

Will You Help Me Find My Lifesaving Kidney Donor?

Website www.yourgiftworks.com/lezieb

Facebook <https://www.facebook.com/AKidneyforLezie>

Yikes, something we all dread is happening to me and I want to let you know the details. Thanks for reading further.

I was diagnosed with Polycystic Kidney Disease (PKD) about 25 years ago, a genetic disease very prevalent in my family. After all these years of stable annual exams, my kidneys are rebelling. The cysts are taking over my kidneys and not leaving much kidney left for function. When you hit stage 4 (which I'm in), two options for treatment are a *transplant* (the long-term solution) and *dialysis* (which is a short-term option).

So far, I've been able to leave the matter in God's hands and plan to keep it there! Please send prayers and good thoughts my way. The most surprising thing is that I feel fine. If I didn't know I needed a kidney transplant, I wouldn't know I needed one!

Two options for a transplant are a *Deceased Donor* and a *Living Donor*. I much prefer the second option as it's the safer, more healthy and timely alternative. Addition to the UNOS national kidney transplant list is required to get in line for a deceased donor. In October 2020, my nephrologist referred me to the University of Utah Transplant Center in Salt Lake City. Once I submitted my application paperwork, they scheduled me for a two-day evaluation at the University Hospital in August 2021. Although the evaluation went well and I was told I'm a good candidate (!) for a transplant, the residual required testing took several more months.

I was officially admitted to the UNOS transplant list in July 2022! This felt like a huge relief and a big goal accomplished. You will hear about the length of time someone is on the UNOS list. The timing starts when you begin dialysis (for me, November 2021), *not* the date you're added to the list (July 2022); as of today, I have 18 months accrued. One good thing about getting on the UNOS list is that Deceased Donor transplants are offered to patients in order of their addition to the wait list. The bad news is that the wait time for a matching kidney for my area is 4-5 years (or more)!

The purpose of *dialysis* is to provide function that the kidneys are no longer able to offer, that is, cleaning toxins from the blood. When my kidney function was down to 7%, I started dialysis at Bozeman Deaconess Hospital. The procedure is not for the faint of heart, but I'm thankful I don't have to drive further than 25 miles (one way) for the treatments.

Now that I'm on dialysis, I'm committed to it until I receive a transplant. (Patients who for one reason or another are not eligible for a transplant must continue with dialysis for the rest of their lives). For me, as dialysis is a temporary solution until a transplant is performed, you can see the benefits of finding a compatible *Living Donor*. One benefit includes shortening

the wait time prior to a transplant, possibly by many years. Another benefit is that transplant surgery can be scheduled once a Living Donor undergoes testing and receives clearance as a candidate for me. I could have the surgery this summer, for instance, if someone is moved to offer me a kidney!

Medically speaking, a *Living Donor* transplant from a volunteer is a better alternative than a transplant from a Deceased Donor for several reasons: according to research, the donated kidney is the healthier method possible, and it is the quickest way to get a transplant (the surgery would take place in Salt Lake City). In addition, dialysis is a big-time commitment (4-hour treatments, 3 times a week). I feel lucky that dialysis is available to me (especially given the alternative, which is no treatment at all), but one advantage of a transplant will be having more time to spend living my life on a longer-term plan than what I'm currently faced with. For instance, my great friends Maxine and Bob Fawcett-Yeske in Colorado Springs, Colorado invited me to spend last Christmas with them. I knew my life was tethered to dialysis treatments (you really can't miss an appointment; you risk your health if you do), but who would have thought it would take three weeks for the local dialysis staff to find a center near my friends' home that had room for me! (The snowy weather and clogged airlines worked against me, and I was unable to travel.)

One huge advantage of undergoing transplant surgery is that dialysis is no longer required. A release from the dialysis schedule would be so freeing (!) rather than spending time in limbo waiting for a more permanent solution. (I've accepted dialysis as part of my life, which encourages me that a transplant will be a successful option for me. You can imagine there is *lots* of information related to dialysis and then transplant that must be learned, not the least of which is dietary requirements. The dialysis diet and the transplant diet are very different, but I'm enjoying the challenge of finding recipes that match the parameters of the foods required to make dialysis a success.)

Dr. Molnar, one of the nephrologists from the University of Utah Hospital Transplant Center, has been proactive in offering me help towards the goal of a Living Donor. His support has been a big encouragement to me because he believes I'm a good candidate for a Living Donor transplant. In addition, Dr. Molnar recommended me to participate in a pilot program called *GiftWorks*, which is offered through the University of Utah Hospital Transplant Center. To my mind, I've received two miracles: the support of my doctor and the offer of marketing help to get the word out, which I seriously need!

I'm so thankful this opportunity has come my way. Research shows that social media plays a major role in finding a living kidney donor. The staff at GiftWorks has prepared a webpage for me. The website address is www.yourgiftworks.com/lezlieb and my new Facebook page can be found at <https://www.facebook.com/AKidneyforLezlie>.

Many of you know I'm very weak in the social media area. Now that the website and Facebook page are launched, I will enjoy regular contact with my friends as well as providing

regular updates. Be assured that I will let you know how to access the web page when it becomes available.

One final note. My sister, Jennifer, also has PKD (as did my late brother, Hugh) along with several other family members. Jennifer had a Living Donor transplant ten years ago. She and the donor had a successful surgical experience and both are doing really well. As Luke Skywalker told his sister, Leia, the force was strong in his family. I can relate: PKD is strong in my family! Thus, the pool of possible living donor candidates in my family is very limited. (I just recently learned that, contrary to popular opinion, a family member is not automatically the best match as a living donor. So, I'm widening the net for my search.)

Anyone who is interested in the *Living Donor* option can be tested: the testing is *anonymous*, the testing can be done in your area, and the cost of the testing and surgery is covered. Apparently matching kidneys is a tricky business; so you can imagine there is a great need nationally for Living Donors, especially ones who match an eligible recipient. If you're interested or have questions, please complete the short contact form on my website www.yourgiftworks.com/lezbieb. Within one business day, a living donor advocate named Laurie will contact you directly to address any questions or concerns you may have. Laurie is a living kidney donor and co-founder of the GiftWorks program along with Amber, an experienced marketer.

Also, kindly pass this letter on to anyone you know who might be interested in my story. Thank you again for your help. I would love to hear from you to catch up with your life, and answer any questions you might have.

Sincerely,

Lezlie Botkin
720-771-32770
lezlie.botkin@colorado.edu