

Crystal Light

Young woman inspires medical fundraiser

By Rhonda Reeves

“**H**ow’s your karma?” The question from the waiter seems a little existential, interrupting, as it does, a recent interview with Crystal Stites about the ongoing medical crisis she’s been tangled in for most of this year. As it happens, ‘karma’s’ just the name of the pesto pizza.

At 29, Stites looks as healthy as the next person (healthier than most). She’s happily engaged, with a 2009 wedding on the schedule, and in the midst of renovating her home. She’s someone who was doing everything right in terms of managing her health care, when this crisis hit. She has a stable, long-term job (as Marketing Manager at Good Foods), since 1999. She has health insurance. And somewhat remarkably for a 20-something, she even has disability insurance (at 60 percent) if she’s too sick to work.

She didn’t *even like* the post-Op painkillers she was offered in the hospital saying they made her feel fuzzy, and gave her “weird dreams, where people kept asking me for the OxyContin.”

Everyone in Lexington has come to expect at least one or two fundraisers a year to help alleviate the exorbitant medical costs of people who have a medical crisis, fall through the cracks, and are crippled financially. (In recent years, Ace has supported fundraising efforts for bass player

Rick Baldwin because of MS, and prior to that, for Kentucky native and food author Ronni Lundy, who had ovarian cancer; prior to that, drummer David White was shot and left *with* an astronomical medical bill and *without* a spleen.)

But a 29-year-old vegetarian on the decidedly crunchy side, who happens to spend her day job working in an environment passionately devoted to whole health eating and lifestyles — surely such a person would be well equipped to withstand anything modern medicine could throw at her?

So when Stites had a bout of eczema and stomach problems last spring, she reasonably suspected the source might be something simple and dietary, like a wheat allergy.

What she has, instead, is a 10 centimeter tumor in her pancreas, a blood clot, a daily regimen of blood-thinning drugs, and an unsuccessful surgery under her belt (literally) that more or less split her stem to stern, and left the tumor right where it was.

When she came out of the O.R., she could see the recovery room clock and knew something was wrong. The surgery should've lasted hours longer.

Her Dad finally confessed, "They told us not to tell you."

He told her they'd been unable to remove the tumor; that it was 10 cm and growing aggressively; and that everyone in the waiting room had been told it was probably cancer.

As to why they didn't do what they went in to do, she says she still doesn't understand, but adds, "It makes me so mad! I *still don't* know why they couldn't take it out. I think they just freaked out and sewed me back up."

One friend in the waiting room, told to keep quiet, accurately predicted, "she's gonna be *so pissed* when she wakes up and finds out they didn't do anything."

Then they brought her beef broth for her first meal (not on the menu for most vegetarians), and the next morning, she adds, "they brought me a *doughnut* for breakfast...in a *hospital*!?"

She's clearly not happy recalling the experience, adding that she did fire one doctor from the team while she was still in the hospital. A Lexington hematologist was refusing to sign off on her release; she called her fiancé and assigned him web-research; then she began calling doctors, disclosing that she had a complicated case and oh-by-the-way admitting, "I'm still in the hospital, so if you take me as a patient, you have to see me tomorrow."

And when she left, she "walked out," adding "literally. I walked out. I wasn't waiting for 'transportation.' It would've been another three hours." (Because, as she's pointed out, everything in a hospital requires a 3-hour wait. That appears to be the

standard minimum.) Asked if they tried to stop her, she smiles and says, "No. I guess they'd already heard I'd fired one doctor."

"My Benefit has a Brand"

While Stites underwent surgery in Cincinnati, the waiting room was filled with friends and family in Team Crystal t-shirts (eventually they ditched the hand-crafted route and went with a screen because demand was too high to keep up). A website was launched. A club fundraiser was held in Louisville (yielding about \$600 bucks). Another is scheduled for Lexington at the Oleika Shrine Temple in August.

Her employer, Good Foods, will be providing the dinner, and additional entertainment and auction items will be donated, and the Southland Association is co-hosting.

The project took on such a life of its own that a "competition" was held for Designers who wanted to create a logo for the project. Stites says, "my benefit has a brand!"

