Patient Empowerment and the World Wide Web
Patient Power Health Issues
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        Dave deBronkart

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Introduction

Andrew Schorr:
Hello. This is Andrew Schorr. Welcome again to Patient Power Health Issues. Here I am in New York City sitting across from my friend and co-host Peter Frishauf. Peter, welcome once again. We're going to talk about a topic near and dear to our hearts.

Peter Frishauf:
Thanks, Andrew. Good to be here.

Andrew Schorr:
We're talking about patient empowerment and the worldwide web, and I'm going to tell you a brief story and then I'm going to pay a debt of thanks to a man sitting with us today. So I was diagnosed with chronic lymphocytic leukemia, something I'd never heard of, in 1996. And I was terrified, as my wife was. So one of our computer savvy friends, remember, 1996 - we were still in kind of the dark ages with the web and all that, we were doing e-mail - said let's go on the computer, on your computer, and let's see if there are any groups of patients who know anything about this, who were talking about it. So taps on the screen, zip, zip, zip, zip. Hey, there's a group talking about blood cancers, and what you've got is a blood cancer. Hence, I was introduced to something called ACOR, Association of Cancer Online Resources, that were groups of patients talking to kind of affinity groups, the people who had that or similar conditions, and really empowering one another. Well, the man who started it in New York City is sitting across if me, Gilles Freedman. Gilles, welcome. I think you saved my life, buddy.

Gilles Frydman:
Delighted to hear this. I hope we can help save the lives of lots of people.

Andrew Schorr:
Well, the internet, Peter, has good and bad and ugly but certainly a lot of good that can help patients if they search, connect with maybe lifesaving information.
Ways to Connect with Others

Peter Frishauf:
Information is the most powerful medicine. That's why we're all here and what we're doing to make it more available, more reliable and better.

Andrew Schorr:
Let me mention that Peter founded a website called medscape.com, which really has become really the preeminent source for so many programs of information for doctors.

And then also joining us from Nashua, New Hampshire is another man who experienced a serious diagnosis, kidney cancer, and that's Dave deBronkart who joins us. Dave, the internet, the information is there to help people, isn't it, if you know where to look?

Dave deBronkart:
Well, the odd thing about that is that in my case. I mean I was Googling before there was Google. I have been a member of online communities literally since 1989 before the Mozilla browser came along, so I knew what I was doing when my life was at stake, and I still could not find on any established website the information that actually made a difference for me. As it happens, my primary physician knows Gilles, and he prescribed ACOR. He handed me this prescription slip that said "ACOR" on it, and it was in the ACOR community where I found people who had answers to the questions that I wanted to ask.

Andrew Schorr:
Well, let's go back to Gilles. So, Gilles, you live here in New York City. What drove you to find a way to connect patients with patients? Where did it all start for you and when?

Gilles Frydman:
It all started seven years prior to the diagnosis of early breast cancer that my wife received in 1995. When she was pregnant the first time around she developed a very, very serious cardiac condition. She had heartbeats of close to 300 beats a minute for a few hours. Miraculously, she survived two episodes like this, and she was saved by an exceptional team of cardiac doctors, cardiologists, and then three months after the baby was removed in a huge emergency C section she had two open heart surgeries, and I became involved in looking for medical information.

And the surgery that she had was highly experimental, and I spent weeks and weeks in the medical library trying to understand what was going to happen, because her surgery failed. She had to go back a week after, and the doctors told me that basically because I was the bridge between the medical team and the patient the patient survived. And then the same doctors that were like amazing cardiologists, seven years later my wife was diagnosed with cancer, breast cancer, and they made a terrible mistake. They referred us within their institution instead of saying our institution does not specialize in cancer, you should go somewhere else.
And the cardiologist, who had become a very close friend, sent us to a doctor who was just a breast surgeon and who within five minutes said, don't worry, it's not a big deal. We're going to do a full mastectomy, and just to make sure we'll do a few rounds of therapy, and just to make sure that there is no other problem we'll do bone scan, liver scan and brain scan. And I left this meeting saying, that's it, my wife is going to die within a few months, and here we go again. And it turned out that in fact my wife had very early stage breast cancer that didn't need to have any of those treatments. No mastectomy needed.

