

Special Feature

What's on the web for nephrology?*

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Introduction

The use of the World Wide Web has increased dramatically during the last two decades. This trend within the general population did not spare patients and relatives: a recent report described an increase in the use of the Internet by patients to retrieve health-related information from 16% in 2000 to 55% in 2006 among patients who attended an ear/nose/throat clinic [1]. Similar data in renal patients are lacking but it is tempting to speculate that Internet use may be even more frequent, not least due to the complexity of diseases and treatments in our field. The use of the Internet by health-care providers has increased dramatically as well and numerous websites compete for our attention. Here, we try to review what the Internet has on offer, both for renal patients and relatives and for their health-care providers. We focus on resources in English although we appreciate that good websites also exist in many other languages.

Online resources for patients with renal disease

A recent study from Canada demonstrated that the majority of dialysis patients (58%) there had used the Internet to access medical information [2]. Proponents of Internet-based patient education argue that this serves to empower patients, carers and relatives [3]. However, problems must be reckoned with: first, the quality of information may be very much variable and must be kept up-to-date. Secondly, information is often written in language beyond the general public's reading comprehension [4]. Language itself may be another problem and a study from the United

States demonstrated markedly reduced use of the Internet by Spanish-reading renal patients [5]. Furthermore, the use of the Internet may vary hugely among our patients whereby younger and more educated patients may employ it more. Therefore, we need to appreciate that elderly, and less IT literate patients may not be amenable to online education. These differences were also demonstrated in the Canadian study: Internet use was much more common (86%) in home haemodialysis patients who are usually younger and very interested in their disease. Finally, not all websites adhere to established standards, such as the Health on the Net Foundation Code of Conduct (HON Code) [4]. We have compiled a list of English-speaking websites (Table 1) and present a selection in alphabetical order.

American Association of Kidney Patients (AAKP)
(<http://www.aakp.org>)

This is a patient-driven US website that focuses on many aspects of dialysis, including access, nutrition and blood tests, as well as transplant matters. It also contains a library of kidney disease that is searchable. This website is professional in its layout and there is a large section in Spanish. It is also an impressive example of the widespread use of these websites in general: this site attracts 120 000 unique users per month on average (AAKP, personal communication)!

Home dialysis (<http://www.homedialysis.org>)

This niche website focuses on peritoneal and home haemodialysis. It is comprehensive with message boards, newsletters, research papers and also advertisements for dialysis centres (DaVita and Fresenius sponsor it). We see its role particularly for the home haemodialysis candidate: there are few, if any, resources for these patients and this website helps to close this gap although it focuses on the US system and advice may not be directly applicable in other countries.

National Kidney Federation UK (<http://www.kidney.org.uk>)

This institution serves as an umbrella for the 69 local kidney patient associations (KPA) in the country. Accordingly the focus of this website is on resources for renal patients in the

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Table 1. Websites for renal patients (accessed 12 December 2008)

