

Effective, Time-Tested, Inexpensive Treatments for Life-Threatening Diseases A New Book by Julia Schopick, Award-Winning Blogger on Health Care and Healing

Questions & Answers

1. Your biographical information states that you have been a public relations consultant for 25 years. What made you decide to become a patient advocate?

I didn't plan to become a patient advocate. It was in the course of caring for my husband and dealing with his doctors that I became first his advocate, then an advocate for others, as well.

In 1990, my husband of five years, Tim Fisher, was diagnosed with a very serious, cancerous brain tumor. For the first five years after his diagnosis, we basically followed his doctors' orders and recommendations. Tim had surgery and underwent chemotherapy and radiation—the commonly prescribed treatments for his condition. But after five years, I began to see that the side effects and complications from the treatments were becoming more severe and were, in fact, beginning to take over our lives. The complications included a radiation-caused stroke, hydrocephalus (water on the brain) and intermittent seizures. There were many hospitalizations and some additional surgeries to deal with these complications. I decided that, if I was to have Tim around for many more years—and in relatively good shape—I'd better start looking for therapies and treatments that might increase his survival and his quality of life. I found many such treatments, and—to my delight and amazement—Tim lived 15 years after his diagnosis. This was 12 years more than his doctors had predicted. I was delighted—and began to take my role as Tim's advocate ever more seriously.

Because of my success with finding treatments for Tim, my friends and colleagues started seeking my advice. This led to the creation of my website, HonestMedicine.com, where I began posting information about innovative treatments that many patients and doctors wouldn't know about.

2. What made you write HONEST MEDICINE?

To my surprise, in the course of advocating for my husband when he was ill, I discovered that his doctors were not interested in the low-cost, effective treatments that I found for him—even though it was obvious that those treatments were working. Case in point, he outlived his prognosis by 12 years. It seemed to me that his doctors only wanted to use expensive pharmaceutical treatments.

Then, something happened that made me become determined to spread the word about non-toxic, inexpensive treatments. In 2002, Tim had a recurrence of his brain tumor and, after this surgery, his suture line wouldn't heal. The doctors performed eight additional surgeries in eight months, trying to make the skin on his head heal. But they didn't work. In fact, the repeated surgeries just made him worse, until finally he was brain injured and paralyzed from the surgical assaults on his body.

As you can imagine, I was frantic, and searched everywhere for answers. Finally, through a doctor friend I found a treatment that worked—Silverlon—and it worked literally overnight. I was delighted, and assumed his doctors would be delighted, too. But they weren't. In fact, they weren't even open to learning about it.

I decided that something really bad was going on in medicine. So I set out to find other treatments that were also inexpensive, life-saving and had stood the test of time—other treatments that doctors weren't interested in learning about.

I wrote this book so that others wouldn't have to go through the struggles I went through to find treatments that are low-cost, effective and time-tested for their friends and loved ones.

That is what *HONEST MEDICINE* is about.

3. Tell us about these treatments.

In addition to the one I just described, **Silverlon**—the inexpensive wound-healing treatment that healed my husband's head—there are three others that I write about in *HONEST MEDICINE*.

- a. **Low Dose Naltrexone**, an off-label use of a drug that was approved by the FDA over 25 years ago for drug and alcohol addiction. In the mid-1980s, a neurologist named Dr. Bernard Bihari found that, in very tiny doses, this drug helped people with autoimmune diseases, such as MS, lupus, rheumatoid arthritis and Crohn's disease. Like Silverlon, most conventional doctors aren't interested in learning about LDN for their patients. But luckily, tens of thousands of patients have found it for themselves and are advocating for it all over the world. Three of them have written chapters for *HONEST MEDICINE*.
- b. **Intravenous Alpha Lipoic Acid** is a natural product that was first used in the mid-1970s by Dr. Burt Berkson to treat end-stage liver disease. His story, told in *HONEST MEDICINE*, is fascinating. Dr. Berkson and two of his patients have written chapters for my book.
- c. <u>The Ketogenic Diet</u> is a high-fat, low-carbohydrate diet with a long history of actually <u>curing</u> children with epilepsy of their seizures. Used since the 1920s at prestigious institutions such as Johns Hopkins and the Mayo Clinic, the diet fell out of favor in the 1940s and 1950s, when seizure medications became popular. Because this diet has so many fewer side effects than drugs, many parents today are advocating that it be offered by doctors from the start, as a viable alternative to anti-seizure medications.
- 4. I understand that some of the patients who have been helped by these treatments have contributed chapters to *HONEST MEDICINE*. Can you tell us about their experiences—one for each treatment?

