Hepatitis C Information on the World Wide Web

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World Wide Web sites about hepatitis C vary from simple Web sites that provide basic information to the layperson to regularly updated medical-information portals. Medical professionals can use these Web sites to obtain up-to-date information on the epidemiological characteristics of hepatitis C and treatment of and information materials for their patients. For researchers in this field, there are Web sites that provide bibliographies, conference summaries and updates, and continuing medical education credits. This review provides an overview of selected Web sites for health care providers and researchers, sites of professional societies, sites created by patients, and sites created by the pharmaceutical industry.

Even before the discovery of the hepatitis C virus (HCV), reports of non-A, non-B hepatitis were frequently encountered in medical journals. The causative agent of non-A, non-B hepatitis was thought to be a virus, and it responded to treatment with IFN-α [1]. The agent was finally described in 1989 [2], and 82% of cases of non-A, non-B hepatitis were attributed to the newly discovered and named HCV [3]. With the implementation of screening of donated blood, the incidence of transfusion-related non-A, non-B hepatitis decreased rapidly [4].

Currently, an estimated 170 million persons are infected with HCV worldwide. In the United States, 3.9 million persons (1.8% of the population) are infected with HCV. Approximately 75% of infected persons have detectable circulating HCV RNA in their blood denoting chronic infection [5]. Both in the United States and globally, the prevalence of HCV infection exceeds that of HIV infection by 5-fold. Approximately 10,000 deaths are attributed to HCV infection in the United States each year.

Entering the terms “HCV” and “hepatitis C” in popular Internet search engines (e.g., MSN, Infoseek, Yahoo, and Google) yields hundreds of “hits,” or matches. The information contained on these Web sites varies from highly technical and accurate epidemiological and genetic information about HCV to information about unusual and untested remedies that are quite unknown to many in the scientific community.

The objective of this review is to facilitate navigation of the Internet for the individual seeking specific information about HCV. It must be mentioned that the authenticity of the information contained on the Web sites that I reviewed cannot be guaranteed, except to note that certain agencies (e.g., the Centers for Disease Control and Prevention [CDC; Atlanta, Georgia] and the National Institutes of Health [NIH; Bethesda, Maryland]) have traditionally provided historically and scientifically accurate information that is supported by scientific studies. I advise persons who visit the Web sites mentioned in this article to scrutinize the sources of information carefully. If a Web site does not provide verifiable sources of its information, the reader should exercise caution when interpreting the assumptions and assertions made. The scrutiny of scientific Web sites should follow guidelines similar to those applied to print media and scientific journals.

METHODS

Using the search terms “HCV” and “hepatitis C,” I searched the Internet with popular Internet search engines. The Web sites that matched these search terms were reviewed individually and were categorized into the following groups: sites for health care providers and researchers, sites of professional societies, sites created by patients, and sites created or supported by the pharmaceutical industry. Because of the large number of Web sites in each category, only a few representative sites were selected for review in this article. The description of each Web
site includes the name of the site, the Internet address, the date that the site was accessed, the sponsor of the Web site, and a brief description of the site. Features of these Web sites are also shown in table 1.

WEB SITES FOR HEALTH CARE PROVIDERS AND RESEARCHERS

A large number of Web sites are specifically designed to provide health care providers with current information on the epidemiological characteristics of disease, information about recent outbreaks, and current treatment guidelines.

The official site of the CDC’s National Center for Infectious Diseases includes a section that is dedicated to HCV (http://www.cdc.gov/ncidod/diseases/hepatitis/c/index.htm; accessed 6 January 2002; figure 1). This Web site is easy to navigate, with simple links provided to direct viewers to a page with answers to many frequently asked questions, including questions about diagnosis, testing, modes of transmission, and outcomes. Links are provided to sections about the CDC’s position on skin tattoos and its national HCV prevention strategy. Links are also provided to sections about other viral hepatitis infections (i.e., hepatitis A, B, D, and E). In addition, a link to the CDC’s publication “Recommendations for Prevention and Control of Hepatitis C Virus (HCV) Infection and HCV-Related Chronic Disease” is provided. The recommendations were published in 1998 and are outdated, because new information became available about treatment with the pegylated forms of interferon in combination with ribavirin, which has become the standard of care [6, 7].