Name of website	URL	Owner	Comment
American Association of Kidney Patients (AAKP)	http://www.aakp.org	Maintained by an American patient organization (non-for profit)	Stylish and professional website disease; covers many aspects of dialysis, transplant and paediatric nephrology; social aspects, such as school, travel and intimacy are also covered
American Kidney Fund (AKF)	http://www.kidneyfund.org	Registered Charitable Organization	The mission of the American Kidney Fund (AKF) is to provide direct, treatment-related financial assistance to kidney patients who are in need, and to provide health education to people with, or at-risk for, kidney disease
Association of Dialysis Advocate	http://www.assndialysisadvocates.org	Independent organization	It is a grassroots organization that comprises volunteers dedicated to patient advocacy to ensure delivery of safe and quality dialysis treatments
BenefitsCheckUpRx	http://www.benefitscheckup.org	National Council of Aging, USA	US-based website, most comprehensive web-based service to screen for benefits programs for seniors with limited income and resources
Cleveland Clinic Foundation Renal Diet Cookbooks	http://www.patientsupport.net	Cleveland Clinic Foundation	An excellent resource for Renal Diet Books
DaVita Patient Citizens (DPC)	http://www.dialysispatients.org	Independent organization.	Its mission is to improve the quality of life for all dialysis patients through education and advocacy
Dialysis Facility Compare (from the Medicare website)	http://www.medicare.gov/Dialysis/Home	Medicare	This website provides important information and resources for patients and family members who want to learn more about chronic kidney disease and dialysis
Dialysisfinder™ Travel help for patients/social workers	http://www.dialysisfinder.com	Independent website	Helps locate Dialysis facilities in USA
Dialysis Units in the USA™ (from Nephron Information Center)	http://www.dialysisunits.com	Founded and is maintained by Stephen Z. Fadem	Its mission is to use this medium to make the public more aware of kidney disease in a sincere effort to prevent it when we can, and to help our colleagues achieve good outcomes in those who already have end-stage renal disease
Home Dialysis Central	http://www.homedialysis.org/	US website maintained by the Medical Education Institute (non-for-profit); sponsors include DaVita, Fresenius and many others	Great tool for the home haemodialysis candidate who wants to know more
Kidney Patient's Guide	http://www.kidneypatientguide.org.uk/	UK site; content by Wrexham Maelor Hospital Renal Unit and Wales College of Medicine (sponsored by Welcome)	Comprehensive and easy to understand with many animations, well structured
Kidney Patient News	http://www.kidneypatientnews.org/	US site sponsored by a renal service provider in Indiana, Illinois, Kentucky and Ohio	Excellent list of cookbooks for renal patients and links to collections of renal recipes
Kidney Research UK	http://www.kidneyresearchuk.org/	Maintained by a UK charity funding kidney research	Superb DVDs on order: Living with Kidney Disease Part 1 and 2
Kidney School™	http://www.kidneyschool.org/	US site sponsored by Amgen	Well thought-through: good structure and presentations as well as PDF for download
National Kidney and Urological Diseases Information Clearinghouse (NKUDIC)	http://kidney.niddk.nih.gov/index.htm	Official US government website (NIH)	Comprehensive resource; covers uncommon topics as well (e.g. ectopic kidney, Henoch Schoenlein disease). Structured educational program and strong section on diet
National Kidney Federation (UK)	http://www.kidney.org.uk	Patient-driven UK charity	Superb website for UK patients; excellent collections of books for patients
National Kidney Foundation (USA)	http://www.kidney.org	Patient-driven US charity	Superb collection of downloadable patient information material
PKD Foundation	http://www.pkdcure.org/	PKD foundation, an international non-for-profit organization	Dedicated to polycystic kidney disease, information packet can be ordered online
Renal Support Network	http://www.rsnhope.org/	US website maintained by non-for-profit organization; sponsored by a variety of pharmaceutical companies	KidneyTalk pod cast, marketplace (kidney jewellery as well as renal cartoons)
Restless Legs Foundation	http://www.rls.org/	US non-for-profit website solely on restless leg syndrome	Excellent collection of brochures and booklets; online community and links to support groups
Wikikidney/Nephron Information Center	http://wikikidney.org/	Open-access website	First renal wiki: unique in its open-access character for authors but currently still in infancy. News desk. Good link collections