**Andrew Schorr:**
Lumpectomy.

**Gilles Frydman:**
Just a lumpectomy.

**Andrew Schorr:**
Did you get on the computer then?

**Gilles Frydman:**
The day when I received this diagnosis I went back home and I looked, and I found there was an existing breast cancer List and within two hours I had information that said your wife has very early stage breast cancer, but on the other hand the pathology that you've been given is very complicated and there are only two specialists in the country. One at Sloan-Kettering and one in San Francisco, Dr. Lagios in San Francisco, and Dr. Rose at Sloan-Kettering. And we went to Sloan-Kettering within two days.

**Andrew Schorr:**
So you were here in New York. And so by connecting with someone on the internet you found out about a resource that was right for your wife but you didn't know about otherwise.

**Gilles Frydman:**
That I could never have found otherwise.

**Peter Frishauf:**
Right under your own nose.

**Andrew Schorr:**
In his own home down of New York City.

**Peter Frishauf:**
Well, in his own creation of ACOR.
Andrew Schorr:
Right. So let's talk about ACOR. So what ACOR.org is, is a compilation of communities, right? A whole bunch of communities on the computer of patients talking to patients. And, Dave, for you and I, you found tremendous support and information there, right?

Dave deBronkart:
Absolutely. Yes.

Andrew Schorr:
Tell us a little bit about it.

Dave deBronkart:
Oddly, on the conventional websites I read things like, outlook is bleak, prognosis is grim, side effects are often severe and rarely fatal. And these are all factually accurate statements, but they did not give me the information that I needed, like, holy crap, what do I do? And that's the difference between doctors or some centralized authority figure dispensing information like, here's what I think you need to know, versus patients talking among themselves, answering questions exactly in the way that Gilles described.

We have a similar situation in the kidney cancer world. There is one treatment for stage IV kidney cancer that has ever been known to produce a complete response, you know, which is the technical term these days for a cure, and every week or two we have somebody new arrive in this ACOR kidney cancer group whose doctor did not tell them that treatment exists. Now, I don't know if it's because the doctor's information is out of date, that's a possibility, or if it's for competitive reasons, but that's not really the point. The point is if the goal of medicine, of healthcare delivery systems ask to produce the best possible result for the patient I'll tell you it's the patient communities that are doing it more than any hospital.

Andrew Schorr:
But how could the doctor not know? I mean, those are the guys or women in white coats, right, Gilles? I mean, they're supposed to know lifesaving stuff.

Gilles Frydman:
The same institution that provided great medical services to my wife when she had early stage breast cancer will never, ever mention the treatment that David received in Boston. We don't know why, but that institution for close to 20 years now has never mentioned that treatment.

Andrew Schorr:
Peter, this stuff makes me really angry.

Peter Frishauf:
Well, it should, and it all goes to the utterly poor way which information is shared. And clinicians need access to this information, patients need access to the information, and
they're not getting it. I think it really has to do with kind of the mentality of trade unionism in medicine, and I'm not saying that in any way to disparage labor unions. That's not what I mean. It's kind of professional egos that get in the way of sharing information and sometimes it's institutional competition, sometimes it's regulatory competition. The FDA doesn't want you to know about that or somebody else doesn't want you to know about that or somebody in Congress doesn't want you to know about that, so it's very, very complicated.

But the solution, the great disintermediator of the efforts to keep you from getting the information is the internet. So our challenge really is to organize it better, to make it more available, to make it more reliable to really qualify, to try and qualify in a meaningful way what research is truly promising and what may be fraudulent or really lead you down a very dangerous path.

**Using the Internet Wisely**

**Andrew Schorr:**
So, Dave, let me ask you a question. There you are up in Nashua, New Hampshire, not a very big place. And towns and cities across America, let's give some advice from the point of view of you the patient on what people can do to use the internet wisely whether they have a potentially fatal diagnosis, kidney cancer, or whether it's just chronic backache. What would you advise them? How do they approach it?

**Dave deBronkart:**
Well, that's an interesting question because the way I envision things will work within the next year, two or three, that Gilles and I are working on doesn't exist today. If you go right now and Google "kidney cancer patient community" you won't find ACOR, and one of the things in the new society for participatory medicine, one of the things we want to do is build a resource like that, a go-to place so you can find the best patient communities.

