

we consume on a daily basis (especially prepared and processed foods).

Like most everyone else, I enjoy eating food. I never thought I would become one of those people who read labels all the time. But I find myself now as a proud, card-carrying member of the club.

The following ingredient list is what

I look for on food labels and what I try to avoid:

- Disodium phosphate Sodium tripolyphosphate Monosodium phosphate Sodium hexametaphosphate Tetrasodium pyrophosphate Potassium tripolyphosphate
- Trisodium triphosphate

Avoiding these ingredients and con-

sistently taking my binders with every meal and snack have made a huge difference in my phosphorus level. It's still a daily struggle to be mindful of your phosphorus intake. I still have a weakness for cold cuts (ham especially) but it's all about moderation. When you know better, you do better.

Transplantation: What every patient and health care professional should know

Lori Hartwell

Transplantation can be an overwhelming process, but in my opinion, it is the best treatment for kidney failure. When I had my first transplant in 1979, there were very few tests and medications to detect and prevent rejection. Today, several options are available to help people with kidney failure receive and maintain the gift of life.

More than 95,000 people are waiting for a kidney transplant from a deceased donor. I live in Los Angeles, where the wait times are the longest (average 8 to 10 years). In other parts of the country, the time can vary greatly. People have the option of accepting an "expanded criteria kidney," which means that although the deceased donor had some medical problems, the kidney is still in good condition. This could be an option for some people and could decrease the wait time.

Some people choose to get themselves added to waiting lists in different organ procurement regions; this involves traveling to centers out of their immediate area to be evaluated. Travel expenses can be costly, but insurance companies will often pay for the evaluation. The United Network for Organ Sharing (UNOS) maintains the national list, but organs remain in local areas unless a perfectly matched kidney (six antigens) is involved. Your wait time starts when you are officially added to the UNOS list, so the sooner you get evaluated, the better.

Living donation is more accepted than when I got my

first transplant. Family, friends, and even individuals with no prior relationship become living donors. Today, you will find a number of people searching for a potential donor on the Internet, and many find someone who is willing to help by donating one of their kidneys.

The evaluation needed to become a transplant candidate or a living donor is extensive and includes an array of tests. By the end of the evaluation, you will know what is right and wrong with you. In many cases, a potential living donor who has come forward has had his or her life saved by the early detection of a serious illness.

You are eligible to get on the transplant list when your glomerular filtration rate hits 20 or less, giving you the opportunity to get a transplant before you need dialysis. Therefore, it is always best to be evaluated by a transplant team as soon as you can.

Vast improvements have been made in matching kidneys, and a number of paired exchange programs are available. If someone is willing to donate to you but is not a match, he or she can be added to a pool of similar donors. Swapping kidneys or creating a chain of transplants is helping many recipients get matched. Also, blood type is not as important as it used to be. Many centers offer kidney transplantation for friends and family members who want to donate but would otherwise not be able to because of an incompatible blood type.

In my case, when I needed another transplant after a 20-year run with my third deceased donor kidney, I had an antibody count of 100%. I have received more than 150 units of blood in my lifetime. Every transfusion involves the risk of being exposed to more antibodies. A friend who has also had a kidney transplant and whose hemoglobin is high



Ms. Hartwell is the founder of Renal Support Network, which marks its 20th year of service to kidney patients in 2013.

enough always banks her blood before a scheduled surgery.

Antibodies fight foreign objects in the body, and a transplanted kidney is always considered foreign. I have been fortunate to stay alive long enough to benefit from many medical advancements; treatment is now available to address high antibodies so your body will not reject a donated organ.

Several people came forward to donate to me. My stepsister Cyndi was the best match. I had to undergo a desensitization process that took a couple of months, but it was well worth it. The transplant went off without a hitch: My laboratory values were normal the following week, and Cyndi was out of the hospital in 2 days.

Preventing rejection requires daily doses of immune suppressant medications and regular checkups from your transplant center, your local nephrologist or both. Medications are expen-

sive, so transplant teams often want to know how you are going to get them after your Medicare benefits run out in 36 months. Luckily, after health care reform goes into effect in 2014, people with pre-existing conditions will no longer be denied insurance, thus allowing transplant recipients to get it.

When I get my blood drawn, I always wait anxiously for the results, and when I see that my creatinine is 0.8, I am elated. My transplant team knows exactly which antibodies I have to my living donor, and a new donor-specific antibody test is run on me every few months to see whether any antibodies that could be a threat to the transplant are detected in my blood. If any are present, they can be treated.

This represents a great advancement in testing. There are two types of rejection: chronic and acute. Chronic rejection—when your creatinine

starts to climb over time until you need dialysis or another transplant—has been difficult to prevent. I think that being able to detect antibodies before they start causing problems is key to the long-term survival of the organ and provides so much hope for keeping it. At the end of the day, learning as much as you can about your options is essential. Different centers have different protocols, and not every center offers all of the options noted in this article.

People often ask me how I was lucky enough to get four transplants. My first two were done in the early days of transplantation never worked; I was on the waiting list for seven years before I got my third transplant, and the last one was a living donation. The key is to advocate for yourself and to stay as healthy as possible to ensure that you can take advantage of the next medical breakthrough. **NN&I**

Resources

There are a host of resources available for the individual with kidney disease, including brochures, videos, books, as well as annual conferences where you can learn more about the variety of treatments available. Many dialysis providers and equipment manufacturers also offer education materials.

Below is a list of organizations in the United States that also provide useful information.

American Association of Kidney Patients

800.749.2257

www.aakp.org • info@aakp.org

Alport Syndrome Foundation

480.460.0621

www.alportsyndrome.org

info@alportsyndrome.org

American Kidney Fund

800.638.8299

www.kidneyfund.org

Dialysis Patient Citizens

866.877.4242

www.dialysispatients.org

dpc@dialysispatients.org

Explore Transplant

888.454.9445

www.exploretransplant.org

info@exploretransplant.org

Home Dialyzors United

www.homedialyzorsunited.org

Kidney Link

www.KidneyLink.org

contact@kidneylink.org

Kidney Registry

www.KidneyRegistry.org

800.401.8919

Living Donors Online

www.livingDonorsOnline.org

Medical Education Institute

608.833.8033

www.meiresearch.org

National Foundation for Transplants

800.489.3863

www.transplants.org

info@transplants.org

National Kidney Foundation

800.622.9010

www.kidney.org

The Nephcure Foundation

866 NephCure (637-4287)

www.nephcure.org

info@nephcure.org

PKD Foundation

800.PKD.CURE (753.2873)

www.pkdcure.org

pkdcure@pkdcure.org

Renal Support Network

818.543.0896

www.rsnhope.com