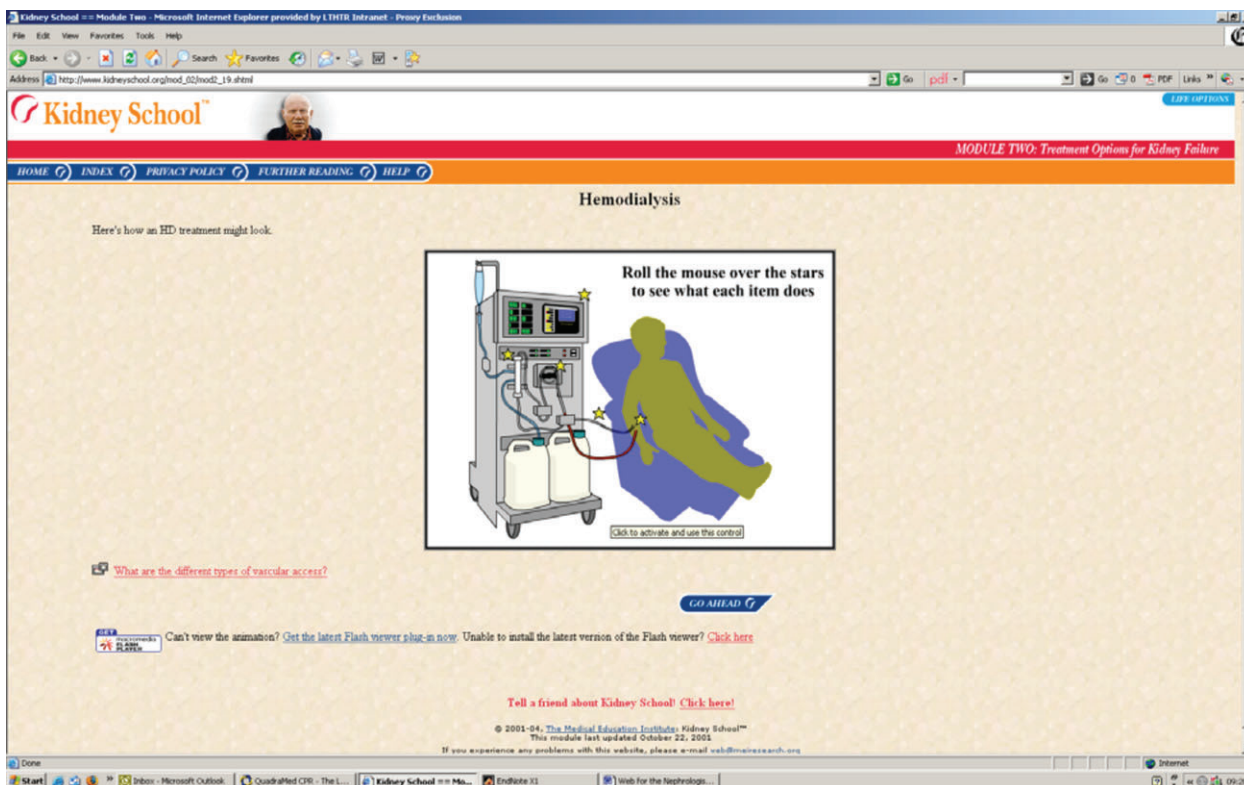


Fig. 1. Screen shot from Kidney School™ (<http://www.kidneyschool.org/>, accessed 20 December 2008).

UK. It is indeed vast with more than 5000 pages and serves as a hub to the renal community in the UK. Books for renal patients are also on offer.

National Kidney Foundation (USA) (www.kidney.org)

This American website is maintained by a leading US renal patients' association, NKF. Not surprisingly, it is a vast website. Its particular strength is a huge collection of patient information material, which is available for download as PDF. Most of the material is also available in Spanish. The quality of the material is very high and uncommon topics, such as end of life care, are also covered.

Kidneypatientguide™ (www.kidneypatientguide.uk)

This is an interactive UK website that provides useful information about living with kidney disease. It is easy to use and covers topics from claiming social benefits to arranging holidays for patients newly diagnosed with kidney disease.

Kidneyschool™ (www.kidneyschool.org)

This is a very structured US website with a series of on-line modules that educate about kidney disease and, in addition, how to live with the condition. It is interactive with questions and diagrams (Figure 1). We particularly liked the positive attitude (e.g. the chapter 'Living Successfully with Kidney Disease'). There is also advice for doctors and nurses with creative ways to use this website as an educational tool.

Renal Support Network (www.rsnhope.org)

The Renal Support Network, a non-profit patient-run organization, created this US web page. This is a patient-centred web-space with patient forums, event calendars and radio shows. We particularly liked the highly entertaining KidneyTalk pod cast. Stephen Furst, an American TV presenter and kidney patient, and Lori Hartwell, author of 'Chronically Happy—Joyful Living in Spite of Chronic Illness', host this pod cast. A patient-driven website, we see its role in providing up-to-date information and fun for US patients with kidney disease.

Websites hosted by individual patients, blogs and social networking: Facebook in nephrology

Websites hosted by individual patients are a first step towards networking in what may be regarded as the global community of renal patients (Table 2). They may offer the story from the patients' perspective and in doing so reassure patients who have been newly diagnosed with renal disease. Many of these websites are well designed (Figure 2) and often full of joy and humour. They may also be of interest to the nephrologist in that patients describe their experience with the disease as well as with different doctors. In addition, they provide amazing insight into coping mechanisms.