Low Dose Naltrexone: The patients who take this drug for their autoimmune diseases are passionate about getting the word out about LDN. There are so many LDN patient advocates out there that I found it difficult to choose which ones I wanted to be contributors to this book. I think the one I'll tell you about here is Malcolm West, a multiple sclerosis patient. MS is a degenerative disease, and the standard treatments for it do not typically halt its progress, but rather—when successful—they merely reduce its symptoms. Malcolm was a very high-paid executive, who had top-of-the-line health insurance coverage. So, even though his

MS drugs were very expensive (they cost a minimum of \$2000 a month), he had no problem getting them. But the medications were *not* helping him, and in fact, his MS kept getting worse. Then, finally, Malcolm lost his job because his MS made it difficult for him to work. Along with his job, he also lost his health insurance, so he would no longer be able to afford the standard MS drugs. It was then that he started using LDN, at a cost of \$35 a month. He hasn't looked back. For the first time in years, Malcolm's MS has stopped progressing, thanks to LDN. I think that his chapter, Chapter 14, is one of the most impassioned in *HONEST MEDICINE*.

Intravenous Alpha lipoic acid—Mary Jo Bean, Chapter 5, is one of Dr. Berkson's many "miracle patients." She came to him in 2002 with end-stage liver disease—a combination of cirrhosis and hepatitis. She was at death's door. After her first treatment with intravenous alpha lipoic acid, Mary Jo began to feel better. Now, eight years later, she has a mailing list of hundreds, through which she spreads the word about Dr. Berkson and IV ALA.

The Ketogenic Diet—One of the stars of *HONEST MEDICINE* is Jim Abrahams, the Hollywood producer of "Airplane," "Hot Shots" and other movies. In 1994, Jim's one-year-old son Charlie began having intractable, nearly non-stop seizures. His doctors gave him drug after drug—and sometimes several combinations of drugs. They even operated on his brain. Nothing worked, and Charlie went steadily downhill.

Like the others in this book, Jim found the Ketogenic Diet through his own research. Against the advice of his son's doctors, he took his baby to Johns Hopkins to be put on the diet. Forty-eight hours after the diet was implemented, Charlie's seizures stopped. Since then, the only recurrence of seizures occurred when he was being weaned off the diet. Charlie is now a teenager, is no longer on the diet, and is entirely seizure-free.

Jim now spends most of his time running the non-profit organization that he founded, The Charlie Foundation to Help Cure Pediatric Epilepsy. Through The Charlie Foundation, the doctors and staff at lots of hospitals around the world have been trained to implement the diet. (Chapter 7)

5. Do these treatments have side effects?

Of course, all treatments have some side effects. But compared to the treatments most often prescribed by doctors for these conditions, the side effects of these treatments are relatively minor. For instance, the **Ketogenic Diet** can cause constipation and kidney stones, so most children are prescribed medicines and nutritional supplements to counteract these side effects. And **Low Dose Naltrexone** can cause "vivid dreams." So, some patients end up taking even lower doses of this drug; in other patients, the "vivid dreams" subside after a few weeks.

As with all medical treatments, it is important that the treatments I feature in *HONEST MEDICINE* be used correctly. For instance, the **Ketogenic Diet** must be carried out under a doctor's and a dietitian's supervision, because the amount of fat, protein and carbohydrates must be calibrated carefully for each individual child. There can be problems if the diet is not begun in a hospital setting, so parents really can't implement it by themselves, without help. Dietitian Milly Kelly, who administered the diet at Johns Hopkins for 50 years—from 1948 to 1998—has contributed a chapter (Chapter 8) to *HONEST MEDICINE*, in which she gives one of the best descriptions I have ever read of how to administer the diet.

Lastly, **alpha lipoic acid** must be infused carefully by a doctor who is trained to do it correctly. When done correctly, patients say they actually feel better than they have felt in a long, long time.