Phil Wyant, president of the Southland Association says, "I've had the pleasure of working closely with Crystal Stites on various Southland Association community projects and events. Crystal, as an unpaid director, has always shared her talents and hard work in very unselfish ways. In spite of her serious medical condition, she continues her work, as best she can," adding, "I'd like to encourage others to try and help Crystal in her special time of need."

Anne Hopkins, general manager of Good Foods, says "I'm awed by her tenacity and strong sense of responsibility. She remains, however, impressed by Stites' stamina and willingness to forge ahead, adding "Crystal's like the Energizer Bunny—despite her many doctors' appointments and days she doesn't feel well, she keeps on working. Any day, she may mix work appointments with getting stuck for bloodwork and checking with her surgeons."

The Ripple Effect

At one moment in the interview, Stites sounds like one of the case studies included by Michael Moore in the health-care documentary *Sicko*, when she says, "You think you're covered..." (Early in the movie, his voiceover proclaims, "I always thought health care was there to help us." Of course the disingenuousness is meant to be ironic; he didn't *actually* think that, or he wouldn't have made the movie. Anyone unfamiliar with the "prudent person pre-existing conditions exclusions" really ought to see the movie for a few eye-openers, regardless of their opinions of Moore.)

In Stites's case, a recent \$4,000 biopsy came back "denied" and classified as "experimental."

Hopkins articulates the problem faced by millions of insured Americans, "Even a good employer health plan doesn't mean an employee is home-free for medical expenses. Crystal was hit with a high hospital deductible, which immediately caused financial hardship. She needs the best medical care, and unfortunately that's very expensive."

For Stites, it's always something.

Because this type of tumor is so rare in a 29-year old, the oncologists recommended a mammogram. But 29 is not the standard age for insurance to cover a mammogram, so special permission had to be requested (and was granted) to get one.

Because of the coumadin she must take

ly good therapist?

Her eyes start to tear up when she talks about the support her friends have given her, and how they always talk about ending up old ladies, sitting on the porch in their rockers, drinking beer.

She cries harder into her pesto-soaked napkin remembering the day she came home and took out her lipstick to start writing on her full-length mirror all the things she wants to do before she dies ("see the world...finish college...travel...")

Other than that, she says, not much sets her off, but she doesn't necessarily know what the triggers will be. Renting *The Fountain* (Rachel Weisz is the dying love of



Crystal Stites celebrated Easter in the hospital

to treat the blood clot, the hematologist wanted her to switch from birth control pills to hormone-free birth control. The most reliable option there is the I.U.D.—not covered by insurance.

Stites admits at the beginning of this process, when she looked up the survival rate for pancreatic cancer (about 3 to 5 percent), she would "just sit and cry."

She says now, of all the confusion and complications of her case, "I thought I had cancer and if I don't, that's awesome, but I still have a 10 cm tumor growing inside me," and that, of course, can't be good.

Still, she and her fiancé continue the renovations at her house.

The diagnosis came only a couple weeks after their engagement, so she says not a lot of wedding planning has gotten accomplished. She does say they "had talked briefly about how to get married—in Thailand" and they're "still planning that way for February 2009."

The only time she breaks down during the interview is after a question about how she copes: is it faith? Is it friends? Is it a real-

Hugh Jackman who travels time to save her) turned out to be an aptly named, if not exactly wise choice. Another time at a brand conference in Virginia this past May, the topic of pancreatic cancer came up and she "just started bawling." She says she just kept thinking "nobody even knows me here," while trying to figure out a way to map a graceful exit "trying not to attract attention."

By the time the August 19 benefit rolls around, Stites will be able to use all the community attention—and funds—she can possibly attract. Being sick is expensive business, and as 'Team Crystal' leader Whitney Breeding puts it, "Since insurance is not going to help us become victorious, we will just have to do it ourselves." ■

The Dinner Benefit for Crystal Stites is Sunday August 19 at the Oleika Temple on Southland Drive. Admission is \$15. The dinner is catered by Good Foods, and tickets are available at Good Foods at 455 Southland Drive. There will also be live bluegrass music, a raffle, and silent auction.

BLOG EXCERPTS FROM CRYSTAL STITES

Read more about fundraising efforts, and Crystal Stites' health-blog at:
<http://crystal.supermegawebsitego.com/medical.html>.

APRIL 11, 2007

I'm Home!

