

About

[EdRen](#) produced by members of the [Renal Unit](#) at the Royal Infirmary of Edinburgh, Scotland, who are employed by [NHS Lothian](#) or by the [University of Edinburgh](#), but it is produced by the Renal Unit, not as a formal publication of either of these organisations. Every page is reviewed by a renal physician before posting and after any amendment, but it is important to read the caution at the foot of the page and [below](#). Production of the site does not have any commercial sponsorship or support or other editorial control. Like what we do? You can [donate or send us a message](#).

Below is some history and [FAQs](#) to answer some common questions about the website and our policies.

The beginning

We realised that as we have a cutting edge research group, we should have a website. So we were thinking what to put on one. However at the same time we were becoming increasingly aware that patients needed more information about what was wrong with them, and were beginning to embark on making leaflets. We made some, but also made web pages. Then we realised you can print out webpages even more simply than you can make a leaflet, and you don't run out of webpages. So the idea for [EdRenINFO](#) was born.

A pilot version of the site began in early 2000. It had a home page with rather clunky frames and the first few articles on [EdRenINFO](#) appeared. These were written by Gemma Browne with Neil Turner. GB was a research registrar in the lab at that time, and had never written a web page, NT had done a few.

EdRenINFO

This remains the most useful and used part of the site. Gemma badgered many members of the department at all levels to write pages, which were then edited mercilessly. Now we make occasional additions but the major work is in regular review of the information provided on existing pages.

It means that we are making available information that we know is correct, whatever else patients read.

When we had done about 15 or 20 of these articles, we began to realise that they were more than just patient information. They are also more than most non-specialist physicians know about the individual diseases we have written about, and they are valuable for other staff on the unit, and for medical and other students too. So it forms a part of our teaching resources, and whenever we give the information to a patient we really have to give it to their general practitioner too, or it wouldn't be fair.

Archiving: from 2009 we have been formally archiving old versions of pages.

Guidelines and Handbook

As the unit grew, Caroline Whitworth and Neil Turner set out to produce a printed handbook for the Unit in early 1999. It was finally published in a loose-leaf A5 folder format in January 2001, after circulation of draft versions over many months. It seemed logical to make this available as an online resource also and this was undertaken progressively during 2001. We thought quite a lot about whether this should be open to the world as a whole, but ultimately couldn't think why it shouldn't be. The format conversion was made possible by the use of a certain amount of child labour. Some editing was required and we haven't published internal administrative arrangements, which form section 1 of the handbook, on the web. The Transplant Unit handbook received the same treatment during 2002; Lorna Marson took over leading the editing of this in 2009. From 2009 Unit Handbooks have been electronic-only.

Funding

Funding is from an NHS endowment fund and occasional donations; funders exert no control over content or editorial policy. Pages are written in the generously donated time of our staff. It is not an official publication of the NHS, or of the University of Edinburgh.

Advertisement

Our website does not host any form of advertisement.

Other content

The [history](#) pages were created because NT was interested in knowing more about the history of the home unit. Many of the characters involved in the early days were still alive but retired. Originally Dichelle Wong, then a medical student, extracted a great deal of information about local history. She did extremely well and published much of this on [EdRen](#) in 2001.

Education pages were partly an obvious resource, but the development of the website also happened at a time when a new curriculum was being introduced in Edinburgh, and a new renal module for all students was planned during year 4 (first run in 2001). However from 2008 our educational resources have been getting much better organised with the birth of our sister website www.edrep.org.

Format - from the outset, www.edrep.org was a database-driven site that could be maintained by multiple editors through a Content Management System (CMS). [EdRen](#) was moved/is moving to a similar system at the end of 2009. Both were also adapted for PDA/iPhone viewing in 2009. This is a bit [technical](#).

FAQs

Why are the EdRenINFO articles so detailed?

If people are going onto the internet to look for information, they aren't generally looking for just a couple of sentences. So most pages are written for the intelligent and moderately informed layman. This makes them too complicated for some. Where a subject is particularly complicated or important, we've attempted to get round this by writing two pages, at differing levels of complexity. You'll see that, for example, in the articles on nephrotic syndrome.

Who reads it?

Almost anyone who uses the Internet. Many of the people who contact us about it are patients, but the range is enormous. Many are from the UK but readers are from all over the world.

How many hits does it get?

The home page received hits from 150 new users/ week by the end of 2001 (20 to 30 per day), 250 per week by the end of January 2002. This had risen to 1000 hits

per day in late 2003, 1500 per day by mid-2004, and a total of 1 million hits by January 2005. This needs updating ...

More up to date info on the [Technical page](#)

Who writes it?

Patient information has been written by various professionals on the unit. Many have been written by doctors, but relevant pages have been written by nursing or specialist paramedical staff including transplant coordinators, dietitians, social workers. They are identified by name but not by job or grade at the end of individual pages. All have been reviewed by other professionals.

The EdRen Handbooks have again been composed by many members of medical, nursing and other staff.

Other pages have been written by research or other staff, usually identified at the foot of each page.

Should I believe it?

All pages are carefully edited by experienced clinicians before posting. Where appropriate we have had pages reviewed by other nephrologists or by non-nephrologists with relevant expertise. So we try to make sure that the information is pertinent and accurate. We really appreciate being told if you suspect it of being misleading or just plain wrong.

The site receives no commercial support and nothing is written deliberately to encourage the use of the products of any particular company.

However note the cautions frequently repeated throughout the site about patients' individual circumstances, and our fallibility.

Please be particularly cautious about drug usage and dosing as these are particularly subject to formatting errors and misinterpretation.

Can you answer a question about me?

This site cannot be a substitute for expert medical advice. We regret that we cannot answer questions about your personal kidney disease or those of your friends or relatives. It isn't usually safe to do that remotely without full info.

Confidentiality and privacy policy

The HONcode Foundation and others require a clear formal statement of our policy. See [cookies and confidentiality](#).

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