**Andrew Schorr:**
So it's a work in progress

**Dave deBronkart:**
It is.

**Andrew Schorr:**
You talked about using a search engine. What about the advocacy groups? You know, there are kidney cancer groups, there are chronic pain groups. Can they help? Can their websites be the place to go, or has your experience been that they leave out things too?

**Dave deBronkart:**
All I can speak about is my own experience two years ago because I haven't continued to be a kidney cancer researcher after I got better, which kind of speaks to how miraculous the treatment was, but I couldn't say whether those communities have grown up since
then. And I was fortunate enough, you know, my hospital is more than an hour away from home. My philosophy has always been, I mean, I was empowered before I knew the word existed because my philosophy has always been to get prepared for when I'm really going to need a doctor for something serious. When I chose to go to Beth Israel Deaconess in Boston, I had no idea that I was going to get a really emergency diagnosis. When I was diagnosed my median survival time was 24 weeks, so I was very glad that I was already hooked up with experts. And I had also made a point of choosing an empowered online physician. My doctor's name is Danny Sands. He's a member of the same e-patient working group with Gilles and me.

Andrew Schorr:
So he supports all this, right?

Dave deBronkart:
I'm also very fortunate that I didn't suffer the kind of mistreatment that Gilles and many patients experienced.

Andrew Schorr:
And your doctor, Danny, who you mentioned, he supported your efforts on the internet.

Dave deBronkart:
Oh, absolutely. The e-patient working group was formed by Tom Ferguson who died in 2006. He was such a visionary. Within a year of the Mozilla browser being introduced he foresaw that access to information and each other would turn medicine on its head, and when we have access to information and each other we would form patient communities and communication could become more efficient. In the 1990s Danny wrote the prototypical guidelines for doctor-patient e-mail. As I say, he was the one who handed me the prescription slip that said "ACOR." So I guess I could say that my advice to patients is get yourself an empowering doctor.

Andrew Schorr:
Yeah, but, Peter, there are many doctors you still can't send an e-mail to just on routine stuff.

Peter Frishauf:
Yeah, that's an awful situation, and that definitely needs to change. And we as consumers and patients, you know, we need to find doctors who we can communicate with that way. And over time that will change, but patients are really going to have to force the issue. It's not going to happen by itself.

And also we have to get over the kind of regulatory barriers to the exchange of information so that everyone know that is it's unacceptable to try and keep information out of the hands of both patients and clinicians. As Dave mentioned before, the shocking
thing is, and Gilles made this point, you go to experts, they may be experts in one area, but they are either ignorant or for one reason or other they don't want to tell you about another area. So we have to get over that. It's the trade unionism problem.

**Making Progress**

**Andrew Schorr:**
Yeah. So Tom Ferguson, who I met years ago, talked about trying to turn healthcare and the doctor-patient relationship on its ear. How have we done so far? Have we made changes? Are we making progress?

**Gilles Frydman:**
I think in some certain areas we have made incredible progresses, but because it happens mostly with the groups for rare diseases the public at large does not pay attention to what has been going on. If you pay attention to the long tail of medicine, those thousands of groups suffering from rare conditions, they have transformed completely the quality of care that they received ten years ago. In many cases you have thousands of people that survived just because they have freed the information and they decided to take control not only of the information but of the research. It's really this empowerment. You have to free the information. You have to free knowledge, and I think that it's high time, considering that healthcare is going to ruin all of us, that we organize as a nation and say enough is enough.

**Andrew Schorr:**
Ruin with the costs, and meaning we're not devoted to prevention. So it's treatment when people get sick.

**Gilles Frydman:**
Prevention is just one aspect.

**Andrew Schorr:**
Right.

**Gilles Frydman:**
The system is so dysfunctional that it's going to ruin all of us. 17 percent of GDP is now spent on healthcare.

**Andrew Schorr:**
Yeah. We don't have it.

**Gilles Frydman:**
No.
Andrew Schorr:
We don't have it. So, Dave, are you hopeful with the Obama administration in trying to put healthcare reform on the agenda again, we've got lots of other issues, that we can make any progress? What do you think, Dave?

