http://www.ilar.org A source of information for rheumatologists, allied health professionals, medical students and the general public

The internet, mainly in the form of the world wide web (WWW) is a rich source of information for a public hungry for information on health and disease. It is also rapidly becoming indispensable as a source of information for healthcare professionals. An indication of the perceived importance of the internet is the speed with which the deposed editor of the Journal of the American Medical Association, George Lundberg, was appointed as the editor in chief of Medscape—a “Premier League” medical web site.1–3 It remains to be seen whether the online peer reviewed journal that he has established will be successful. This is not the first such venture but its provenance is perhaps a pointer to the future of at least part of scientific publishing.

What does this mean for rheumatology? In common with many aspects of medicine, the doctor/patient relationship is changing. Thanks to the internet the public now has greater access to information than ever before. However, all too often they can be misinformed by inaccurate or misleading web site content, frequently because the sites in question exist primarily for commercial gain. Despite a number of attempts to introduce a formula for judging web site quality, no generally accepted gold standard has yet emerged.4 Highly publicised medical mishaps and the trend towards greater openness and provision of information are pushing patients to question, more than ever, the interventions that we recommend. This provides an important challenge to all doctors. There is a requirement to keep abreast of new developments and to be able to “negotiate” with patients when planning their management. Fortunately, access to all kinds of information is at least as easy for the rheumatologist as the patient. Acknowledging the importance of the internet as a means of communication, rheumatology organisations have begun to establish a web presence and this process seems set to continue.5 6 The existence of a web site can facilitate communications between, and with, members of the specialty and also functions as a “shop window” and source of information for members of the public and other interested parties including pharmaceutical companies and the press.

Understandably, professionals working in a particular field look to their national organisation first when seeking information. The British Society for Rheumatology has recently established a web presence7 and in time, this will become the main source of information about British rheumatology. However, there has been an increasing tendency for rheumatologists to cooperate beyond national boundaries and the regional organisations (in the UK’s case, EULAR) are increasing in importance and stature. Support for EULAR is such that its congresses will now take place annually and the Annals of the Rheumatic Diseases has become its official journal from the beginning of 2000. It too has a dedicated web site with full text of the journal available online for subscribers.8

It is likely though, that not all of the readership of this journal is fully aware of ILAR, the International League of Associations for Rheumatology. Although established more than 70 years ago, and although the founder of the Regional Leagues worldwide, its activities have seldom impinged on the daily professional life of the average rheumatologist. However, as a worldwide organisation, it may have a greater part to play in the future. The steadily increasing globalisation of information on the one hand and the drive towards evidence-based medicine on the other will presumably result in a gradual harmonisation of medical practice, albeit perhaps slowly. ILAR is well placed to play a central part in communications between healthcare professionals as that happens. Phenomena such as increasing international air travel and the internet
Gateway to World Rheumatology
http://www.ilar.org

Information about organisations
ILAR and its activities
Regional Leagues (AFLLAR, APLAR, EULAR, PANLAR)
National Societies
Patient Organisations and Support Groups
Arthritis Foundations
Allied Health Professionals
Individual Rheumatology Units

Links to other sources of information
Medline
Rheumatology Journals
Disease-Specific Information Sites
Major Medical Sites (e.g. Medscape)

Other features
Glossary
International Meetings Listing
(including contact details and downloadable abstract forms and other details where available)
Online Poll
Interactive Rheumatology Quizzes
What’s New Listing

http://www.ilar.org – An independent and objective source of information and links throughout the Galaxy, free of any commercial interests.

Figure 2 ILAR web site features.

contribute to making the planet seem smaller so that what is going on elsewhere in the world is becoming of more relevance to everyone. ILAR’s mission is to foster links between rheumatological organisations worldwide, particularly links to the Regional Leagues of Associations for Rheumatology of Africa (AFLLAR), Asia and Australia (APLAR), Europe (EULAR) and the Americas (PANLAR). Through its standing committees and links with other bodies such as the World Health Organisation (WHO), ILAR has also sought to heighten awareness of the importance of rheumatic diseases, improve education and raise the profile of rheumatology as a specialty with the ultimate aim of improving outcomes for sufferers from rheumatic diseases.

Before the recent evolution of the WWW, ILAR was probably best known to most rheumatologists as an organisation that has been responsible for organising an international rheumatology meeting once every four years, most recently in Singapore in 1997. Those who have taken an interest in matters pertaining to clinical research, education and epidemiology in rheumatology across continental boundaries will have become familiar with the ILAR activities of OMERACT and COPCORD, for instance.

The WWW seems the ideal medium for an international organisation like ILAR to communicate with interested parties. The creation of an ILAR Website (http://www.ilar.org) was therefore a natural development launched by its current president Jan Dequeker (fig 1). Established in the summer of 1998, it provides detailed information about the organisation and its activities. It also functions as a central source of information about rheumatology activity worldwide for the benefit of workers in this field. In addition to this, ILAR recognises the crucial importance of education about rheumatic diseases, not only for undergraduate medical students (embodied in the UMER 2000 project) but also for healthcare professionals, sufferers and the general public as a whole.10 11 Hence, the web site also provides many links to other important sources of information elsewhere on the WWW. Although we cannot hope to include everything, we selectively link to sites with high quality information.12 As indicated in figure 2, there are links to other organisations whose activities are relevant to both healthcare professionals and patients in this field. Specific groups of links lead the user to rheumatology journals, sources of general medical information and information about specific rheumatic disorders as well as Medline. Additional features include an international meetings listing, a comprehensive glossary and interactive features such as an online poll and interactive quizzes.

One of the virtues of the ILAR web site is its complete freedom from commercial support. The WWW’s uniquely powerful nature as a publishing medium has been quickly recognised and exploited by entrepreneurs motivated by commercial ends.15 16 The difficulty of ensuring that web publishing on health matters (so called “e-Health”) conforms to acceptable standards has been the subject of much debate. In February 2000 an e-Health Ethics Summit meeting will be held in Washington DC by the Internet Healthcare Coalition to try to arrive at a consensus.13 Importantly, patient groups will be fully represented in these proceedings (personal communication).

As judged by the frequency with which it is already accessed, the ILAR web site has become an important stopping off point for many “surfers”. Within less than a year of being established, the site was receiving page “hits” at a rate approaching 1000 per day and the numbers are steadily increasing. We invite you to visit the site and to contribute to its further development by suggesting means by which we may make it more interesting and relevant to your needs and those of the public.

RAY ARMSTRONG
Rheumatology Unit, Southampton University Hospitals NHS Trust, Southampton SO16 6YD

JJ (HANS) RASKER
University of Twente, Department of Rheumatology and Communication Studies, the Netherlands

Correspondence to: Dr Armstrong

3 http://www.medscape.com
7 http://www.rheumatology.org.uk
8 http://ard.bmjournals.com
15 http://www.thehealthcoalition.org