**Ask the Doctor with Dr Cristy Kessler: Speaker, Author, Survivor**

**About Dr. Cristy Kessler: Speaker, Author, Survivor**

*Cristy Kessler Couldn’t Get The FDA To Approve A Proactive, Lifesaving Transplant Let Alone Coverage From Any Health Insurance Company.*

Her health took a nose dive along with the emotional effects of waiting to die and plummeting finances. Cristy, with the help of her rheumatologist, set out to find a way to navigate healthcare and made a choice to live. In 2011, she was the recipient of a lifesaving stem cell transplant. Three years later, Cristy has used her expertise as a patient (who has seen at least a hundred different doctors in a 16 year period) and her award winning talent for teaching (over 20 years of teaching K-12 and higher education) to design 5 S.T.E.P.S. to Being Your Own Patient Advocate. Today, she is inspiring the world as a motivational speaker, published author, and survivor. A longer bio can be found here<http://cristykessler.com/blog/about/>

For a free electronic copy of her book, *5 S.T.E.P.S. to Being Your Own Patient Advocate*, is her gift to you for simply joining her email list.<http://forms.aweber.com/form/15/970994515.htm>

To purchase a hard copy, please go to her site, [www.cristykessler.com](http://www.cristykessler.com/), and click on the **Buy It Now** link.

**Questions and Answers**

**Q: You had a great doctor on your side, your rheumatologist. What can a person do that has no such person to help them or the resources to continue to just try one doctor after another?**
**A:** I am so fortunate to have the team of doctors I have in Hawaii as well as the team I have in Turkey. It didn’t happen overnight. Like many of you, I spent years trying to find the best team for me. Through the years of searching I developed my T-Chart system for two-way communication between patient and doctor. This T-Chart system can be adapted and used as a way to track your own health issue so when you reach out to a medical tourism company, you have everything you need to be your own patient advocate.

**Q: How did you find a reputable medical tourism company?**
**A:** Coming across the notion of medical tourism was purely by accident as I was surfing the internet every day looking for current research studies in the United States for scleroderma. Since I kept using Google and searching for current stem cell transplants for scleroderma, I started getting ads on the side of my screen for medical tourism companies. It was August 2010, and I was declining much faster. So, out of ideas, I clicked on one of the ads. It was a gimmick but it did open the idea to me for medical tourism. So I Googled “medical tourism companies and stem cell transplants”. The list is long. Research, it all comes back to research. Because at this point, I had no idea which company to choose. So I Googled “How to pick a medical tourism company”. I quickly learned that there were two things I needed in a Medical Tourism Company; A solid A+ rating from the BBB (Better Business Bureau) and the company needed to work with hospitals that had accreditation from Joint Commission International. For the next two weeks, I filled out as many inquiry forms as I could for as many companies as I could. I had nothing to lose but time. In the larger scheme of things, my time doing this ultimately saved my life. I received form replies from many companies. But I got a personal email from Janet Kwan. Janet is a registered nurse (RN, BSN) who works for WorldMed Assist and she made me feel like I was the only patient she was working with. She made me feel important and valued. By the tone of her email I knew in my gut I was going to go as far as I could with WorldMed Assist. But getting down to one company was not easy. I do offer consultations for people who are going through the same process.

**Q:** **We are continually warned that going offshore is "risky" and yet you found a company that was credible and ended up having treatment in Turkey. Why is there so much negativity about medical tourism in your opinion?**
**A:** Because we have been told all of our lives that medical care in the United States is the best. We also live in a world that divides everything into categories. For example, how can a Third World Country be further ahead than us in technology, or medicine, or manufacturing? Or if the United States has been at the forefront of some many innovations in history, how can some other country do anything better than us? And the flip side of this is that there have been documented cases of people going to other countries and ending up suffering at the hands of unaccredited doctors and hospitals. Unfortunately, until recently these are the cases that have gotten the press.

**Q: You did fundraising in order to go to Turkey for treatment. If a patient does not have funds, can you suggest the best ways to raise funds?**
**A:** I know many patients struggle just to stay alive and having to organize or help raise funds may be very difficult without help but that help may be difficult to find as well. When reality set in that I was drowning in debt from a lifetime of medical bills, and that if I found a doctor who would perform a stem cell transplant I would have to pay cash, a close group of family and friends created The One Of Our Own Fund. Through the website for the fund, our webmaster (Sharon, who is also my co- author) introduced me to the world by telling my story and describing the medical issues I faced. She posted updates on my condition and the progress of my diseases and treatments. She put up a PayPal link and sent out regular emails soliciting donations to meet my medical expenses, which were building dangerously high. It was important to post updates regularly and to reach out to additional people, taking my story beyond what I considered my inner circle. The website became an extremely important means of educating a large number of people. The group also help silent auctions and benefit dinners. Now we have access to crowdfunding where most of this done by a third party. I will say that as a patient, I could not have done any fundraising by myself. I needed to turn it over to someone else. My job was to focus on staying the course and staying alive long enough to survive the transplant. My best advice here is to recruit a very close friend or family member who you can trust to carry out your wishes with fundraising. The last thing you need is someone who is doing it so they can please their own ego.