So my week in the hospital is over and I'm finally home on my bed with my kitties and finally some Myspace! Thank you all for your love, positive energy and prayers.

I also got to come home to my own extreme makeover home edition. My dad and step mom have been slaving away at my house. My basement remodel is now done with new windows to boot! I also got all kinds of small jobs done around the house. Once I can paint - I can start in 6 weeks. I'll have people over. Health permitting of course.

So surgery was unsuccessful although my healing is awesome. I'm very upbeat and have all my spunk back. I just can't lift anything over a gallon of milk for 6 weeks. I'm on coumadin to work out my blood clot and I go Monday to talk about chemo. We go to that after I'm healed from surgery. Healing is number one right now.

APRIL 17, 2007

We went to Cincinnati today to have my follow up appointment with Dr. A. They took out my staples (I had a few over 50) and put pieces of tape on the wound. I have to leave the tape on for a week. (It looks like packaging tape, the white kind with the stronger strands in it, not the tape stitches things).

My biopsy results came back inconclusive from the samples they took from surgery... They are pretty sure it is cancer although they do not have enough evidence to prove it at this point... They do not want to do chemo until there is stronger proof it is cancer.

They are also making an appointment for me to talk to an oncologist so I may ask questions about chemo. I'm scared to do chemo. I'm glad that I have more time to educate myself about it and ask questions before they are ready to start with it. I'm also

doing all sorts of natural stuff now on my own through diet and supplements, and I'm glad I have a little more time to let it work first. So if you have chemo knowledge please pass it on my way. I'll be on-line searching for information over the next few weeks.

I asked about radiation treatment versus chemo and Dr. A said he has had better results with chemo. He said by not doing radiation they are able to do higher doses of chemo and get results quicker. He prefers the chemo only route.

I also asked about natural methods through actual MD's, specifically Dr. Gonzales in NYC. I was answered with a very medical opinion and explanation of the items discussed in the excerpt I had him read. Obviously there is bias on both sides, but I wanted to see if the enzyme therapy Dr. Gonzales does is anything that Dr. A has heard of or explored. I'm going to call Dr. Gonzales and see what happens. The enzyme therapy I can somewhat recreate on my own, however I cannot be on the coumadin to do it. I'm on coumadin for at least three months before they do a CT scan to see the progress of the blood clot thinning.

I can drive now too! As long as I'm not on pain meds, and I rarely take them. Only if I'm really hurting and at night.

APRIL 25, 2007

I went in this morning to UC hospital to have another scope/biopsy done. I'm fine, just a little groggy from the sedation...

APRIL 30, 2007

The benefit in Louisville this past weekend was a success raising over \$600 to help me pay my medical bills. Over 100 people showed up in support. Special thanks to all of those who helped throw the event - Marea and Jason Clark, to Kim for making them not smoke in the main room, Jason, Head, Ben, and Angel Alanis, and everyone else who helped!

MAY 4, 2007

Yesterday I met with both Dr. A and Dr. S (an oncologist in

Cincy who specializes in pancreatic chemo). My test results from the last biopsy also came back inconclusive, this makes three times...

Dr. A said basically at this point it is up to me and an oncologist of what I will do next...

MAY 11

First, I'm back to work full-time this week. It was easy Monday and Tuesday but after an 8am training I had to teach Wednesday and another 8am meeting Thursday—I AM exhausted! Life as usual is hard work after 5 weeks of nothing.

JULY 7

I have been seeing my family doctor regularly to monitor my coumadin. I've also been following the natural path and looking into sending my records to Johns Hopkins and the Mayo Clinic. Monday I shipped three fat packages of my records off. In two weeks, I have a phone conference with the medical researcher in San Fran, and I'll follow up with Johns Hopkins and Mayo in a few weeks to see if they think they can offer any more than the doctors in Cincy. On July 23rd I have another CT scan and on July 30 I go back to see Dr. A in Cincy. He will check the status of the blood clot and the size of the tumor from the CT and give me those results on the 30th...

Jason and I are almost done with the basement and 2nd floor remodels...

I'm working a full schedule at work again—42 hours a week—even with the doctor appointments and half day to work on medical and benefit stuff. So that equals some long days at the office 4 days a week...

