

Powerful Patient #16

Host: Joyce Graff, WebTalkRadio.net

The Parent as Advocate

When Nechama brought her infant adopted daughter home from VietNam, she was a brand-new mother with a business background. She never expected to be thrown into a terrifying two-months-long medical journey. But she “learned on the job,” as most of us do, how best to support her daughter, and how to be an effective advocate for her.

Through a long list of tests, treatments, and possible diagnoses she worked with the medical professionals and became an integral, respected member of her daughter’s medical team. At the same time she created a lasting bond with her infant daughter.



Nechama and Ashira on her first day of school, 2007

1) About Our Guests

Nechama has a background both in business and in Jewish education. Trained as a rabbi, she works part-time as a cantor. She lives with her daughter in Massachusetts.

Joyce read three small excerpts from the book “How Doctors Think” by Jerome Groopman, M.D. (New York, 2007).

Nechama sings her original song, “For Ashira,” copyright 2001.

2) Finding Help on the Internet

These days you can do a great deal of research with a computer on the internet. If you don’t own a computer, go to the Patient Resource Center at the hospital, or to your public library. Both of these have staff people who are ready and willing to help you. There are also internet cafes and some copy shops (like Kinkos) who rent time on their equipment.

Go to a search engine, and begin looking for the key words the doctor has used. You can ask the doctor or nurse to write them down so that you will spell them correctly.

Google tends to find if anything too much; Yahoo sifts through the finds a little better and presents you with fewer but usually more targeted options. It’s a bit like using the index in a large book – it will find many things that talk about the topic you have described, but not all of them will be relevant to your objective. So you may need to skim through several sites before you find just what you need.

Nechama began with the diagnostic words she was given, like “SCID”. If you start with too common a word, like “immune system” you will get tons of “hits” (candidate responses). Today I looked for “immune system” and got 2,508,441 hits. Then I looked for “SCID” and got 360,163 hits -- still a lot, but somewhat lower. On the first 1-2 pages of the search engine’s report you will probably find the most useful information. Most of the rest are random inclusions of the acronym “SCID” in various papers. The top hits are the ones that mention it most frequently or that users have found most useful. In addition to the objective search, some engines add in a “popularity” factor.

You remember the old adage “don’t believe everything you read in print”? Well, it’s even more true on the internet. While there is a treasure trove of information out there, there is also a wealth of drivel. You want to know who wrote the information, for what purpose, and how much does that person know? Was this information published in a medical journal, where it is carefully reviewed by other professionals before it is published? Or published by a group that is careful to publish only medically reviewed information (like a hospital or a reputable health organization)? Or by a graduate student doing a research paper? Or one patient telling his or her story? Perhaps a dissatisfied patient venting anger? How can we tell?

From that first page of hits, I chose

- [The SCID Homepage](#)

Primary immune deficiency, the defining characteristic is usually a severe defect in both the T- & B-lymphocyte systems.

www.scid.net

There are other definitions, but this one seems to be the most on target. But who is preparing this information? Go to the bottom of the homepage (front page), and look for something that will tell us. I chose “About Site” and read the description given by the man who founded this site and the parent support group around it. He is a parent of a child with SCID. This will give you some idea of the reliability of the information, and whether or not it is medically reviewed.

Be careful in reading a “blog” (short for web-log), and kind of online diary of one person’s experience. That person may or may not have the details straight, and may or may not be presenting the information fairly. While it can be helpful to read one person’s experience, it might also be depressing or alarming. You want not just one person’s experience, you want a breadth of experience, and boiled down to the essence if at all possible.

Be careful too about sites owned by pharmaceutical companies. Just know that they will have a bias toward their product. As long as you understand that, you can still get a lot of good information from such a site, just remember their bias.

For example, let’s look for “cholesterol”:

[High Cholesterol Levels?](#)

GetCholesterolInfo.com Find Out How Your Numbers Compare To The Cholesterol Guidelines

[Cholesterol Information](#)

www.LIPITOR.com Visit LIPITOR.com to learn about ways to lower your cholesterol.

[Cholesterol Must-Knows](#)

AmericanHeart.org/FacetheFats

Of these, which one is likely to have the most unbiased information?

At the bottom of the homepage for GetCholesterolInfo.com we learn that this site is owned by Astra Zeneca to promote the sale of Crestor. Lipitor is a product of Pfizer. While I'm sure both sites contain a great deal of useful information, the American Heart Association is probably the least biased toward a particular way of handling high cholesterol. There are non-drug alternatives as well.

Among patient support organizations, like the American Heart Association, look for their medical advisory board, and for information about the site as we did before. On their homepage I chose their "Ethics Policy" and their "Contact Us" page which lists their offices, staff, medical advisors, etc. Looks good, and of course they have a widespread recognizable image. When you are dealing with most rare diseases, however, the organizations will not have a well-known image.

Ratings like HonCode, BBB, and NORD will also tell you who is making an effort to show their compliance with ethical practices and adherence to the HealthOnNet principles.

3) Online Support

Another feature of the SCID site is the offer of a ListServ.

[Email Listserv](#)

[Find out about the SCID Email Listserv Support Group](#)

They are sometimes called Online Support Groups or Discussion Groups. They are an electronic meeting-place where you can find support from other folks in the same boat, even in the middle of the night. There's nearly always someone awake on the internet.

If you don't already have an e-mail account, you can create a free one in minutes. In a search engine, look for "free e-mail" (with or without the hyphen), and you will get pointers to a number of options. With a web browser from your public library you can read your mail.

Nechama joined the ListServ and put her question out there, asking for advice. Particularly in the case of a rare disease, this is a good approach. Among the rare diseases, this is as good an approach as any to getting information on what is going on. If

you can find another parent who has experienced what you are going through, you can at least learn from their experience what worked and what didn't work for them, and then talk with your doctor about how relevant that may or may not be to the current situation.

4) Sources of Support for Parents

- Your local community and any religious institution you are affiliated with
- The hospital chaplain
- The hospital social worker
- The Patient Resource Room at the hospital is a library on premises where you can do some of this research.
- Use the internet to reach out to find other parents in the same boat. There are support groups even for very rare conditions
- Look for the diagnosis on the internet and find a support group around that condition
- National Organization for Rare Disorders has an online support community for diseases for which there is not yet any organized support.

<http://nord.clinicahealth.com>

When a young child is in the hospital, most hospitals now encourage one parent to stay with the child. There is often a recliner, and many hospitals will bring in a cot if you ask so that you can lie down. Ask where you can shower or if there is an exercise room for parents. As long as you are cooperative and make an effort to become a constructive part of your child's healthcare team, they will usually welcome your presence. The staff is there to care for your child, not you. If you add to their burdens, you will not be welcome.