6. How do the side effects of these treatments compare with the side effects of the treatments that most doctors prescribe for these conditions?

This is an interesting, and very important, question. To answer it, I'd like to discuss the most-often prescribed treatments for MS and epilepsy, all of which are highly toxic. The most-often prescribed drugs for MS are the C.R.A.B. drugs, with C.R.A.B. being an acronym for Copaxone, Rebif, Avonex and Betaseron. When these four drugs fail, patients are often prescribed a drug called Tysabri. Each of these drugs—all are expensive injectables—can have extremely serious side effects. In fact, Tysabri can lead to a deadly brain infection, Progressive

Multifocal Leukoencephalitis (PML), a rare and usually fatal viral disease characterized by progressive damage to the white matter in the brain. In Malcolm West's chapter, Chapter 14, he states that one out of every 1,000 Tysabri users develops PML, and that, as of October 2009, twenty-three people had developed the brain infection. This is serious stuff!

Epilepsy drugs have very serious side effects, too, with bad news about them being published on a pretty regular basis. For instance, just the other day, a Canadian study found that these drugs raise the risk of fractures in the elderly. And in 2008, another study linked anti-epilepsy drugs to suicidal thinking. In one of the most powerful chapters in *HONEST MEDICINE*, Jean McCawley (Chapter 10) describes the horrific side effects her infant daughter Julie experienced after taking Phenobarbital, the very first anti-seizure medication she was prescribed. As Jean describes, many of these anti-seizure medications can cause a deadly condition called Stevens Johnson Syndrome. Jean created a non-profit organization, the Stevens Johnson Syndrome Foundation—sjsupport.org—to educate the public about this disease.

At one point, the FDA was seriously considering including a "black box warning" on the package inserts of nearly every anti-seizure medication. (A "black box" warning is a type of warning that signifies that the drug carries a significant risk of serious or even life-threatening adverse effects, as revealed by medical studies.)

7. Are the treatments you write about in HONEST MEDICINE effective?

Yes, they are. As *HONEST MEDICINE's* cover says, "More than 100,000 people worldwide have been helped." And this is true. So many patients have been helped by these treatments that I have coined a new term: **patient-evidence based medicine**. I think it is very important—especially when so many people are experiencing excellent results with treatments like these—that this kind of medicine be taken seriously and given respect. I believe these treatments should be offered to patients by their doctors as one of the first recommendations.

8. Why don't these treatments have more clinical trials done on them?

Since these treatments are relatively inexpensive, it's not likely that large-scale clinical trials will be performed on them anytime soon. Pharmaceutical companies conduct most of the clinical trials on their own drugs today and, frankly, these treatments wouldn't give a company a reasonable return on their investment. But lots of smaller, very promising trials have been conducted on several of these treatments. In England, Dr. Helen Cross did conduct a large class-1 randomized double-blind study of the Ketogenic Diet. Like all the smaller studies before it, conducted since the 1920s, Dr. Cross' study turned out very positive results showing the effectiveness of the Ketogenic Diet.

9. What did you hope to accomplish by writing HONEST MEDICINE?

I hope that patients who need treatments like those I feature in *HONEST MEDICINE* will learn that they're out there and will take action to get them.

10. How do I get my hands on these treatments?

Be aware that most conventional doctors don't yet know about these treatments. But fortunately, more and more integrative doctors do know about them. I think the easiest treatment to get is **LDN** for autoimmune diseases, because all that is needed is a doctor's prescription. And LDN costs around \$40 a month. The LDN patient advocates have amassed a huge amount of information, both on- and offline. They have collected the names of doctors who will prescribe it, and compounding pharmacists who prepare it. Some of the best LDN websites are **LDNinfo.org**, **LDNResearchTrust.org**, **LDNers.org** and **LDNAware.org**. There is even a website for doctors, **LDNScience.org**. Lots of patients are pointing their doctors to this site for more technical information.

The best resource for the **Ketogenic Diet** is Jim Abrahams' website, <u>CharlieFoundation.org</u>. There, Jim has listed all the hospitals that implement the diet. The list is constantly growing.

Intravenous alpha lipoic acid is a bit more problematic, in that there is not yet a large network of doctors who are proficient with it. Your best bet is to

contact Dr. Burt Berkson in Las Cruces, NM. His contact information is in *HONEST MEDICINE*, as well as on my website, <u>HonestMedicine.com</u>.