Dave deBronkart:
It's a great idea, and my great concern is that enormous amounts of resource might be poured into idiotic initiatives. There's a big debate going on right now on the e-patients.net blog about the issue of how you get data out of legacy systems and into new wave medical record systems. I did this a couple of weeks ago. I punched a button to move my data into Google Health, and I found insanity. Just a whole bunch of ridiculous historical information with no dates attached to it showed up, and it set up an urgent alarm in Google Health.

The thing that really gets me, I'm involved in software marketing. My day job, I work on Route 128 in Boston in high tech. I've been studying tech trends for years. I observe how new technology comes online and changes things. This industry is decades behind other industries, and there appears to be a serious lack of comprehension of how data actually works. That's the only possible explanation for the crazy experience that I had.

Now, meanwhile, those of us who just come from the software business know these problems are not unsolvable. For instance, Phil Longman wrote a terrific book a few years ago called Best Care Anywhere: Why VA Healthcare is Better Than Yours. Now, the VA has gotten a lot of bad publicity in the last couple of years, but most of that publicity is not valid, but separate from that, he's talking about things that happened in the 1970s and 80s where overtaxed doctors banded together in self-defense and wrote open source medical record code with a top priority that the data be interoperable, be able to move from system to system reliably. And Longman got onto this project. He was assigned Fortune magazine to go out and prove that, quote/unquote, socialized medicine, "Hilary-care", could never work. Unfortunately, you know, I like to say people get radicalized when it gets personal, as is true for most of us here. His wife had been through a very unpleasant terminal breast cancer episode a couple of years earlier, and he had experienced x-ray films getting lost, so there was no record of them, half of the blood test results that they paid for got lost, all kinds of craziness.

And when he started researching this article for fortune what he found was in JAMA and NAJM and everywhere, study after study, the VA healthcare system had the best quality scores and outcomes. It's funny, he says in the introduction to the book, I knew they would kill the story, and they did. Fortune killed the story. There was no way they were going to tell that to the public, and so he went off and wrote the book.
Andrew Schorr:
Wow. Dave, we've got to run, as we wrap up this segment of Patient Power Health Issues. And I want to wish you all the best as a survivor of kidney cancer but also all the best in your efforts in empowering patients. We're going to continue our visit with Gilles and we want to thank you. He's a great example, isn't he, Peter?

Peter Frishauf:
He sure is. And thank you, Dave. It's with smart people like you we can figure this out. And I'm sure, you will get your records straightened out at Google Health, and you'll teach them how to do it too.

Dave deBronkart:
Very good. Thanks. It's been a pleasure.

Andrew Schorr:
All the best to you.

We will be back with more of our discussion on patient empowerment and how to find answers, which we hope will continue to get better, but it did, I think, save my life, and the man who helped do it is with us on the worldwide web. We'll be back with more of Patient Power Health Issues. I'm Andrew Schorr.

Peter Frishauf:
I'm Peter Frishauf.

Andrew Schorr:
Remember, knowledge can be the best medicine of all. Stay with us.

ACOR

Andrew Schorr:
Welcome back to Patient Power Health Issues. I'm Andrew Schorr broadcasting from New York City with my friend and co-host...

Peter Frishauf:
Peter Frishauf.

Andrew Schorr:
And we're talking about patient empowerment on the worldwide web, and I said earlier it made a big difference for me, didn't it, Peter?

Peter Frishauf:
It sure did. Saved your life.
Andrew Schorr:
And so I really owe you, the loyal listener, an explanation. So Gilles Freedman is with us, and Gilles was the founder for something called acor.org, Association of Cancer Online Resources, and so that's patients talking to patients. And so back in 1996 when I was diagnosed, as I mentioned in the first half hour of our show, a neighbor came by and helped me find this group, ACOR, and patients with my same illness, blood cancers and specifically leukemia called chronic lymphocytic leukemia. Should I tell the rest of the story?

Peter Frishauf:
Yeah, please do. What happened?

