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Surfing for rheumatologists—a guide to rheumatology resources on the Worldwide Web

Terms such as Internet and Worldwide Web (WWW) may have passed into common usage, but to many people the idea of “surfing the net” is about as likely as walking on the moon. However, for devotees, communicating by electronic mail, participating in newsgroups, and managing Web pages has become an integral part of daily life.

The rheumatological community appears to reflect this polarisation. On the one hand there are those who have embraced the new technology and are already exploring avenues for its use in clinical practise, research, and the general dissemination of information. On the other hand there are those for whom a computer is at best a word processor and at worst a phobia.

Many in the field of rheumatology are asking whether it is worth investing time, effort, and money in this new technology. Is the WWW a seven day wonder or will it have a major influence on the practise of rheumatology in the future? Quite clearly the impact that computer technology has already made on medicine and medical research is immense. The development of the information superhighway is a logical progression in this rapid evolution which amplifies the effectiveness of the stand-alone computer by providing a link to millions of other computers. Each computer links to a host, which in turn is connected to a regional centre, which in turn is linked to national and international gateways, hence the concept of a “web”-like structure of communication. In theory, this quantum leap in technology should result in profound changes in the way rheumatologists and allied professionals interact with each other, with patients, with other interest groups and with the world in general.

The potential of the Web is vast. It is already possible to send text, graphics, data, software, photographs, sound, movies, and even money to another Web user anywhere in the world within seconds. One recent highly publicised example was the potential use of the Internet to allow battlefield surgery to be performed by robotic arm while the surgeon “operated” from the safety of a hospital hundreds of miles behind the front line.¹ Perhaps a physician wants to obtain a second opinion on an x ray or MRI scan from a colleague in another hemisphere. This is possible over the internet in minutes. Likewise, an operator can attach a patient to an ECG machine in one city and a physician can view and analyse the traces in another. There is, however, one urgent problem which needs to be addressed for all

internet communications and that is the relative lack of security on the Web, which is particularly important where patient confidentiality is concerned.

Other features of the internet are also making an impact on the medical environment. Videoconferencing through high speed Web links could be a cheap alternative to organising costly international meetings. Whole virtual communities and discussion groups have already developed on the Web. Individuals from all parts of the world who are never likely to meet in person are able to share information and interests on a daily basis. Distance learning takes on a whole new meaning when comprehensive multimedia course material is available on-line to students in any continent at any time of night or day. Essays can be submitted, marked, and discussed electronically without tutor ever having to meet student.

Aside from the obvious sociological implications of the new technology, other pitfalls in the information superhighway are becoming apparent. The question of the moment is whether current investment in the infrastructure and management of the network will cope with the phenomenal growth in usage which is predicted for the next few years. Already there are an estimated 12 million computers connected worldwide, supporting over 70 million unique pages of information on the Web. At peak times, when the majority of US citizens are awake, accessing popular overseas Web sites can be a severe test of patience. The slowdown in data transfer can be such that it becomes impractical to download anything more than one or two pages of text. Furthermore, when searching for rheumatology information, Web pages are not peer reviewed or edited for content. For example, it is possible to find a comprehensive guide to the management of fibromyalgia written by a world authority on one page and a recipe for the latest herbal suppository to cure all forms of arthritis on another. It is therefore important not to treat the Web as an encyclopaedia. The quality and authenticity of information provided must always be viewed in the context of its source.

Medical and scientific publishing is also being affected by this revolution. Most publishing companies are developing electronic versions of books and journals, either on CD-ROM or in a form that can be downloaded from the Internet on payment of a subscription. In many cases, medical and scientific journals now accept manuscripts

Table 1 URLs for WWW search engines and other introductory sites

Name	URL (Uniform Resource Locator)
Jumpstation II	http://www.stir.ac.uk/jsbin/jsii
Lycos	http://www.lycos.com/ http://lycos.cs.smu.edu/
Netscape	http://home.netscape.com/
Webcrawler	http://webcrawler.cs.washington.edu/WebCrawler/WebQuery.html
WWW worm	http://guano.cs.colorado.edu/www/
Yahoo	http://www.yahoo.com/

Table 2 Rheumatology newsgroups and mailing lists

Topic	URL (Uniform Resource Locator)
Arthritis	news:misc.health.arthritis
Lupus research	http://www.hamline.edu/lupus/
Lyme arthritis	news:sci.med.diseases.lyme
Osteoporosis	news:sci.med.diseases.osteoporosis
Outcome measures in RA	http://www.tile.net/listserv/omeract.html
Pharmacy	news:sci.med.pharmacy
Seronegative arthritis	http://www.mailbase.ac.uk/lists-p-t/seronegative-arthritis/
Sjogren's syndrome	http://tile.net/lists/ssl.html

Table 3 A selection of twenty Web sites relevant to the rheumatological community