Social networking on the Internet is an increasing trend globally. Not surprisingly, this trend has now reached the renal world and renal groups have emerged. The largest

Table 2. Sites maintained by individual patients and blogs (accessed 12 December 2008)

Name of website	URL	Owner	Comment
Barbara's Kidney Web Site	http://members.tripod.com/gopaws/	US patient with FSGS	Provide a quick overview for recently diagnosed kidney patients that are pre-ESRD (early stages) and need to know where to start 2501 members across the world
Facebook Kidney Disease, Dialysis, and Transplant	http://www.facebook.com/group.php?gid=2229039880	Open group. This group offers a place to rant and rave about all the ups and downs of this disease with people who have been there as well	
Fearful Symmetry	http://www.livejournal.com/users/sebab	From a composer and haemodialysis patient who recently received a kidney and pancreas transplant	Focuses on the live changing event of a kidney pancreas transplant
Home Dialysis Forum	http://forums.homedialysis.org/	Offspring from Home dialysis Central	Focuses on PD and home HD. Several chapters of online discussion boards; online video collection (e.g. needling)
Jack's Kidney Adventure	http://jakidney.blogspot.com/	Jack Nowicki, a US dialysis patient with ADPKD in Austin, Texas	Covers a broad variety of renal and non-renal issues
MyKidney.com (Stories about Life (and living!) with Less-than-Perfect Kidneys)	http://www.mykidney.com/blog/	Krissi Bates, a young American patient with FSGS	Covers Krissi's experience from dialysis to successful live donor transplantation
My Twenty-Eight Years on Dialysis	http://www.cc.utah.edu/~cla6202/DrF.htm	Richard L. Faber PhD, a dialysis patient and retired mathematics professor	Good insight into personal experiences over decades of dialysis
Nathan's PKD	http://www.nmccart.blogspot.com	From a peritoneal dialysis patient who switched to haemodialysis and is awaiting a transplant	Very detailed blog, many aspects of the post-transplant follow-up are covered
The life of a twenty-something with lupus	http://flowonlupus.blogspot.com/	Miz Flow, a young patient with lupus and renal failure in New York	Beautifully designed, covers many aspects of lupus from immunosuppression to renal transplant (Figure 2)
The Renal Gourmet	http://www.kidney-cookbook.com/	Mardelle "Mardy" Peters, a US haemodialysis patient	A good source of renal diet including recipe of the month
Terie and Ger's Transplant Adventure	http://www.transplanteriedonorger.blogspot.com	A blog by a kidney and liver transplant recipient and her donor, both nurses	Interesting insight into the relationship between recipient and live donor