I'm planning on starting a mini-second job in the next few months. It's short term and hopefully starts after the benefit. ■

A Close Perspective

By Jason Shelton

I am the fiancé of Crystal Stites. Since we live together, I see the day-to-day bills and was there in the hospital staying overnight for 5 of the 8 days she was there (I haven't seen *Sicko* but Crystal and I are interested even though Michael Moore is a bit of a propagandist.)

The whole experience angers me and puts me in a place that questions health care practices and policies.

I think health care in America needs a major overhaul.

Lucky there is insurance, but seeing the day-to-day bills Crystal receives, there is something definitely wrong with charging \$50 for a single bandage.

The five days spent in the hospital, the room and board alone was \$31,000 and the quality of service was absolutely garbage.

I was there most of the time helping Crystal do things the

nurses were supposed to be doing, from bathing her to making sure her menu was a vegetarian diet which all too often wasn't.

Recently she received a bill from some lab we had never even heard of and had a hard time finding more about through the internet because it was so vague.

Once we contacted them, the test they ran for blood analysis [was classified] "experimental" and naturally the insurance company she runs through won't help pay for it. This analysis was \$4,000.00.

In what other industry can your business pick up a customer, and never tell him when, for what, or how he is being charged. It's like going on a



Crystal & Jason

test drive and the dealer informs you [that] you owe \$100,000 for a Mustang.

Had we been more informed about its costs, we wouldn't have made that snap judgment until we were certain we could retain costs from the insurance company.

It's a harsh reality when it happens to you or someone extremely close to you—especially at such a young age and even more so to start a new life with my fiancé in debt, which is also a reality for many Americans across the nation unfortunately. ■

The Meaning of Team Crystal

By Whitney Breeding

The whole “Team Crystal” name came out of this idea I had one night. I thought it would be supportive of course, but also somewhat silly and whimsical, if everyone in the waiting room was dressed alike. Why?

Well, for a time Crystal would dress up almost every Saturday night to go out in costume. And I don’t mean a nice dress and heels. I mean a cheerleader with pom-poms and knee high socks. So, I thought it’s only right to be in costume for her. Add a little fun and silly to a depressing situation.

Why the “Team Crystal” on the front? Well, to anyone who knows Crystal—she is kind of like our coach. She does everything right: she eats right; she is a great friend; and she would do anything for any one of her friends.

A memory from the hospital: it is toward the end of her hospital stay after she has been cut open in the shape of a peace sign the entire width and length of her torso for really no good reason.

Knowing that the cyst/tumor is still in there, it is probably cancerous and she will probably have to go through Chemo in the near future, I walk in to her hospital room and see diagrams of her plant room and her garden at home. Crystal is so much a ‘glass is half full’ person.

“Since insurance is not going to help us become victorious, we will just have to do it ourselves.”

**—Whitney Breeding,
Team Crystal organizer**

She has such a positive attitude and on the outside it appears that not beating this is not an option.

She is planning her wedding, finishing up her house, planning to beat this. Crystal never talked about her illness in the hospital. She did her breathing exercises even when it hurt.

She wanted to get up and walk as soon as she could.

Nothing is keeping Crystal down and we are her team to make sure nothing happens to her.

We are Crystal’s cheerleaders and would like to recruit some fans for a worthy cause. Since insurance is not going to help us become victorious, we will just have to do it ourselves.

We just have to get through this so Crystal can finally get to those diagrams she drew in her hospital room.

We all love Crystal very much. We just want her to be healthy. ■



Review:

How Doctors Think
By Jerome Groopman, M.D.
269 pages

A hospital would be a scary place to be, even if you weren’t sick.

The environment brings back a vulnerability most of us haven’t experienced since infancy. You have no control over anything—when you sleep, when you eat, when the lights are on or off, when you go to the bathroom, when you can sit, when you can lie down, when you can walk—someone else is calling all the shots. Theoretically that person is a doctor or a nurse or a health care provider who has only your best interests and well-being at heart...in reality, funny joke.