11. How do I get my doctor's approval if she or he doesn't know about these treatments?

The best advice I can offer is to give your doctor lots of information, available in *HONEST MEDICINE*. I have links to so many resources there. All you have to do is follow the links. And since links are difficult to access from a printed book, I have a website set up that contains every link to every resource in *HONEST MEDICINE*. For these links, go to <u>HonestMedicine.com/hyperlinks.html</u>.

The other bit of advice I can give is that general doctors are much more open to innovative treatments like these than are specialists. So try talking with your general practitioner first.

12. If these treatments are so effective, why aren't more doctors prescribing them?

From what I can tell, from my research for *HONEST MEDICINE*, most doctors are not comfortable prescribing treatments that their fellow doctors are *not* prescribing. This is a huge problem. Dr. Berkson describes it this way: He says that doctors are trained, not educated, and that they are trained *not* to be curious about anything new. My feeling is that the more patients there are who lead the way, the more their doctors will start prescribing these treatments.

13. The Ketogenic Diet was popular and well-respected in the 1920s, and in fact, was the standard treatment at that time. What happened that it went out of favor? And what happened to make it popular again today?

Basically, when anti-seizure pharmaceutical medications began to be discovered and patented in the 1940s and 1950s, the use of the diet declined dramatically. There is no way around it: Even though the drugs have heavy side effects, they are much easier both for doctors to prescribe, and for patients to take. The diet

must be carefully planned, with relation to the correct amount of fat, protein and carbohydrates.

Most of the credit for the diet's rebirth must go to Jim Abrahams. Once his infant son Charlie became cured of his seizures in the mid-1990s, Jim decided to devote the rest of his life to getting the word out about the diet. He has been extremely successful, and through his non-profit organization, The Charlie Foundation, there are now hundreds of hospitals worldwide that administer the diet.

14. How did Dr. Berkson discover that intravenous alpha lipoic acid (ALA) was effective for liver disease?

This is a fascinating story. When Dr. Berkson was an intern in the mid-1970s at a major US teaching hospital, he was assigned two patients, a married couple, who were dying of mushroom poisoning. Mushroom poisoning destroys the liver, and this couple was not expected to live more than a few days. Dr. Berkson's superiors told him that nothing could be done for this couple, and that he was merely to observe their death and take notes.

But Dr. Berkson wasn't one to give up that easily. He called the National Institutes of Health and asked Dr. Fred Bartter there whether he knew of *anything* that could regenerate organs. Dr. Bartter told him about intravenous alpha lipoic acid. He sent the IV ALA to Dr. Berkson by plane. He infused his patients and they revived. Unfortunately, the doctors at this hospital were not happy with Dr. Berkson because he had not followed orders. Also, he had used a treatment that they hadn't heard of. They weren't even curious about it. Somehow, Dr. Berkson prevailed. The story of how he prevailed is told in *HONEST MEDICINE*. (Chapter 4)

The first couple that Dr. Berkson treated with IV ALA—Eunice and John Goostree—are alive and well today. In fact, I am in contact with Eunice, and she is so happy that their story is told in *HONEST MEDICINE*.

15. You believe that patients should do their own research. What about all of the unreliable information out there online?

Yes, there is a lot of unreliable information online. But the truth is that there is also lots of terrific, very reliable information out there, as well. I think it is important for people to learn how to recognize the good information, and how to shun the bad information. This becomes easier the longer you spend researching online. It was fascinating to me how many of my chapter contributors first found the treatments I describe in this book online.

One way you can discern the quality of the information on the Internet is to take note of who is backing a particular website. Who is funding it? Who, if anyone, is advertising on the site? And who benefits from the information posted there? Use your best judgment to decide whether or not the information is in your best interest or has been put forth primarily to benefit the deep pockets of a pharmaceutical company or another commercial interest. Or is the information put forward by a nonprofit organization, or a person who clearly wants to help you? These are some of the questions you can ask when you look at the information you're researching.

I have been researching treatments for many, many years, and feel that I am proficient at it. I am planning to conduct workshops and webinars to teach people how to recognize good versus bad medical information.