

# Why the Internet may be bad for what ails you

Online health advice can be great - or just plain wrong

Excerpt  
The Ottawa Citizen  
September 28, 1999  
(published on Ayala's  
12th birthday!)



Ayala Ravek, 11, of Nepean, uses her Web site to chat with other children who share her rare disease.

BY TOM SPEARS

Teenage patients come to Dr. Arlette Lefebvre, their faces swollen by a steroid treatment for lupus. They are convinced this drug, which they hate, is poisoning them.

And why wouldn't they think that? Didn't they read on the Internet that prednisone, a common steroid, is poison? A killer sold by heartless drug companies? Must be true. It was on the Internet.

Dr. Lefebvre, a Toronto psychiatrist who helps children and teenagers cope with chronic disease, sighs. "They're very vulnerable to messages like this," she says. The kids hate the drug to begin with because their swollen faces make them feel disfigured, their bones weaken and their skin tears.

In fact, prednisone is useful in fighting inflammatory diseases such as rheumatoid arthritis and inflammatory bowel disease, and can calm their effects. But the drug's side effects are visible and uncomfortable, and can be dangerous. It can weaken bones so much that they break.

The Internet has many terrific health sites - information on research, on support groups, on new treatments, on unusual diseases that a physician may only see once in a lifetime. But there are also scare sites, the ones that reach out for vulnerable minds. And there are the "miracle cures" - the cure for all cancers that's always just

around the corner, the purifier that will kill every virus. Patients read these sites, picking up groundless fears and false hopes.

"It happens a lot," says Dr. Lefebvre, a psychiatrist at Toronto's Hospital for Sick Children who helps children with chronic illnesses. "Doctors are faced by patients who bring in piles of stuff, a lot of it junk. And they (patients) ask, 'Why didn't you tell me about that?'" Despite the problems, Dr. Lefebvre is a huge fan of health information on the Internet. She is co-author of a new book called *Taking Your Kids Online: How and When to Introduce Children to the Internet*.

She says some people with certain diseases "have done a wonderful job" of setting up sites that tell how they live with their illness. Cancer, chronic pain, lupus - they all have Web sites emphasizing information by mainstream medical groups specializing in research and treatment. "That's extremely useful. When it comes to living, one good role model is worth 1,000 shrinks," Dr. Lefebvre says.

In Nepean, 11-year old Ayala Ravek started her own Web site with her parents' help to explain what life is like with reflex sympathetic dystrophy, or RSD, a rare syndrome that causes acute, lasting pain, often following a comparatively minor

injury, usually in a foot or leg.

Ayala's site is called the No Pain Zone. Through it she has invited and received dozens of e-mail letters from classmates and from other children and teenagers with RSD.

"It would be nice hearing from another RSD Soldier," says one letter. Others offer encouragement. Ayala pastes them in a scrapbook.

She started the site, she explains, "just to learn about RSD and to get people who have it to know they're not the only ones. And to give them some hope if things aren't going so well."

It's a cheery collection of pictures and messages that also pack a punch as they explain how the disease attacked her, and show her during a recent stay at Sick Kids, where she met Dr. Lefebvre.

"Be strong. Be positive," she tells her young readers, and ends one section with a quote from Dr. Lefebvre: "Life is a tragedy full of joy."

"She's so tired of explaining how it started and where she's been for treatment, and so on," says Ayala's mother, Pamela. The Web site allows Ayala to explain her medical problem but at the same time it paints a vivid picture of a real girl, not just a case in a medical text.

... sites such as Ayala's offer hope...