Andrew Schorr:
Okay. What happened was is that my own local doctor was not particularly knowledgeable in this disease in younger patients and was recommending chemotherapy right away. And as I learned a little bit about who the doctors were who were knowledgeable through your List, I name-dropped with the local doctor. What about Dr. Keating from Houston? I had never heard of him before, never been to Houston, but I heard about him from other patients, and he was an expert in my illness. And he said, oh, Dr. Keating would say you should have chemotherapy now. And I said, well, how long would that work for? Would that cure me. No, wouldn't cure you. What? Work maybe four years. What do you do then? Maybe we can use it again, it will last another two years. And I said, what then. And he said, well...

Peter Frishauf:
You die.

Andrew Schorr:
You die. I mean basically that's all we have. So he was convinced that that was what Dr. Keating would say. Well, as I corresponded, Gilles, with some of the people you know - GrannyBarb Lackritz, right? And other women, and men who were on there. You can feel free to jump in, too, Gilles, people you know well, they said go see Dr. Keating, right?

Gilles Frydman:
Well, your story is typical of what has been happening on all the ACOR lists. Most of the people joined a List because their doctor told them this is how we're going to treat it, and then they join a group of a thousand or two thousand people with the same disease who told them almost instantly, it sounds like your doctor really doesn't know what he's talking about.

Andrew Schorr:
Right. And that's what I was hearing. So I went to Houston. The people on this internet ListServ, GrannyBarb and others, gave me the phone number of the doctor to call. My wife and I found ourselves on a flight to Houston, had ten tubes of blood pulled from the lab in the morning, bone marrow biopsy, see this Dr. Keating in the afternoon. And I
said, Dr. Feldman back in Seattle said I should start this chemotherapy right away. He said, hell, no. And I said, well, he said you'd say that. He said, hell, no, maybe a year ago. Things have changed. Not anymore. You don't need any treatment now, and when you do I'll have something better. And then my wife said, you know, Dr. Keating, we thought Andrew would be dead but we've always wanted to have a third child. Do we have the confidence to have one? He gave her a big hug and said, go have your baby.

So today after being in a clinical trial, ultimately, not with that drug but with two others, but revolutionary new stuff in a clinical trial, I'm in remission now all these years later, like nine years later, and we have a kid. And so I was diagnosed in '96. This is 2009. So he was born a year later. Pretty cool story.

**More Internet Groups**

**Gilles Frydman:**
So let me tell you the story of another group.

**Andrew Schorr:**
Sure.

**Gilles Frydman:**
For a very rare disease called leiomyosarcoma.

**Andrew Schorr:**
Wow.

**Gilles Frydman:**
When we created the group we created it with two patients who were living both in cities of half a million people. Their doctors had never seen another case of that disease. Then we reached 50 people, 100 people, then 500, 600, 700 people, many more than what was known in the medical literature. When this group started to grow, we started to notice that a sub group of people were doing very poorly. They were treated with chemotherapy, and they would die very fast.

Then one man whose wife was diagnosed with leiomyosarcoma went back to the archives and found the reference of someone that was in a phase I clinical trial and asked if anybody else was on this trial. It turned out that eight of the ten participants of the trial were on that List, and they started to communicate. And from that moment on whenever somebody would come on that List saying this is how I feel, and my doctor has told me to take chemotherapy, instantly one of those eight people would say, you know what, it sounds like your doctor really doesn't know. It's not his fault because this is a brand new test. You should go back to your doctor and ask to be tested for this new protein. And almost invariably people would come back and said thank you very much. And then they would learn that they were all misdiagnosed, and therefore they were treated for a disease that they did not have.
Andrew Schorr:  
Whoa.

Gilles Frydman:  
And then Gleevec came along, and they were all taking this drug, this pill, and eight, nine years later many of them now have a chronic disease.

Andrew Schorr:  
Yeah, they're still alive.

Gilles Frydman:  
And their life expectancy at the time was less than eight months

Peter Frishauf:  
That's amazing. So, Gilles, how do people find you?

Gilles Frydman:  
We asked that question for many years, and really for many years we didn't have a clue, and now we know that most of them find us through Google. But we have a problem because the exchange of information is really intense, and people speak to each other as real people. We have big issues with privacy, and therefore all the content of the conversation is hidden from the search engines. It's a terrible problem for marketing, but this is what we have to do.