The official site of the NIH and the National Institute for Diabetes and Digestive and Kidney Diseases (http://www.niddk.nih.gov/health/digest/pubs/chrnhepc/chrnhepc.htm; accessed 7 January 2002) provides a quick overview of information about HCV infection, from its epidemiological characteristics to treatment. The site is meant to be a starting point for physicians who want to obtain basic knowledge about the epidemiological characteristics, diagnosis, clinical features, and treatment of HCV infection. Ten references are provided, which are mostly review articles on the topic. Algorithms are used to outline the treatment of HCV infection, and links to patient-education materials are provided. The NIH is a trustworthy source of information. However, the most recent reference in the bibliography is from 1998, thus making the treatment information obsolete.

Information about the NIH Consensus Development Program can be found at http://odp.od.nih.gov/consensus/cons/105/105_intro.htm (accessed 7 January 2002). The NIH provides consensus statements on major diseases (including this statement on HCV) that are prepared by a nonfederal, nonadvocate group of experts in the field. However, the Web site’s usefulness is limited by its date of publication (1997), which makes some recommendations and consensus statements obsolete. Significant advances in treatment have been made since the publication of this consensus statement [6, 7]. Unfortunately, no bibliography is provided; however, the consensus statement is based on the opinion of a diverse panel of experts in the field. The most recent consensus conference on HCV infection occurred in June 2002, and the new consensus statement is available at http://consensus.nih.gov/cons/116/116cdc_intro.htm.

The Clinical Trials Web site of the NIH (http://www.clinicaltrials.gov; accessed 7 January 2002) lists >5700 ongoing clinical trials that are supported by pharmaceutical companies, the NIH, and other federal agencies. The index page provides a search string that can be used to access information about trials involving a specific condition or disease, such as HCV infection. At the time of access, 27 clinical trials were listed for HCV infection. The search results are well arranged, and visitors can obtain details about individuals trials or multiple trials (by clicking multiple check boxes). For each trial, the Web site lists the purpose of the study, the eligibility criteria, and the location of and contact information for the trial. This Web site does not provide any information about HCV infection itself.

The Web site of the National Library of Medicine–NIH (http://www.nlm.nih.gov/pubs/cbm/Hepatitis_C.html; accessed 7 January 2002) provides references about selected conditions, and there are extensive references provided with regard to HCV infection. However, the most recent articles are from 1997, which makes the site’s information obsolete for researchers. For persons beginning to look at HCV literature, this Web site provides useful references and classic articles on the subject, and the search results are arranged in sections for easy browsing.

A useful feature of the World Health Organization Fact Sheet Web site (http://www.who.int/inf-fs/en/fact164.html; accessed 7 January 2002) is the table specifying the global prevalence of HCV infection. Beyond that, there is little information available on this site. The information is limited, and no bibliography is provided. Disease-specific information is also absent.

Medscape (http://www.medscape.com; accessed 7 January 2002; figure 2) is a commercial medical-information portal sponsored by WebMD Medscape Health Network (New York). The site has a hepatitis C resource center in which one can find recent publications from selected journals and conference summaries and news about drug approvals from the US Food and Drug Administration. Editorial commentaries on articles and conference presentations, a scan of journals for related articles, and links to practice guidelines are included. Continuing medical education credit is available after completion of a self-test module related to articles posted on the Web site. Readers can register for automatic e-mail subscription of modules related to their specialty and subspecialty. Updates from
Table 1. Features of selected hepatitis C virus (HCV)–related Web sites.