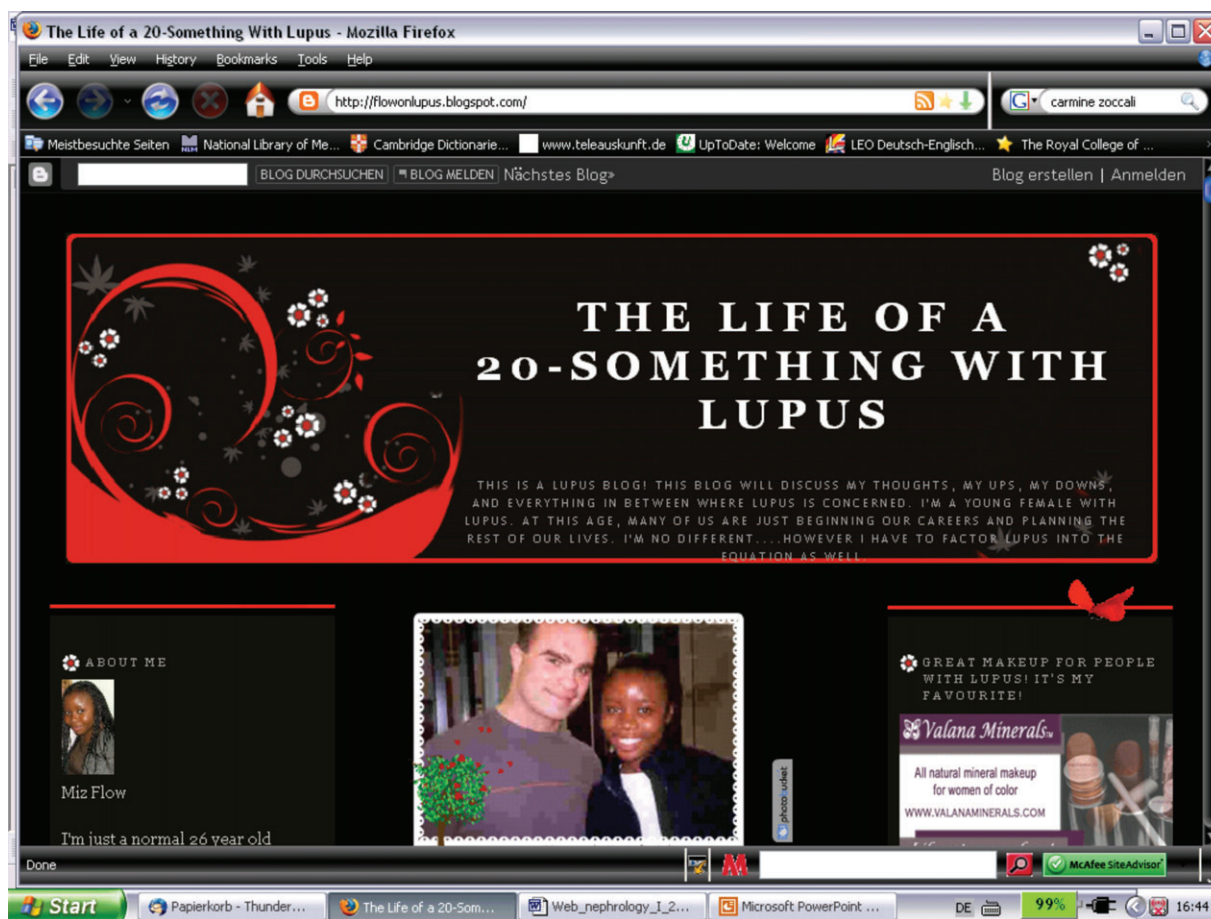


Fig. 2. Screen shot from 'The life of a twenty-something with lupus' (<http://flownlupus.blogspot.com/>, accessed 21 December 2008).

(<http://www.facebook.com/group.php?gid=2229039880>) has grown to 2501 members in December 2008 and continues to grow. We are not aware of how this compares to an 'average' Facebook™ site. Suffice to say that in total Facebook attracted 132.1 million unique visitors in June 2008. This site allows easy posting and chat for patients with kidney disease or transplant in the Facebook environment that many of our young patients are familiar with already.

Online resources for nephrologists

Learning in renal medicine has come a long way from the days of lectures and textbooks. In addition, the Internet may be used for making a diagnosis in clinic: The use of Google™ in diagnosing difficult cases has been described [6] and a recent case report in the *New England Journal of Medicine* reported that the 'Google strategy' arrived at the correct diagnosis in the first two hits [7]. Access of medical information by health care professionals may seem rather innocent and without obvious problems but it is not. A recent study examined the qualifications of respondents who provided advice in a paediatric nephrology sub-specialty forum [8]. Surprisingly, the respondents had a broad variety of qualifications whereby out of the eight most frequent

providers of advice only three were board-certified in paediatric nephrology [8]. Even in seemingly unbiased and well-established resources, such as Uptodate™, one has to appreciate that the advice given may only represent a part of the spectrum of current practice and that not all of the information may be peer reviewed. Finally, some sites are sponsored or even provided by the pharmaceutical industry. These websites usually insist on their editorial independence but subtle and less subtle ways of bias are conceivable [9]. We have compiled a list of websites for nephrologists (Table 3) and discuss a selection in alphabetical order.

Haemodialysis clinical nephrology (HDCN) (<http://www.HDCN.com>)

This is primarily an educational website that is endorsed, among others, by the American Society of Nephrology. It was founded by Dr J. T. Daugirdas, a prominent US nephrologist, and is divided into a free and key area. The latter is only available after paid subscription. This website hosts an excellent selection of articles and talks, both in audio format and as slide presentations. One minor criticism is that audio talks may be somewhat less useful at holding the listener's attention although they may still serve their purpose during a long daily commute or on the plane. Another

Table 3. Websites for nephrologists and other renal professionals (accessed 12 December 2008)