Finding Trustworthy Information

Andrew Schorr:  
Now, earlier in our program, Peter, Dave, e-patient Dave he likes to call himself, was talking about the internet for health still being the Wild West, that we weren't there where you could be sure you were getting reliable information, and so while people go to the internet there's so much out there that's baloney. Here are examples of lifesaving information, life changing information, but sometimes people feel it's a needle in a haystack. How do they navigate it today? We want to apply many better systems, but we don't have them yet.

Peter Frishauf:  
So I think there are a lot of questions. One question is how do you know who to trust? Not everybody who is out there peddling a treatment or advocating for a treatment, even people who mean well, really know what they're talking about. So, Gilles, how do we know that patients can find solid, trustworthy information on ACOR or any other service on the internet?

Gilles Frydman:  
Well, let me be very clear early on that the best way to avoid receiving inaccurate information is to participate in a large group of people that have the same disease.
act like the best filter possible, and you can be sure that when you speak with a group of a thousand people they are going to be able to tell you if this new treatment makes any sense, if this new theory has any value. And ACOR was always based on the fact that whenever somebody would come with a new idea we would say you have to go to PubMed and bring us scientific references, because if you cannot prove what you are saying then it's certainly not valid.

Andrew Schorr:
So I've heard this term, Peter, "wisdom of crowds." Tell me about how that applies here on the internet related to health.

Peter Frishauf:
Well, it's the classic long tail that Clay Shirky and others have written about so well and so eloquently. And basically there are many, many small diseases or diseases that occur in small numbers where there are populations located often across the world who can put together little bits of information that turn out to be very instructive, and in your case and in the case of many, many others, lifesaving.

Andrew Schorr:
All right. Now, some people search on big conditions, you know, just hypertension or, you know, heart disease, whatever it may be, high cholesterol, typical things that people search on, and there are a lot of commercial interests at work. So how do you sort through who is just trying to sell you something and what's reliable information?

Peter Frishauf:
Well, it's certainly buyer beware, but not everybody who is trying to sell you something is a bad guy. Gilles mentioned Gleevec before. It's very important that patients have access to information both from ethical manufacturers as well as other patients as well as people who are doing studies and trials. Information itself isn't the enemy. It's a good thing. It can be misleading. You do have to be careful. You can post questions on reputable Lists to your peers who can help you understand this. By all means ask the clinical experts in the field what they think, but be a consumer. Don't be shy. Do as much research as you possibly can. Have confidence in your own ability to understand it, and when you can't, ask people who can help you understand it.

Gilles Frydman:
Since 2008 it's your responsibility to become an informed patient and to find the information that relates to your condition so that you can have a much better interaction with your clinicians.

Andrew Schorr:
So it used to be, when we were growing up, Gilles, you just went to the doctor, you know, looking for a solution and trusting the doctor that they would have it. And if they didn't
know it just didn't exist. But it sounds like what you've been learning is that, in your own personal experience and now probably hundreds if not thousands of times you've heard it again, you can't go that way. You have to take on responsibility yourself.

**Gilles Frydman:**
Who said that you should trust your doctor?

**Andrew Schorr:**
Well, I mean, we grew up with that, you know. I remember the doctor sitting on the edge of my bed when I was a little kid, and it was Dr. Landis, and he gave me, whether it was simple cough medicine, and then I'd get well. And I just grew up for so long thinking that's the way it was.

**Gilles Frydman:**
So it may be, but we are now living 15 years past the beginning of the public internet, and we now know that really doctors cannot know everything about all the conditions, and if you are in this long tail of medicine the chance that a regular doctor is going to know anything about your condition is almost nil.

**Andrew Schorr:**
Wow.

**Gilles Frydman:**
And therefore if you get diagnosed by a doctor who doesn't know, you are sure that you are going to receive sub optimal care.

**Andrew Schorr:**
That's scary, Peter.

**Peter Frishauf,**
It sure is. And e-Patient Dave made another great point with this huge problem that we have about the lack of interoperability of data which is data in health records about ourselves. It's either lost or it's inaccessible to search engines to being collected, and he mentioned Google Health and Google and Microsoft are really doing great work in trying to create repositories of health records information. And he also mentioned the incredible problem of extracting data about his health and having it placed into Google Health, and he's working on that problem, and that's a great thing.