<table>
<thead>
<tr>
<th>URL</th>
<th>Sponsor</th>
<th>Quantity of information on HCV</th>
<th>Easy to navigate</th>
<th>Practice guidelines available</th>
<th>References provided</th>
<th>Links to other Web sites provided</th>
<th>CME credit provided</th>
<th>Information is recent</th>
<th>Contains advertisements</th>
<th>Patient information provided</th>
</tr>
</thead>
<tbody>
<tr>
<td><a href="http://www.cdc.gov/ncidod/diseases/hepatitis/c/index.htm">http://www.cdc.gov/ncidod/diseases/hepatitis/c/index.htm</a></td>
<td>CDC</td>
<td>Good</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
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<td>NIH/NIDDK</td>
<td>Fair</td>
<td>Yes</td>
<td>No</td>
<td>Limited</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
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<tr>
<td><a href="http://bibd.od.nih.gov/consensus/cons/105/105_intro.htm">http://bibd.od.nih.gov/consensus/cons/105/105_intro.htm</a></td>
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<td>Fair</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td><a href="http://www.nlm.nih.gov/pubs/dcm/Hepatitis_C.html">http://www.nlm.nih.gov/pubs/dcm/Hepatitis_C.html</a></td>
<td>NIH</td>
<td>Reference material only</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
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<td>No</td>
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<tr>
<td><a href="http://www.who.int/inf-fs/en/fact164.html">http://www.who.int/inf-fs/en/fact164.html</a></td>
<td>WHO</td>
<td>Small</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td><a href="http://www.medscape.com">http://www.medscape.com</a></td>
<td>WebMD Medscape</td>
<td>Good</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<td>Yes</td>
<td>No</td>
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<td><a href="http://www.acg.gi.org">http://www.acg.gi.org</a></td>
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<td>Poor</td>
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<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
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<tr>
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<td>Poor</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
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<tr>
<td><a href="http://www.idsociety.org">http://www.idsociety.org</a></td>
<td>IDSA</td>
<td>Poor</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
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<td>No</td>
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<tr>
<td><a href="http://hepatitis-central.com">http://hepatitis-central.com</a></td>
<td>Individual</td>
<td>Good</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td><a href="http://www.hepprimer.com">http://www.hepprimer.com</a></td>
<td>Individual</td>
<td>Good</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
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<tr>
<td><a href="http://www.hepassoc.org">http://www.hepassoc.org</a></td>
<td>Individual</td>
<td>Good</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td><a href="http://www.hepatitisinnovations.com">http://www.hepatitisinnovations.com</a></td>
<td>Schering-Plough</td>
<td>Small</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><a href="http://www.roche.com">http://www.roche.com</a></td>
<td>Hoffmann LaRoche</td>
<td>Poor</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td><a href="http://www.hepnet.com/hepc.html">http://www.hepnet.com/hepc.html</a></td>
<td>Schering Canada</td>
<td>Good</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
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</tr>
</tbody>
</table>

NOTE. AASLD, American Association for the Study of Liver Disease; ACG, American College of Gastroenterology; CDC, Centers for Disease Control and Prevention; CME, continuing medical education; IDSA, Infectious Diseases Society of America; NIDDK, National Institute for Diabetes and Digestive and Kidney Diseases; NIH, National Institutes of Health; WHO, World Health Organization.
most major educational meetings are provided in a timely fashion. In the infectious diseases section of the Web site, updates are available from the 41st Interscience Conference on Antimicrobial Agents and Chemotherapy (December 2001), the 52nd Annual Meeting of the American Association for the Study of Liver Diseases (November 2001), and the 39th Annual Meeting of the Infectious Diseases Society of America (October 2001). Registration is required to use this Web site, but access is free.

SITES OF PROFESSIONAL SOCIETIES

Most patients with HCV infection are treated by providers who specialize in gastroenterology, hepatology, or infectious diseases. The Web sites of 3 professional societies (the American College of Gastroenterology, at http://www.acg.gi.org; the American Association for the Study of Liver Diseases, at http://www.aasld.org; and the Infectious Diseases Society of America, at http://www.idsociety.org) representing these specialties were accessed on 8 January 2002. Although all 3 sites were well designed and easy to use, there was a uniform lack of information about HCV infection. Practice guidelines were available for other disorders in these fields, but there were no guidelines for HCV infection on any of these Web sites.

SITES CREATED BY PATIENTS

A large number of Web sites have been created by patients who have been infected with HCV and who were motivated to provide education and support to other patients as a mission. These Web sites vary from very basic pages to elaborate multilayered sites with information that can match or even exceed the information on the official Web sites of infectious diseases and hepatology societies and organizations. These Web sites provide links to the sites of support groups, the sites of other patients, recent literature about HCV infection, and information on books written by patients about their experiences. Some sites provide searchable information on physicians who treat HCV-infected patients. The information on physicians is gathered from Web site visitors and patients and solicited from physicians themselves. A few representative sites were chosen for this review. Many other Web sites that are not mentioned here provide quite similar information.

