

Patients find lifelines on the Internet

SPENCER HO

FOR PEOPLE WITH END-STAGE renal disease, the world can often feel like a desert island, but a popular Internet tool is helping connect dialysis patients in ways that never seemed possible.

Last August, Bill Halcomb, a 13-year veteran of dialysis, created *ihatedialysis.com*, a message board for dialysis patients. He calls it “a site for patients by patients” where people on dialysis can go to vent their frustrations—with ESRD, dialysis, doctors, or anything they feel like—and talk about everyday issues that have nothing to do with their disease.

Halcomb’s site is not the first dialysis patient message board. In fact, he created it out of frustration with his experiences on other forums. He has been a member on the Home Dialysis Central, Global Dialysis, and Davita forums.

“The corporate boards are very moderated,” he said. “They delete posts, edit posts, and it made me feel silenced. I got fed up with it, and said ‘...I’ll just start my own board.’

“The next step was to decide on a name for the site. Lots of sites start, but never get off the ground, so I wanted something that would shock people, but also interest them, and that’s where the name comes from.

“Hate is a strong word, but it’s true. I am grateful for dialysis and will kiss the ground the creator of dialysis walks on, but I hate living with it, and I hate what it does to my body and how it makes me feel.”

Just as Halcomb’s site has become an important part of the dialysis patient community, other boards remain an important asset to the patient community.

Message boards—a sample

Global Dialysis

(www.globaldialysis.org)

Global Dialysis, an organization that helps traveling patients find dialysis cen-

ters around the world, recently restarted their message boards after having to shut them down for a while because of spammers.

“When the boards went down, we got emails from both patients and professionals who said they felt isolated and wanted to get to know others outside of their circles,” said Michelle Lindsley, business development director of Global Dialysis. “When we heard that one of the most visited dialysis forums was shutting down, we contacted the administrator, Scott Brumley, to see if we could take it over. We never got a response, but we used the threads from that site as a model for ours.”

Lindsley and IT director Russel England, who is also one of the founders of Global Dialysis, are the administrators of the forums.

Home Dialysis Central

(www.homedialysis.org)

Homedialysis.org had the same idea in mind when they started their message boards in July 2004, said Dori Schatell, executive director of the Medical Education Institute and a forum administrator.

“It is hard to build a dialysis patient community because in general, patients do not see each other every day,” Schatell said. “Through our message boards we hope to create a place where people can easily share information and give each other support.”

Interestingly enough, *homedialysis.org* deleted one of Halcomb’s posts promoting his own website, which led to an interesting dialogue with Schatell about home dialysis. This helped convince Halcomb to look into the alternative therapy, Schatell added.

Halcomb confirmed that he is training to do home dialysis with the NxStage System One and was slated to start last month.

The *homedialysis.org* forums are for all dialysis patients, but they serve as a testament to the possibility of success with home dialysis, Schatell said.

“Folks who visit the message boards would be surprised at the education and knowledge level of patients. People who don’t believe patients can do home therapy just need to look there for proof that they can.”

DaVita Inc.

(www.davita.com)

In some ways, DaVita’s message boards represent the crown jewel of this group. Since starting in May 2004, the DaVita forum has attracted over 3,300 registered members. Meanwhile, Davita hopes to accomplish the same goals as the other boards, but, because it is a corporate sponsored board, to a slightly different tune.

“DaVita invests heavily into its website and message boards,” said Stephanie Prial, a spokesperson for DaVita. “We want to show that a company can also be a community, and this is part of what we offer to develop.”

While DaVita’s boards have more members than the other three groups combined, they are often the focus of Halcomb’s gripes and with the dialysis industry in general.

DaVita will often edit and delete posts on their forums that say bad things about the company or its doctors, which is one of the downfalls of having a corporate sponsored message board, Halcomb said.