But we do have to recognize that we are at the beginning of a journey which really could revolutionize our access to our own data and information about it, and it's the dawn of a new age in healthcare in which the empowered patient is really going to be at the center of an equation that's going to make us better.

**Gilles Frydman:**
But e-Patient's story about his EHR or PHR--
Andrew Schorr:
His health record.

Gilles Frydman:
His health record shows something very disturbing. We now learned, thanks to his effort, that data without contextual information around it is ineffectual and can be very dangerous.

Andrew Schorr:
All right. Whoa. Whoa. Wait a minute. Okay. So first of all when I used to go to the doctor, and many of us still do, and you go up to the receptionist, there are all those colored files, and as you get older the files get bigger, and I always wondered what was my color and my letter, the tag and all that. So I get it, but if you put it on an electronic medical record it should make it more efficient, hopefully fewer mistakes, and we'd hope that that record could get around to the other doctors or providers who need it. What you've been saying is that we've got a long, long way to go. Even though I know the Obama administration says billions of dollars can be saved we've got a long way to go to fix it. And as e-Patient Dave was saying is that, you know, just trying to get it to move it around and use it, and he found inaccurate stuff.

Gilles Frydman:
All those systems were built for one specific thing. They are always build so that the doctors can get reimbursed. And that is really--

Andrew Schorr:
Huh? I thought it was to know what was going on with me, give me better care.

Gilles Frydman:
No. It turns out that really, I mean, the main reason for building the systems is to make sure the doctors and the hospitals get reimbursed by whoever pays for it. And as a result the information that is transmitted is inaccurate because all the doctors, everybody knows that in order to get reimbursed you have to change the reality because the coding system is not designed for 90,000 conditions. It has 10,000 codes, and when you don't have an exact code for this condition you have to find something that fits more or less.

Andrew Schorr:
Whoa. Now, wait. Whoa, whoa. This is a big thing. So I should tell our audience my co-host and friend, Peter Frishauf, has really been one of the pioneers in medical education on the internet. So, Peter, this is quite an indictment of the records we have if that's colored the accuracy of what's in there.

Peter Frishauf:
It goes without saying that bad data is really worse than no data. Having said that, I hope we have no problem with doctors getting reimbursed for care that--
Andrew Schorr:  
No, no. They should be paid. Sure.

Peter Frishauf:  
They should. And in many, many cases they don't get paid or reimbursed or they get reimbursed for the wrong thing. They get reimbursed for procedures and not for thinking and talking and discussing, and so the problem, technology is part of it and the paper record is clearly part of it, and it does improve patient care if you have a drug list in a patient record which is in a patient's personal health record and in an EMR so that it can be read correctly, it can be filled correctly at the pharmacy, etc. There is no defensible reason that in this country a majority of prescriptions are still written on a piece of paper. That's bad patient care.

So things like e prescribing clearly help improve medical care. Things like the electronic digital transmission of laboratory data so that it gets into an EMR correctly and not through a fax and then can be shared with a patient who can share it with other people, all of those things have real benefits to patients. So I wouldn't throw out the baby in the bath water here. The Obama administration's $20 billion commitment to support digital health, there's a lot of merit to it. But there are huge execution risks, and just saying everybody is going to have an EMR isn't going to do the trick. There are a lot of really bad systems out there. So I agree with him, but not entirely.

Gilles Frydman:  
So all those EMRs, all those big systems have been designed now for years by groups of professionals that had no input from patients. They specifically never asked patients to participate in the conversations. And just as ACOR has demonstrated that when patients take charge of their disease, get informed, they do better, I guarantee you that when patients take charge and own their data the EMRs and the EPHRs are going to be much better than they are today.

Andrew Schorr:  
Well, I look forward to that. Now, let's get back to just the typical searching for information on the web for a second, okay? All right. So somebody themselves, a family member, you know, your aging parent gets sick or you think they're sick and you're worried about certain symptoms and you go searching, okay? How do you go from first of all learning about that to then finding others? Maybe you could weigh in on that, Peter, and then Gilles.

