survivors should be revaccinated or get a flu shot every year, Drs. Keith Sullivan and Robert Witherspoon at the Fred Hutchinson center in Seattle addressed the issue and provided a list of recommended immunizations, which are posted on the BMT Web site.

Ms. Stewart is now updating and revising her handbook on allogeneic bone-marrow transplants—those requiring a donor—to reflect recent advances in the field, including the rapidly growing technique of stem-cell transplantation (stem cells are "master cells" that can become whatever kind of cell the body needs). She is also putting together a second book on autologous transplants.

And she has nearly completed the first major directory of U.S. and Canadian transplant centers. The directory won't rate the facilities, but it will say what diseases each specializes in and what age group it treats. It will be available both in hard copy and on the BMT Newsletter Web site.

LAUREL SIMMONS'S BMT-TALK

In April 1987, at age 25, Laurel Simmons learned from a routine blood test during a wisdom-tooth extraction that she had chronic myelogenous leukemia. Fortunately, one of her three brothers was a bone-marrow match, and she soon had a successful transplant at the Fred Hutchinson center.

Ms. Simmons returned to work later that year at the Massachusetts Institute of Technology, where she was a facilities manager in the artificial-intelligence lab. But in 1990, she relapsed, and faced daunting odds of surviving a second transplant. With the help of friends, she combed medical and scientific journals looking for help, consulted her doctors at Fred Hutchinson, and ultimately rejected a second transplant in favor of what was then a new therapy—an infusion of white blood cells from her donor brother to beat back the recurrent leukemia.

It worked, and Ms. Simmons found herself brimming with information about her disease and treatment options that she wanted to share with others going through the same thing. "I thought of volunteering at a hospital, or writing a book, but then I came upon the idea of an Internet mailing list," says Ms. Simmons, who had encountered a cancer mailing list in her own research. With the help of an MIT colleague, she started BMT-Talk in 1994.

Like other Internet mailing lists managed by ACOR, BMT-Talk allows you to subscribe simply by sending an e-mail asking to be put on the mailing list. You can also "lurk" anonymously and just read the traffic. The daily volume of mail can be overwhelming, so it's best to subscribe to the list in digest form, getting one summary daily with all the messages attached. There is also an archive of correspondence on subjects ranging from financial assistance to physical complications from the procedure.

Joseph Smudin, a 35-year-old risk arbitrager, found BMT-Talk while surfing the Internet for information after he was diagnosed with chronic myelogenous leukemia in 1997. He was weighing a bone-marrow transplant from an unrelated anonymous donor. While he knew he was lucky to have located a match, he hesitated to proceed with such a harrowing procedure, preferring to stay on interferon. "I sent an e-mail stating that I was having difficulty with the decision to have the transplant," he says, "and I guess I was looking for encouragement."

A FLOOD OF RESPONSES

Mr. Smudin received a flood of responses, many telling him they knew exactly what he was going through, and offering sympathy and advice based on their own experiences. "I'm sad you have to join us, but have courage," said a former transplant patient responding from Israel. A 55-year-old nurse told him she hadn't hesitated to get a transplant because it was the

only hope for a cure—and the sooner the better. “Just do it,” she urged him.

Mr. Smudin, who developed a bad reaction to interferon, ultimately decided to go ahead with a transplant at Fred Hutchinson earlier this year. Looking for someone his age who’d had the disease, he had no luck when he asked for help from a local cancer-support organization.

“They were never able to find someone to hook me up with so I could compare notes and chat,” he says. In BMT-Talk, “you have this tremendous resource that enables you to bounce something off hundreds of people going through the same thing,” he says. “If you’re having an edema or some strange side effect, you just throw it out there and see who else has had it and what’s to be done about it.”

For Jacob Safarty, a 39-year-old Denver software consultant, BMT-Talk provided crucial support after his wife died of lung cancer in February, leaving him with three young children. The day after her funeral, he learned from tests taken during a routine doctor’s visit that he had leukemia himself. None of his siblings could provide a bone-marrow match, so he began searching for an unrelated match through the National Bone Marrow Donor Registry.

Mr. Safarty says he approached his disease with the attitude of the project manager that he is. BMT-Talk proved a valuable research tool, putting him in touch with a dozen or so people who chimed in with well-researched opinions and pointed him to other reference material. “If you read enough and ask enough questions, you can pretty much separate the good from the not-so-good advice,” he says.

Mr. Safarty is still searching for a donor, but he says BMT-Talk has made him far better able to ask questions of his doctors. “Sometimes they tell me I don’t need to know all

that stuff,” he says. “But I feel I have to assemble as many sources as I can to make the best decision I can make about what to do about this.”

Susan Hatfield, who was diagnosed with chronic myelogenous leukemia at 33 in 1996, found BMT-Talk several months after having a stem-cell transplant in San Antonio, where she is the budget director for a school district. Talking to others about what it was like to convalesce after a bone-marrow transplant “has proved to be an important part of my complete recovery and adjustment back to the real world and a better life,” says Ms. Hatfield. “I only wish I had found it sooner.”

Ms. Simmons, who is completing a master’s degree in health-policy management at Harvard University, has recruited other former patients into her list as “co-owners,” and the group has already held a reunion, where many of the correspondents met face-to-face. “Each time a patient posts a message, it is adding value to the health system in the world, and the e-mail discussion group is a great format,” she says.

But valuable as such groups are, Ms. Simmons says, the next step is to draw the medical community into the process more. “My goal is to expand the model,” she says. “We need to be connected to authoritative sources of information in a very direct way—more than just someone saying, ‘Oh, I read an article in Scientific American....’”

Ms. Landro, a senior editor for The Wall Street Journal in New York, is author of the book “Survivor: Taking Control of Your Fight Against Cancer.”

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