The Hepatitis Central site (http://hepatitis-central.com; ac-
cessed 7 January 2002) has a few features that some of the Web sites of official societies may want to emulate, such as sections on clinical manifestations, modes of transmission, treatment of HCV infection, as well as patient concerns. It provides recent information, including articles from January 2002, and a follow-up visit to the Web site on 20 March 2002 revealed that the site contained references to articles published in March 2002. It has features that are helpful for patients as well as physicians, including a chart on liver biopsy scores and tables for converting numbers to log values. Primary care physicians who refer their patients to experts may find the information on liver biopsy scores and virus load helpful for interpreting the status of their patients. One useful feature for physicians is the availability of the full text of articles about HCV infection, although these are limited to articles that are available free of charge on the Internet. The Web site also has a searchable list of health care professionals who provide care to HCV-infected patients. A few advertisements by commercial vendors are present on the Web site.

The Hepatitis C Primer site (http://www.hepcprimer.com; accessed 7 January 2002) is a primer on HCV infection for HCV-infected patients. The site provides information similar to that provided on the other sites, and it includes an extensive list of references, with abstracts conveniently listed according to topic. The topics covered include the epidemiological characteristics of, risk factors for, and treatment of HCV infection. Links to multiple sites are provided, as is information on support groups for HCV-infected persons.

The advocacy Web site HepC Alert (http://www.hep-c-alert.org; accessed 7 January 2002) contains mostly superficial information and news that focuses on firefighters and emergency medical personnel. A list of the agency’s educational activities and information on how to participate in them are provided. The information is superficial, and no references are provided.
The well-designed Web site of the Hepatitis C Association (http://www.hepcassoc.org; accessed 7 January 2002) is easy to navigate. A section on updates from recent meetings (e.g., the meeting of the American Association for the Study of Liver Disease that was held in Dallas in November 2001) is written by activists who are knowledgeable and who attend scientific meetings regularly.

The Deutsches Hepatitis C Forum (http://www.hepatitis-c.de; accessed 8 January 2002) is primarily for German-speaking visitors to the site, and it is a good example of the power and global reach of the Internet. The Web site provides easy-to-navigate information that is similar to that presented in the aforementioned sites. Much of the information is referenced, and some of the content is written by physicians. Like several other sites, it includes links to patient-authored literature on HCV infection. A section about recent studies provides abstracts of articles on HCV infection that are arranged according to the month of publication, although publications for a few months are missing. German translation of several abstracts is available on the Web site.

SITES CREATED OR SUPPORTED BY THE PHARMACEUTICAL INDUSTRY

Schering-Plough makes IFN-α2b (Intron A), a combination of IFN-α2b and ribavirin (Rebetron), and pegylated IFN-α2b (PEG-Intron). Their Web site provides only very basic and superficial information about the disease (http://www.hepatitisinnovations.com; accessed 8 January 2002). Two particularly helpful features of the site are the package inserts for the aforementioned products and information on a program to help needy patients who are unable to pay for these expensive drugs. Schering-Plough claims to have provided drugs free of cost to >31,000 patients since the inception of this indigent patient program.

Roche manufactures and markets IFN-α2a (Roferon A) and ribavirin. Roche’s version of pegylated IFN-α2a (Pegasys) is awaiting approval in the United States. Their Web site (http://www.roche.com; accessed 8 January 2002) is well designed, but the information on HCV infection and its treatment is difficult to access. This information can be accessed through the search function, but the material is limited mostly to media releases about the company’s products. A link to an HCV-specific area of the Web site is mentioned, but I could not access it, despite several attempts (http://www.Roche-HepC.com).

The HepNet Web site (http://www.hepnet.com/hepc.html; accessed 7 January 2002) is sponsored by the Canadian division of Schering-Plough. It contains information on the disease, some of which is written by experts in the field. The most recent information, which is from November 2000, is not as old as the information on some other sites, although the rapidly increasing amount of knowledge in this field demands even more recent information. A designated physicians area, conference summaries, and a bibliography are provided. An area of the site for patients provides Power Point slides with information about HCV.

References