Peter Frishauf:  
Well, I'll take a first crack at it. I'd certainly like to hear what Gilles has to say about it. If you're not sure of what to search for a good place to start actually is with your clinical team, your physician, your nurse practitioner, your physician assistant. It is helpful to speak to somebody who knows what has blood gas is, for example, and many consumers, many patients have no idea what terminology like that means. And of course search
engines often can only be as smart as the terms that you throw at them. So if you don't have a fairly sophisticated or a reasonable level of medical understanding, get some help from a savvy person who will help you get a good search result on the internet and perhaps evaluate of results.

If you ask your healthcare team for this kind of help and they are dismissive or they are not interested in participating with you in doing it, you probably have the wrong group of clinicians as your caretaker. So I would kind of start with that premise in terms of refining my search.

Andrew Schorr:
Okay. And, Gilles, so then people say, okay, I know what my diagnosis is, or mom's or dad's or my kid's or my spouse. And I know some of these terms that go with it and I've gotten all of stuff, but now I need help of somebody who has worked in these shoes before me. Where is this community? How do I find it?

Gilles Frydman:
If you have cancer it's easy because you will find this group of communities and then you are done. For sure on ACOR you're going to find one of those communities. If you suffer from any other types of diseases, including any of the 6- to 8,000 rare diseases, it's very hard to find. There is no central resource that you can look into with the exception of one place in France that is trying to do a census of all those organizations. But it is very, very difficult. And Google to the rescue, because unless you have Google you probably cannot find it.

Peter Frishauf:
Gilles, give us some sense of how many patients are using ACOR, how many have used it, how many disease conditions your List covers.

Gilles Frydman:
We have 165 online communities. We have served over half a million people. The largest community today is about 2800 people. The smallest one is 35 people. They suffer from an extremely rare type of cancer, and those 35 people say, 35 of them say, without this group they would all be dead.

Andrew Schorr:
Wow. And by the way, if you're wondering, we keep saying ACOR, Association of Cancer Online Resources, ACOR, A-C-O-R, dot org. Gilles Freedman founded it when his wife became sick with breast cancer and they were concerned about whether they were getting reliable information. They did connect with reliable information, and it made all the difference. So it made a difference for me in leukemia, and Dave, who was with us in the first half hour from Nashua, New Hampshire, made a huge difference in renal cell carcinoma or kidney cancer. And we should mention we then heard about a treatment that he wasn't being offered and then he got it, and that we should mention is Interleukin 2. Kind of a difficult treatment for renal cell carcinoma or kidney cancer, but he believes
he's here today because it, and he wouldn't have heard about it otherwise.

**Gilles Frydman:**
Well, it's the only treatment for kidney cancer that provides the chance of a full cure, so it's a very hard treatment. It's done at only a few major hospitals, and because it is a difficult treatment you really should go to one institution that does a lot of those procedures.

**Andrew Schorr:**
Right. So the answers are there, Peter. So are we going to get better? So next year, the year after, because you've been at the internet since the beginning, will this get easier for people searching for information for their own personal health?

**Peter Frishauf:**
Absolutely. I think we're really at the cusp of some enormous improvements of being able to find meaningful information. And consider how far we have come. When I launched Medscape with the founders group of five people back in 1995, just providing access to reliable clinical information in and of itself was kind of a revolutionary concept. But what became fascinating was how people around the world, in Hong Kong, in Indonesia, in other places, all of a sudden they had the same access, just access to trusted information, that we had in Manhattan or anywhere else. What an incredibly leveling, empowering position that was to be able to do that. It was really an honor to be able to do that.

Well, now we've come a long, long ways from just providing access in terms of helping people really understand and identify resources that can help them. And communities like ACOR, which started at about the same time, for patients really helped blaze that trail as well.

**Andrew Schorr:**
Gilles, are you optimistic that we'll just get better? I mean, you've been on the ground floor of this. We have come a long way.

**Gilles Frydman:**
I really think we are right on the cusp of something very important. Some of the best engineers, software engineers in the world are working on developing brand new systems that are going to completely transform how people get their information. By integrating the information that you can get from any test or any doctor and having very, very complex algorithms, people are going to be able to get really very precise information about what they should do.

**Andrew Schorr:**
Well, very exciting. We're going to have to go. Gilles Freedman, with ACOR, acor.org, thank you so much for all you've done for me and thousands and thousands of others. I'm Andrew Schorr with my buddy here...
Peter Frishauf:
Peter Frishauf.

Andrew Schorr:
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