Name of website	URL	Owner	Comment
American Nephrology Nurses' Association (ANNA)	http://www.annanurse.org	American Nephrology Nurses' Association	Excellent educational resource for renal nurses and access to nephrology nursing journal
American Society of Diagnostic & Interventional Nephrology (ASDIN)	http://www.asdin.org/	American Society of Diagnostic & Interventional Nephrology	Resources focussing on interventional procedures, access and renal ultrasound. Upcoming events and bibliography
American Society of Transplantation (AST)	http://www.a-s-t.org/	American Society of Transplantation	Including 'ask the expert' (free), good pod casts (also free) and a selection of lectures (subscription only)
American Society of Transplant Surgeons (ASTS)	http://www.ast.org/	American Society of Transplant Surgeons	Position statements (e.g. live donation, commercial transplantation etc.) as well as surgical videos (subscription only)
Canadian Association of Nephrology Nurses and Technologists (CANNT)	http://www.cannt.ca/en/index.html	Canadian Association of Nephrology Nurses and Technologists	Resource for nurses and technicians with practice and technical standards (also in French)
Dialysis Outcomes and Practice Patterns Study (DOPPS)	http://www.dopps.org/	Arbor Research Amgen Study Coordinating Committee	Data and presentations from DOPPS, partly in slide format
Doctors Net Nephrology	http://www.Doctors.net/Nephrology	Doctors.net.uk Limited (UK)	Free access to Oxford Textbook of Nephrology, and is being regularly updated with interesting articles and case reports (ecases)
EdREN Handbook	http://www.edren.org	Edinburgh Renal Unit	Protocols for common problems encountered in renal medicine
European Dialysis and Transplant Nurses Association/European Renal Care Association (EDTNA/ERCA)	http://www.edtnerca.org/	European Dialysis and Transplant Nurses Association/European Renal Care Association	Discussion board and a variety of educational modules for download
European Renal Association–European Dialysis and Transplant Association (ERA-EDTA)	http://www.era-edta.org/	European Renal Association–European Dialysis and Transplant Association	Provides information on European Nephrology and related matters
ERA/EDTA Registry	http://www.era-edta-reg.org/index.jsp	European Renal Association–European Dialysis and Transplant Association	Another must if you are interested in the epidemiology of renal disease: European registry data with annual reports and presentations
HDCN	http://www.hdcn.com/	Medtext Inc. (the Daugirdas family)	Largest collection of audio and slide presentations on a broad variety of renal topics; new sticker and selection of full papers
ISPD Guidelines	http://www.ispd.org	International Society for Peritoneal Dialysis	A good resource for the peritoneal dialysis (PD) aficionado, including peritonitis and exit site infection guidelines as well as questions on PD
Kidney Disease Outcomes Quality Initiative (KDOQI)	http://www.kidney.org/Professionals/kdoqi/	National Kidney Foundation (US)	Evidence-based clinical practice guidelines on a broad variety of renal issues
Kidney Disease: Improving Global Outcomes (KDIGO)	http://www.kdigo.org/	KDIGO is a non-profit foundation governed by an international Board	Growing database of international guidelines
Kidney end of life coalition	http://kidneyeol.org/	Kidney end of life coalition, a US non-for-profit organization with representatives from many renal bodies	Unique resource dedicated to end of life nephrology, presentations and other resources

