

Waiting for a Transplant



National Kidney
Foundation®



*“When you are tempted to give up, confide in someone.
A problem shared is a problem solved.”*

— Ian Netherway, waiting for a kidney/pancreas



*“It is important for me to get answers. I want to know
what I have to deal with.”*

— Susie Garfulo, liver recipient

This book has been written especially for you by those of us who have waited. These pages reflect our sincerest wishes, thoughts and prayers for your well-being.

If you are not able to read this booklet today, please put it aside; you may be able to return to it at a later time.

If you have any questions or concerns while waiting for an organ transplant, please contact one of the professionals listed below. Professionals at your treatment or transplant center have educational materials and answers for your concerns.

For more information:

Contact _____

Address _____

Phone _____

Notes _____

Dedication

To all candidates and their families: May you find courage, love & hope.

*Hope is the thing with feathers
That perches in the soul
And sings the tune without the words
And never stops at all*

— Emily Dickinson

“Our thoughts are with you.”

— NKF's transAction Council

Our Heartfelt Thanks...

To the heart, lung, liver, pancreas and kidney recipients who shared their most personal experiences about their wait for a donor organ. We are grateful for their generosity in sharing their innermost feelings and strengths.

Darryll Chappell

John Landers

Nancy Swick

Debbie Delgado-Vega

Dr. Amy Lazar, MD

Trent Tipple

Thomas R. DiBartolomeo

Tamra Wiley Lewis

Vanessa Underwood

Brenda Dyson

Kathleen M. McManus

Laura Weber

Ray Gabel

Lawrence F. McManus

Alex Whitetaker

James Gleason

Jessica Melore

Rachel S. Wong

Oliver Hale

Gerard Migliore

Kelly Helms

Andrew Silverman

Kally Heslop

Alexis Southworth

And to those who shared their thoughts as they wait for a transplant, we extend a very special thanks to:

Ted Latour

Celeste Lee

We thank the following transplant social workers, nurses, clinical transplant coordinators, physicians, surgeons and educators for sharing their experiences to enrich this book:

**Carolyn R. Atkins,
RN, BS, CCTC**

**Mary Beth Callahan,
ACSW/LCSW**

Marilyn Campbell, RN

Sandra Cohen, LCSW

Charles Corr, PhD

Gabriel Danovitch, MD

Francis Delmonico, MD

Vivian Dolkart, MSW

Jane Harrison, LCSW

**Rebecca Hays,
MSW, APSW**

Sue Miller, RN, CCTC

**Catherine Paykin,
MSSW**

**Nancy Swick,
RN, BSN, CCTC**

**Charlie Thomas, ACSW,
CISW**

Linda Wright, MSW

Finally, our thanks to the following National Kidney Foundation staff:

Gary Bronz

Erin Kahle

Jim McCann

Staci McKeown

Bernard Rittersporn

Sunil Vyas

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“I was very shocked and angry when I realized I was sick. I needed time to process this information. Then I was able to shift perspective from bitterness to thankfulness to be alive through whatever means. I found insight into my own mortality and the true blessing of life.”

— Alicia Guerro, kidney recipient

.....

“Many of my questions truly had no answers. It was my faith and trust in others that I turned to.”

— Vanessa Underwood, kidney recipient

.....

“I made patience my friend...”

— Tamra Lewis, kidney recipient

Should I consider transplantation?

What is an organ transplant?

An organ transplant is an operation that places a healthy organ from another person into your body. The organ can come from someone who has died (a deceased donor) and has signed their state's donor registry or told their family of their wishes to become a donor. In the case of kidneys, a kidney may also come from a living donor who may be a close relative, spouse or friend. It can even come from someone who wishes to donate a kidney to anyone in need of a transplant. Living donors can also donate part of a lung, liver, intestine or pancreas, but these types of surgeries are not as common as living kidney donation.

The transplant operation and details of your surgery will be discussed at length by your surgical team. The recovery period varies depending on the individual. You will need to take medications called immunosuppressants which will help your body to not reject the new organ. You will have to take these medications for as long as you have the transplant, but they may change in type or dosage as decided by your doctor. You will need routine lab studies which will decrease in frequency the longer you have the new organ and are well.

Transplant is a treatment option, not a cure, but you can live a long productive life if you follow a healthy lifestyle with diet, exercise and knowing your individual limitations.