Organisation	URL (Uniform Resource Locator)	Comments
American College of Rheumatology	http://www.rheumatology.org/index.html	Includes Arthritis & Rheumatism and ARHP
Annals of the Rheumatic Diseases	http://www.bmj.com/bmj/bmjpubs/jard.htm	Contents pages from 1996 issues & information to authors
Arthritis & Rheumatism Council (UK)	http://rheuma.bham.ac.uk/arc.html	So far only address and telephone details
Arthritis and Rheumatism Links	http://www.treaty7.org/links/health/arthritis.htm	Expanding site with links to major arthritis sites
Arthritis Foundation	http://www.arthritis.org/	Arthritis Today, fact sheets & links to other organisations
Biomednet (L)	http://BioMedNet.com/	Worldwide club for biological and medical scientists
Birmingham University Rheumatology Dept	http://rheuma.bham.ac.uk/	Includes a very good primer on the rheumatic diseases
British Journal of Rheumatology	http://www.oup.co.uk/jnls/list/brheum/	Contents & abstracts from current issue
British Medical Journal	http://www.bmj.com/bmj/archive/curr.htm	Contents, abstracts and editorials from current issue
British Society for Rheumatology	http://www.oup.co.uk/jnls/brheum/	Site under development but will eventually appear here
Duquesne University RA multimedia guide	http://www.duq.edu/PT/RA/RA.html	Excellent RA teaching resource for students (large files)
Fibromyalgia Resources	http://www.hsc.missouri.edu/fibro/	Frequently asked questions and educational resources
Martindale's Health Science Guide	http://www-sci.lib.uci.edu/HSG/HSGuide.html	Vast collection of teaching resources in most medical fields
National Library of Medicine (USA) (L)	http://www.nlm.nih.gov/	A wealth of medical and scientific information (busy site)
Nature	http://www.nature.com/	News, feature, jobs and much more - an exemplary site
Pharmacy Information Network	http://pharminfo.com/	US site with comprehensive drug database, news links
Public domain software archive	gopher://sunsite.doc.ic.ac.uk/	Thousands of freeware and shareware programs (PC & Mac)
Rheumatology Resource Pages	http://www.crl.com/~fred/rheum.html	Links to many rheumatology sites but last updated 10/95
Scleroderma Pages	http://peggy.mt.unifi.it/scleroderma.html	Regularly updated list of scleroderma-related sites and info
Washington Uni Musculoskeletal Radiology	http://kayla.wustl.edu/	Includes an atlas of MRI anatomy & visible human project

(L) charges are made for some resources at these sites.

and correspondence from authors by direct electronic mail. Such changes in procedure and in publication technology should greatly enhance the output and assimilation of medical and scientific information by the rheumatological community.

The origins of the WWW were within the academic community, and in the past most information was freely available. Today, however, commercial organisations are realising the marketing potential of the Web and we are in the midst of an advertising explosion which is fundamentally changing the whole ethos of the internet. Another major effect of this commercialisation of the Web has been the proliferation of information pages and databases only accessible after registration and payment of subscription charges. Most companies accept payment by credit card, although it is inadvisable to give card details over the internet due to lack of security. Ultimately it will be possible to purchase international "internet currency units" which can be transmitted directly between users in payment for goods and services. Although trials are in progress, it will probably be several years before virtual money transfers are routine. There can be no question that the commercial concept of the WWW as a multimillion pound market place is rapidly replacing the original altruistic intention of its being an international forum for the free exchange of ideas and information.

It is surprisingly straightforward to access the WWW. All academic institutions and most large commercial organisa-

tions already have high speed links for electronic mail and an increasing number have either personal or communal access points to the Web. Contacting your institutional computer advisor for access privileges and initial instruction should suffice. If no existing link is available, or you wish to browse the Web from home, then this can be achieved with an IBM compatible PC running Windows 3.1 or Windows 95, or an Apple Macintosh computer. Links to the Web are then possible with a 14.4 or 28.8 kilobaud modem (£80-£200) connected to the telephone system or to a higher quality ISDN line. Your institution may offer its own dial-in service to employees. If not, then there are increasing numbers of commercial Internet service providers who will link you to the Web and provide electronic mail services for between £6 and £12 per month plus telephone charges at local call rates. They should provide free software to communicate with the host computer, browser software such as Netscape or NCSA Mosaic to enable you to visualise Web pages using the HTTP (hypertext transfer protocol), and software to create and receive messages and files by electronic mail. Many companies offer a free trial period of one to two months for new users. Once access to the Web has been gained it is possible to visit over 12 million Web sites, each with its own URL (uniform resource locator) but...where do you start? Your Internet service provider will have its own home page and this should offer gateways to other useful services on the Web. There are also powerful search engines available

(table 1) which will rapidly seek out pages containing relevant keywords. For example, searching the Web using Lycos and the keyword "rheumatology" will find approximately 1700 relevant pages of information, while "arthritis" unearths 5200. These searches may then be refined as necessary. As you search the Web, you will find newsgroups on many rheumatological topics. Some of these are provided in table 2. The home page for a particular newsgroup or mailing list will provide details on how to join and contribute to the debate or how to browse previous topics of discussion.

It is impossible to give comprehensive listings of rheumatological Web sites within the confines of an article such as this, but in table 3 I have attempted to provide a selection of sites which will provide a useful springboard. After some experience of the Web, it will not be long before many surfers want to create their own Web pages. Page layouts are defined using a standard language known as HTML (hypertext markup language). Until recently the programs which generate HTML files were only for the experts, but a plethora of user-friendly programs has recently appeared. These have been reviewed on the URL http://www.utirc.utoronto.ca/HTMLdocs/intro_tools.html. Internet service providers will often provide space to publish your pages on their host computers. Commercial providers may include a small number of pages within their monthly charge. It is also possible to publish pages directly from your own computer as long as

it is directly connected to the net with its own unique internet protocol (IP) address. As with all publications, whether on paper or on the Web, no one will read them unless you advertise their existence. Details of your pages can be submitted to Web search sites for inclusion in their databases and also managers of major sites associated with your specialty can be contacted so that a link to your particular site can be included.

The word processor was still a novelty 10 years ago. Today, few of us would consider using anything else to write a paper, article, or research grant. With the rapidly accelerating development of the WWW, it is a sobering prospect to consider that within the next 10 years, postage stamps and envelopes could be consigned to history along with text books, photographic emulsion, and dare I say.... the printed specialist medical journal.²

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