MD Consult™, Nephrology	http://www.MDConsult.com	Elsevier publishers	A compilation of textbook and journal articles as well as various guidelines and other related articles. Good for extensive unselected reading but not user friendly
NDT Educational	http://www.ndt-educational.org	NDT	Presentations in slide format, full paper review and online polls. Sub-specialty resources, such as urine microscopy. Very entertaining interviews with famous nephrologists
Nephrology Now	http://www.nephrologynow.com/	KM Medical Publishing (sponsored by Genzyme)	Online access to a variety of articles (including those from non-renal journals); good forum for online discussion of recent studies
Nephrology Rounds	http://www.NephrologyRounds.org	Brigham and Women's Hospital (sponsored by Amgen)	Regular issues with one review article and added CME questionnaire
Online Mendelian Inheritance in Man (OMIM)	http://www.ncbi.nlm.nih.gov/sites/entrez?db=omim	US National Institutes of Health (NIH)	Superb resource for inherited disease, e.g. Nephronophtisis, Neurofibromatosis, Polycystic Disease
PDServe	http://www.pdsolve.com	US website sponsored by Fresenius Medical Care	Dedicated PD website with newsletter for download
Sonoworld	http://www.sonoworld.com	A division of MedimageWorld, Inc. sponsored by many companies that manufacture ultrasound equipment	A must for everybody with an interest in renal ultrasound. Excellent case and image collection with >300 renal ultrasound images
UK Renal Registry	http://www.renalreg.com/	UK Renal Association	Excellent website on epidemiology of renal disease with annual reports and slides for download
U Kidney—Internet School of Nephrology	http://www.ukidney.com	Division of Nephrology at St. Michael's Hospital, Toronto, Canada (sponsored by several pharmaceutical companies)	Presentations of good quality as well as renal videos ('Youtubule'); access to the Kidney Atlas
Uptodate™	http://www.uptodate.com	Uptodate Inc.	Superb online reference for Internal Medicine, also available as desktop and handheld stand-alone version
US Renal Data System (USRDS)	http://www.usrds.org	NIH	Excellent website if you are interested in the epidemiology of renal disease with annual reports, free slides for download and the option to request data
USTRansplant.org	http://www.ustransplant.org/	University of Michigan at Ann Arbor as sub-contractor of the NIH	Transplant data from the United States: annual reports and research resources

minor issue is that the flow of emerging lectures is variable and some lectures may be outdated. Nevertheless, this is an excellent resource, for example if one is tasked with an unfamiliar lecture subject: A structure for almost any talk will be readily available as well as some ideas on how to tackle difficult topics.

NDT educational (<http://www.ndt-educational.org>)

This website can be regarded as the European pendant to HDCN. It is primarily educational with presentations in slide format as well as full paper reviews. It also serves as a communication tool for the European renal community and online polls are also available. Highly entertaining interviews provide an opportunity to get to know famous European nephrologists.

Nephrology Now (<http://www.nephrology.com/>)

This website regards itself as ‘an editorially independent and free service to help you stay up to date with new developments in Nephrology’. Genzyme sponsors it. Monthly issues feature numerous journal articles with some full text access, not least from Journal of the American Society of Nephrology (JASN). A particular strength of this website is that articles from the non-renal world are also included as well the forum for online discussion of recent articles. This sounding board for research may be somewhat faster than traditional letters.

Nephrology Rounds (<http://www.NephrologyRounds.org>)

This website is co-edited by Drs Barry Brenner and Joseph Bonventre at the Nephrology Division of Brigham and Women’s Hospital. Sponsored by Amgen, it focuses on education and comes in regular issues with one review article and added CME questionnaire. A regular scientific update is in the pipeline.

U Kidney—Internet school of nephrology
(<http://www.ukidney.com>)

This is once again a good website, moderated by Dr Jordan Weinstein from Toronto, Canada. Access is free. It hosts a moderate number of presentations of good quality. A collection of videos (‘Youtubule’) was introduced very recently. We also liked the free online access to the Kidney Atlas—excellent material for lectures.

Uptodate™ (<http://www.uptodate.com>)

This is surely the most extensive and widely used online resource in medicine today, not least due to the fact that its founder, Burton Rose, is a nephrologist. It features evidence-based reviews of diseases and guidelines for management compiled by opinion leaders in the respective field. Where there is a lack of proper evidence, Uptodate™

provides common practice and recommendations. There is also a section with patient information material. An excellent and must have resource that is also available, via subscription, as the stand-alone software for computers and handhelds.

Conclusion

The increased use of the Internet has undoubtedly benefited doctors and patients although potential problems need to be appreciated as well. Whether we like it or not: the Internet is a reality that is expanding and the average patient under the age of 50 will probably consult the Internet after a first appointment with the nephrologist. The 120 000 or so unique users who attend the AAKP website every month and the increasing use of social networking within the renal community underpin this assessment. It is for us to choose: either Google™, Yahoo™ and the pharmaceutical industry decide on what our renal patients know about their disease or we endeavour to provide some guidance through this plethora of information. In our unit we provide a leaflet entitled ‘Books and websites for patients with kidney disease’ and this approach is very popular, especially among younger patients. Further uses of the Internet include new ways of communicating with patients, electronic health records and much more. The profound implications for the relationship between patient and doctor are discussed elsewhere [10]. We hope that the resources presented here encourage others to include the Internet into their framework of patient education.

Conflict of interest statement. None declared.

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