Prial said that she does not think that the message boards suffer from the corporate sponsorship. “I think this is a good board because of all the people [who participate]. DaVita does not have much to do with [the boards]. It’s more about people reaching out to people.

“As a corporate sponsored [message board], though, we have the benefit of all the resources the company can provide,

like stability, state of the art technology, and quality moderating,” Prial said.

ihatedialysis.com

While DaVita’s forum is established with the most members, ihatedialysis.com is growing with more than 230 members, 800 topics and 7,100 posts, and continues to grow every month, which Halcomb said he hopes will send a message to the dialysis community.

“I’d like to see this site help level the playing field a bit, get rid of the hierarchy so that nurses, doctors, technicians, and executives see us as people, not just patients or Medicare numbers.

“If just one doctor sees that something he does upsets patients and does something about it; if an executive sees that patients are upset about the company’s cheap Christmas gifts and gets better presents next year, if this site helps one other patient; then

I’ve succeeded.”

Halcomb’s members appreciate his efforts to create a place where everybody can feel free to say what they want.

Darla “rerun” Irwin started dialysis last year after her kidney transplant failed. When she found out she had to do dialysis again, she wanted to die and cried through the whole first session, she said.

In desperation, she typed ‘people who hate dialysis’ into her favorite search engine, Dogpile.com.

“I found the site that was calling my name,” she said, “a place where I could go that [had] people like me who understood my feelings.”

Irwin became one of the first regular posters on the board, and has since become a moderator. “I am so glad I found this place. It’s given me freedom. All the anger I had is gone.”

After seeing the way his message board has touched people’s lives,

Halcomb has changed his view on his life somewhat.

“Sometimes I ask why my kidneys failed. Nobody has ever been able to tell me why. Doctors think it might be congenital, but nobody is sure. My kidneys just shrunk. It’s a mystery.

“But so many people have told me that this site means so much to them or has changed their lives that it feels like this is why I have been on dialysis the last 13 years.”

Halcomb’s message board is the first and only dialysis message board owned and run completely by patients, and that makes it special. It is important to remember, though, that every other board out there has something of its own that makes it special as well. And more importantly, all have one important thing in common: they help make life a little less lonely for people all over the world affected by ESRD. ♦

A site for patients by patients

Meet the owner and creator

AT 33 YEARS OLD, I HAVE BEEN fighting ESRD for almost 13 years—no transplant. To this day, I do not know what caused my kidney disease. I was sick for about a year that I can remember, and my only symptoms were vomiting in the mornings and tiring very easily. Finally my family convinced me to go to the ER, and the rest is history.

I decided against a transplant due to the risks. Do I regret that decision? Yes, sometimes. I deal with a lot due to my kidney disease: 13 years of in-center hemodialysis and severe osteoporosis that has led to two broken hips (pins

holding me together) and six years in a wheelchair. I had to have my parathyroid removed and had thyroid cancer, which led to operations that damaged my vocal chords to the point where I had to learn how to speak all over again. In addition, I have an enlarged heart due to the many years of dialysis, have suffered from high blood pressure, and my teeth have been ruined due to all the calcium being pulled from my bones.

During all this my wife (Trina) and I are raising a healthy nine-year-old son, Nick. He is my future and my wife is my strength. Without them, I could not go on emotionally.

When I started dialysis 13 years ago, the Internet was around but unlike today, there were no sites devoted strictly to kidney disease. With all the sites and tools today, I find the most useful tool is the message board.



Mr. Halcomb is the owner and administrator of ihatedialysis.com

BILL “EPOMAN” HALCOMB JR.

Now, there are many message boards dedicated to kidney disease, but I was always disappointed that whenever I wanted to rant or vent some dialysis-related frustrations, my posts would be deleted or edited. Being silenced infuriated me.

