What patients want from your Web site

In a recent On the Net column (CMAJ 2001;164[6]:860), Dr. Michelle Greiver described the Web site she designed to tell patients about her practice. Now an American otolaryngologist has asked patients what they actually want to see on physician-designed Web sites.

At the recent meeting of the Head and Neck Surgery Foundation of the American Academy of Otolaryngology (www.entnet.org), Dr. Steven Mobley presented results from his ongoing study of Internet use by otolaryngology patients.

Using a standardized survey, he and his colleagues asked patients to tell them how they currently use the Internet. In addition, the patients were asked what they would actually like to see on the Internet.

Mobley found that age appears to have no impact on Internet use. Older patients used it as often as younger ones to troll for health information, but usage did increase according to income level.

Respondents had used the Internet 1.9 times during the past year to search for health information; 41% reported they looked for information about a specific symptom or diagnosis. Twenty-one percent looked for a physician on the Internet, but 30% of their searches were unsuccessful.

Mobley determined that patients want to learn details of their physician’s education, experience and malpractice record. They also want to make appointments over the Internet and to access things like laboratory and test results.

He concluded that physicians’ most vital role in dealing with patients via the Internet is to provide information that is reliable, secure and — above all — useful.

For more information about what details physicians should provide on their Web sites, visit Medscape’s primer (www.medscape.com/medscape/homepages), which includes a sample home page. — Michael OReilly, mike@oreilly.net

Hospital moves to assure public that autopsies are respectful, legal

In the wake of controversy surrounding one of its former pathologists, a hospital has reached out privately to the families of children who underwent autopsies and publicly to anyone who will listen.

At the centre of the controversy is Dr. Dick van Velzen, a Dutch pathologist who practised at the IWK Grace Health Centre in Halifax for 2 years before being fired in 1998. Last year Halifax police charged van Velzen, who now lives in Holland, with “improperly or indecently interfering with or offering indignity to a human body or human remains” after children’s organs were found in a Halifax storage locker. (According to the Halifax Chronicle-Herald, the charges facing van Velzen in Halifax relate to 8 organs from 1 or 2 children. Van Velzen has denied the charges, and no decision has been made on whether to seek his extradition to face the charges.) The story moved to the international stage early this year when van Velzen was accused of removing organs from the bodies of more than 850 children at the Alder Hey Children’s Hospital in Liverpool, England, without their parents’ consent.

In Halifax, the IWK Grace responded with a direct appeal to parents. “With this whole experience, there is a risk that parents will be reluctant to consent to autopsies,” CEO Rick Nurse said in an interview. “And only with autopsies do some families get closure.”

Nurse said the IWK Grace wanted to reassure parents that the situation in Britain was unlikely to happen here because the hospital, like all Canadian pediatric centres, has protective policies in place: documentation of all tissue and organ removal is required, and no organ can be removed without formal permission.

He added that the working environment at the IWK Grace would help prevent a physician from acting improperly because “we have a number of pathologists working quite closely.”

Nor would pathologists allow unacceptable behaviour to go unreptored, said Dr. Kent Dooley, director of pathology and laboratory medicine at the IWK Grace. Van Velzen, who worked there from 1995 to 1998, was fired after colleagues expressed concern.

“We had individuals willing to come forward and speak up,” said Dooley. “They didn’t have that in Liverpool.”

Dr. Fred Alexander, president of the Canadian Association of Pathologists, says pathologists must have informed consent before removing organs permanently during an autopsy. He says it is normal to retain tissue samples and sometimes an entire organ for teaching purposes, but only if permission has been granted. “That is common,” he said, “but taking them willy-nilly is not.” — Donalee Moulton, Halifax