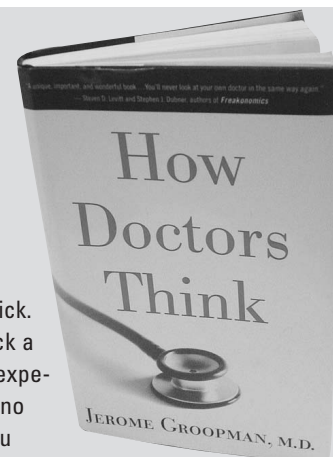
Dr. Jerome Groopman demystifies a lot of medical professionals’ thought processes in *How Doctors Think* (the title’s self-explanatory)—and he’s honest about disclosing the good and the bad (and sometimes the outright mean) ways they think.

Good treatment with a good doctor, he acknowledges, takes time, while admitting “time is the greatest luxury in today’s medical care. Those who see medicine as a business rather than calling, push for care to be apportioned in fixed units and tout efficiency. A doctor’s office is not an assembly line. Turning it into one is a sure way to blunt communication, foster mistakes, and rupture the partnership between patient and physician.”

That being said, patients have a responsibility to be informed and use what time there is wisely, even if it’s confusing. (It helps to just ASK every person who walks into the room if they’re a doctor, or a P.A., or a Nurse, or a Tech, or Transportation. It’s hard to ask the right questions if you have no idea who you’re talking to. The janitor won’t check your blood pressure.)

It makes little economic sense (for either party) to pay a cardiothoracic surgeon \$8,320/hour (roughly) to reminisce about the time you broke your wrist on a college ski trip (unless that trip gave you a heart attack). When you see a mechanic, you know perfectly well that time’s money, and that’s fair. What’s different about the doctor’s office and the hospital is that the money’s truly astronomical (you can definitely fix your Volvo with less expense and anguish, no matter how bad off it is), and patients have a right to expect a level of care that’s commensurate with that cost, and with its life-death nature.

Doctors and health-care providers may find Groopman’s book useful, but it’s written for laymen—i.e., patients. Why? He says, “because doctors desperately need patients and their families and friends to help them think. Without their help, physicians are denied key clues as to what is really wrong. I learned this not as a doctor, but when I was sick; when I was the



patient.”

He draws on Roter’s and Hall’s studies about the preconceptions doctors bring to the table, and their likes and dislikes of any given patient (whether disclosed or not). Doctors, for example, tend not to “like” a patient who’s called non-compliant (a diabetic who eats candy; a cardiothoracic patient who smokes; anyone who “refuses” to lose weight).

They tend not to like hypochondriacs, although statistics indicate sometimes they really do get sick (even a broke clock is right twice a day). If the chemistry’s bad, and interfering with patient care, Groopman advises treating it openly, “patients should politely but freely broach the issue with their doctor. ‘I sense that we may not be communicating well,’” and that “compatibility” may be resolved with “candor” or more likely, by moving onto another doctor.

Groopman himself chronicles a case where—still acknowledging the like/dislike bias—he damaged a patient because he identified so closely with him, and felt such genuine affection, that he failed to subject the patient to routine testing that would’ve been embarrassing to the man, but both necessary and life-saving. And the results were nearly fatal.

Particularly enlightening are the chapters Groopman devotes to his own time as a patient, “Surgery and Satisfaction.” He details a quest with multiple doctors and multiple years trying to get appropriate treatment for his damaged hand. (It took three years and he IS a doctor.) He writes, “in the case of my problem hand, did it all turn out pretty well because I am a doctor? Of course, I am at a great advantage being a physician and being married to one. But much of this three-year odyssey was guided by my having suffered earlier from a failed operation on my spine. Yes, my technical knowledge was key. ‘There is nothing in biology or medicine that is so complicated that, if explained in clear and simple language cannot be understood by any layperson. It’s not quantum physics,’ Dr. Linda Lewis, my mentor at Columbia once said on rounds.”

It’s a good thing, because most patients and their families will be in charge of most of their own medical research, and they will be expected to make life/death decisions based on how much they can learn. Ideally, a medical team will play a primary role in that process.

Still, a book like this one is valuable to any patient lost at sea—even if medicine isn’t quantum physics, the extra insight helps. Maybe at the end of the day, Groopman’s no Dr. Oz (Oz’s *Smart Patient* books should be on every nightstand in every hospital room), but *How Doctors Think* is a good start on re-defining the “managed” in managed care. Buy your docs a copy of each. (And send the bill to Blue Cross.)

—RR