I tried many dialysis sites but none

fit what I was looking for: “a site FOR patients BY patients,” a place where members could come and talk about a center, company, nurse, technician, doctor, or anything they wanted free from worry that it will be edited because the site has a corporate sponsor. I wanted a site that offered more than dialysis, like perhaps an off-topic section where members can discuss other issues important to them. After all we are not just patients, but people with interests, hobbies, and families—maybe a live chat room, a cartoon section, and up-to-minute kidney disease news from around the world. I decided I would create it, but I did not want just another

kidney site, I wanted something different—something nobody else offered.

Now, I had the idea, but I still needed a name. I wanted something that encapsulated my feelings for this terrible disease and would shock people and get their attention. So I came up with ihatedialysis.com

Don't be fooled by the name—we are not being negative. We just hate dialysis. Just as a cancer patient deals with chemotherapy and does it to survive. Even though dialysis keeps me alive, I hate it.

The site is for everyone on dialysis (all types), as well as spouses or caregivers, and anybody working in dialysis. Even

if you have a transplant and it's working great, you're welcome here. This site is for everyone who is somehow affected by kidney disease.

With this site, I hope to create a place where everybody can come and ask questions, or just talk about something that is bothering them about this disease. Hopefully, along the way, doctors, nurses, executives, and even political figures will get a better understanding of what we patients go through on a daily basis as we struggle to survive. So don't judge a book by its cover. Come take a look at the site, and then judge us for yourself.

Some members share their experiences struggling with dialysis and how ihatedialysis.com has helped them:

I am a high school teacher, living in the British Virgin Islands, but originally from the island nation of Barbados. Last September (2005), I was diagnosed with end-stage renal failure due to a combination of diabetes, hypertension, plus the side effects of some of the drugs I was taking. It was rather overwhelming for me, especially since a brother passed away in November 2004 after 10 years on dialysis. I was sorry that I hadn't asked him more about what he was going through.

On one forum on the Internet, there was this guy, Epoman, inviting people to his site with this intriguing name—I Hate Dialysis.

I clicked on it, and was immediately caught! This site has been indispensable in preparing me for the challenges I would face on dialysis. My questions were answered, some of my fears assuaged and more than all of that, I found a caring community of people who understand what I am going through, and who allowed me to vent when necessary. Sometimes medical practitioners are unable to see things from the perspective of the patient and fail to explain things in a clear and coherent way, and that is what this site does for me.

— **Patsy A. Barker**

a.k.a. “bajanne2000”—Site Moderator

When I first found out that my kidneys had failed, due to a genetic disorder. I couldn't believe it. I had always thought that this wouldn't happen to me until I was married, had kids, and a steady job. But at the time, I was only midway through my first year of university.

I started dialyzing three times a week for four hours at Christmas time. It was really hard at first to deal with my full-time course load as well as the trials and tribulations of dialysis, but when I found ihatedialysis.com, I found a great source for answers and support. These are people who are going through the same things as I am, and have shared both the ups and downs of life on dialysis. Some people on the forum have just started dialysis, while others have been at it for 10+ years. But knowing that I'm not alone is what has really helped me cope with life on dialysis, and more importantly, life beyond dialysis.

— **Liam Portt**

a.k.a “hyperlite”—Canada

It is difficult, to say the least, to watch your spouse struggle with an illness like kidney failure. In January, my husband and I were devastated to learn his kidneys had failed to the point where he would need dialysis. After a whirlwind week of medical appointments, outpatient procedures, and many sleepless nights, I started to research end-stage renal disease online. I was fortunate to find the I Hate Dialysis website almost immediately.

This site, with its members, has provided a great deal of support and “insider information” for me. From the forums, I learned things that no doctor ever thought to tell us: what life is really like on dialysis, how the feelings we were going through were normal and to be expected, and that there can be light at the end of the dark tunnel that is kidney failure. Real communication between doctor and patient has been severely lacking in my experience. Bill and his forums have helped to fill that void, and for that I will be eternally grateful.

— **Sara Alicando**

a.k.a. “Sara”—U.S.—wife of a patient