BOOKMARKS: Circulating information – a guide to leukaemia information

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This edition of the Bookmarks column focuses on the information available to Internet users about adult leukaemia. Due to differences in terminology, units of measurements and health care systems, this article only features UK-based sites.

The two major gateways to health information were searched, OMNI and NHS Direct. A search of OMNI using 'leukaemia' resulted in 64 'hits'. Some of these were discounted as either they were full text subscriber journals, focused on treatment relating to children or sites based in North America (US and Canada). Several of the links retrieved pointed to the Leukaemia Research Fund site, which will be explored in depth later. OMNI listed three links to NICE reviews of therapeutic agents used in the treatment of leukaemia. Two of these links, confusingly, point to two different sets of guidance for the same drug, imatinib. Review no 70 <www.nice.org.uk/cat.asp?c=89859> contains the current guidance for imatinib. The full guidance document is available in PDF format only,

whereas the guidance for fludarabine <www.nice.org.uk/cat.asp?c=22177> is available in both PDF and HTML formats. The guidance is clearly marked with the date of creation and the date that it will be reviewed.

The information contained in the leukaemia section at NHS Direct <www.nhsdirect.nhs.uk/ en.asp?TopicID=286> is aimed towards the health consumer rather than the health professional. Nevertheless, there is a section that lists some references to academic papers. A useful facility is the hypertext link that is placed next to some of the references. In one case, the link takes the user straight to the full text. In the case of the others, the link takes you to the home page of the New England Journal of Medicine. Unfortunately, this journal is only accessible by subscription or payment for single papers. The sections for selected links and information partners point the user towards CancerBACUP, CancerHelp and the Leukaemia Research Fund.

CancerHelp UK <www. cancerhelp.org.uk/default.asp> is

managed and supported by Cancer Research UK. It carries the crystal mark approved by the Plain English campaign. The information given is of a general nature but the site provides links to other sites which contain more specific information. It is refreshing to note that the site alerts the reader that the linked sites may be written in more technical language, are more likely to be text rather than diagram based and that some of the linked sites are American. The CancerBACUP site <www.cancerbacup.org.uk/Home> lists the individual types of leukaemia in the contents list of the site <www. cancerbacup.org.uk/Cancertype>. The site offers a facility to order information booklets and other 'hard copy' resources direct from the organisation. However, the information booklets contain essentially the same information that is presented on the site. There is a useful guide to UK leukaemia information <www. cancerbacup.org.uk/Resourcessupport/ UKpatientinformationguide/Cancertype/ UKleukaemiainfoguide>. It is interesting to note that the site does not link directly to the Leukaemia Research Fund leaflets that are downloadable from the fund's site.

Googling for leukaemia retrieved a number of different URLs for the Leukaemia Research Fund (LRF). The two URLs retrieved from the first page of results from the Google search were <http://dspace.dial.pipex.com/lrf-/>, and <http://phoenix.jr2.ox.ac.uk/LRF/ LRFHOME.HTM>. This latter page acted as a re-direct to a URL, <www.leukaemia-research.org.uk> which points directly to the initial URL <http://dspace.dial.pipex.com/lrf-/>. The organisation's e-mail address is Irf.org.uk which, when entered as a URL <www.lrf.org.uk>, again directly points to the pipex.com URL. The LRF

site, unlike the CancerHelp and CancerBACUP sites, is totally focused on leukaemia and related disorders. Unlike those sites however, it appears to be frame based and thus it doesn't allow direct linking to the diseasespecific areas. The site caters for both the professional and the patient. All the information on the site is 'free-to-air' in that there is no registration required to access the information directed at the professional. The booklets aimed at patients <http://dspace.dial.pipex.com/ Irf-/diseases/index.htm> contain considerably more detailed information concerning the individual disease process than the previous sites discussed here. Selecting a specific disease from the dropdown box produces a page where, for example, the user can access the booklet either as a PDF or HTML document. Links to other pages and other information such as books and meetings specific to the disease process are also listed on this page. Disappointingly, the link to the page that lists the advisors used in the compilation of the booklets results in a '404 not found'.

There is a spectrum of information on leukaemia available on the Internet, e.g. NHS Direct, CancerBACUP and CancerHelp. They all stress the need to speak to the specialist involved in the care of the patient and do not contain any detailed prognosis statistics. The structure of these three sites all conform to best practice guidelines in that they clearly show when information was last updated and show the sources of their information. In the case of CancerHelp, the site is also clear about the policy they have used in selecting links from other sites <www.cancerhelp.org.uk/help/ default.asp?page=2647>. The LRF site contains the most detailed information by making their patient booklets freely available. These contain detailed statistics and indicate possible treatments and indicative prognoses.