**Q: Do you think Right To Try laws will significantly improve the chances for patients like to get treated with stem cells in the U.S.?**
**A:** I hope so. This is still somewhat new and I am still learning about the laws and the states where they are offered. I still get quite frustrated thinking about the notion that the FDA can decide if I can get a transplant 30,000 + people get a year in the United States for blood cancers, but because I had scleroderma, they said no. My Health. My Body. My Voice. If I am of sound mind, then I should have the right to decide if I want to attempt a treatment option.

**Q: There are certain very vocal individuals in academia and research and at least one global organization that I know of that seem to want to do or say anything to discourage and disparage medical tourism. How do patients fight back and get the healthy public to understand our plight?**
**So many people believe that the FDA is protecting the public and these individuals push that narrative when the real truth is that the FDA is asking many of us to die a safe death. We need our collective voice to be heard. How?**
**A:** I am trying to break through that barrier. If I could afford to, I would send my book to every member of the Senate and Congress. Then the next step to change is getting the press on our side. Currently I am trying to find mailing or email addresses that will put me in contact with Associate producers of tv and radio shows so I can send them my book. Instead of focusing on the horror stories of a select few who had bad experiences, I want my voice to be heard. I want the press to know that although I am not a cute puppy or small child (pardon the example, but it’s true in terms of the press), that I am a 44 year old who still has a lot of life to live, can contribute to society, and I was worth saving when I was 40. I needed the press to step up in 2010 and hear my story, but I need it to be heard even more now. I want people to get the treatment they need. And no one, I mean no one, should have to leave their home for two months, go across the world, risk dying and not having family nearby, to get a lifesaving treatment. That’s just not right.

**Q: Do you consult with patients looking for offshore options?**
**A:** Yes. I will do whatever I can. My expertise is research, both as a patient and professor/teacher. If you need help, I want to talk to you. Please call Debbie at 615-405-5380 and let her know you want to consult with me. Debbie is on the mainland so it is easier to get her through normal hours then trying to catch me between university classes in Honolulu. I also do a lot of motivational speaking and keynote addresses.

**Q: Your story is so inspiring. Any plans to make a documentary?**
**A:**I want to do a documentary. I really do. I would certainly welcome a collaboration since I have no documentary experience. If anyone can help me get this done so my voice is heard and my story is told, please get in touch with me.

**Q: I think most patients fighting the system would agree that the FDA needs a complete overhaul. Unfortunately, it seems like the agency's powers are expanding as more regulatory actions are taken against doctors who perform simple adult stem cell treatments. I think this opens the door to more and more medical tourism. I don't see that as a bad thing, but simply a result of patients trying to control their own health care choices. Why do you think doctors are letting the FDA encroach on the practice of medicine? There doesn't seem to be any organized resistance by the medical profession to what is happening. Patients are far more vocal than doctors about over regulation. I'm discouraged.**
**A:** I think doctors are also victims of our healthcare system. My mom has been in the healthcare business for 38 years so I grew up hearing her stories even before I was old enough to be in charge of my own healthcare. When you have a system that is controlled by big pharmaceuticals, the FDA, and health insurance companies where all of these entities are in it for the money, patients, doctors, and nurses are the ones who suffer. What can a doctor do when their liability insurance keeps rising at an alarming rate because we are a courtroom happy country and health insurance companies are taking a larger and larger share from each patient they see? And then you add in the FDA who decides what treatment options can and will be accepted by insurance a doctor has their hands tied. They either play by the rules of a business minded system or risk losing patients because insurance companies refuse to work with that doctor. I don’t think it’s a case of patients being more vocal; I think it is a case of doctor’s voices not being heard and shared through the press and in other forums. We need a voice loud enough to bring doctors, patients, and nurses together to fight for the same cause. My question isn’t why is this happening, but How can we all get together and be the cause of change?

**Q: There are some in the stem cell industry that claim a person could have their health insurance cancelled if it was found out that they had stem cell treatment overseas. Do you know if there is a shred of truth to that or is it just one more rumor that those who are fighting patient access to stem cells in the U.S. use to frighten people?**
**A:**I can only answer this from my own experience, but so far I still have insurance. And while we hear a lot of press regarding the Affordable Care Act, one thing it does do is guarantee we can’t be cancelled for pre-existing conditions.

**Q: Are there some countries in the world that you would say to avoid when it comes to medical tourism choices?**
**A:** It all comes back to research on the part of the patient. I like to say, “Never judge a book by its cover.” Dr. Zafer Gulbas, who performed my transplant is world renowned in his field. Honestly, he has had more experiences and training from the best institutions in the world then the doctor I saw at the Mayo Clinic. Some countries, regardless of how they are categorized (first-world, third-world) are willing to invest in medical professionals and centers that are much more cutting edge, state of the art then most I have been in in the United States.