Who are organ transplant candidates?

Organ transplant candidates are people like you and me who have had their lives interrupted by illness. We are of every age, and of many different cultures and religions. Although every one of us is unique, the transplant journey has many universal experiences we all share. We all face uncertainty; loss of our life as we knew it; a variety of emotions as our physical health ranges from critical to okay; a wait of unknown duration; and a fear of “Will I beat the clock? Will I live or die?” Success rates for heart, liver, lung, kidney, pancreas, and all transplants continue to improve each year. Some of us have been candidates only once. Others of us have been retransplanted and have waited two or three times for a donor organ.

The benefit of an early transplant

Early kidney transplant is transplanting a patient before they require dialysis or within the first year after dialysis. Early diagnosis of end-stage organ failure gave us the advantage of being able to plan ahead for a transplant. This means finding a transplant center, being evaluated and getting placed on the waiting list as early as possible, so your condition deteriorates as little as possible before transplant. For people with lung, liver and, particularly, people with end-stage kidney failure, it can also mean asking if there is a potential living donor in your lives. Data exists about the benefits of an early kidney transplant or a preemptive kidney transplant. A kidney transplant occurring before dialysis begins (preemptive) or within the first year after dialysis starts (early), has been found to result

in a better functioning transplant — one that will last longer and work better. If you are reading this book in anticipation of needing a transplant in the future, you could be healthier for it. We are not talking about delaying dialysis if you need it, but planning ahead for a living donor transplant before your kidneys fail.

How will I pay for a transplant?

In the midst of our anxiety and concern about our well-being, we also had to deal with hospital/physician payments and job security. This was confusing at times and caused us to worry about our families' future financial security. If a friend or family member was our living donor, some recipients also worry about and plan for some anticipated living donor expenses.

Find out what your insurance covers and what it does not. If you have a choice of coverage, pay particular attention to co-payments for medications. Understand your benefits. Is there a maximum amount your insurance will pay yearly or for your lifetime? What paperwork is involved? Negotiating with insurance carriers, case managers and employers for increased benefits can also help.



“I don’t know how long I have to live. Sometimes I cry, sometimes I feel disgusted, like giving up. Then I turn it over to God.”

– Artis Fox, waiting for a heart

Transplant programs usually have financial administrators and social workers who can help you apply for federal, state, local or charitable benefits, or they can direct you to other types of coverage. You may need to revise your family budget. Sometimes relatives pull together and help out in unexpected ways. Sometimes family and friends raise funds with a reputable nonprofit organization. Some candidates' houses of worship (churches, mosques, synagogues) assist with fundraising. Some of us have worried that our families have to "go without" in order to pay for our medical care. It helps to share these painful feelings and to work with professionals, family and friends to find solutions.

The experience of waiting

Living with illness

Those of us whose illness is recent or of sudden onset have experienced anguish and stress at this unexpected change in life as we know it. Those of us who have lived with a chronic or terminal illness for months or years continually seek new ways of coping and grieving for all we have had to give up and leave behind. Waiting can provide you with the opportunity to overcome difficult feelings, such as denial or anger at being ill.

What do people think?

Appearance is so important in our culture. When we have an illness and our body changes, we may become self-conscious. Some of us, for example, might look sick because we carry oxygen tanks around, and may be self-conscious about the attention we may attract. Others of us may not look sick. Some of us men, for example, have felt the pain of watching our wives or children carry heavy packages from the car, knowing that the neighbors probably thought we just didn't care. Although we look fine on the outside, no one could tell that a heart transplant candidate's heart is operating at 10 percent.

Some of us have concerns about our body image and wonder if we will ever look like we used to. Perhaps only you notice that your skin tone is not the

same or your eyes are not as bright. Perhaps you have more noticeable physical changes to your body. None of us ever look the same forever; we all grow and change.

We have found that paying attention to what makes us feel good about ourselves can make a difference. For example, you can wear colors that perk you up.

Don't let self-consciousness and fear of attention keep you from things you want to do. Some of us have put others at ease by tying ribbons on oxygen tanks or on our IV poles, giving others permission to look, interact and respond.

Family and friends

As difficult as this is for us to accept, our illness can be equally as difficult for our loved ones. Some may rise to the occasion and really be there for us; others may find it just too painful to provide the support we need.

We wonder if loved ones will still care for us if we become sick. Some of our friends and family have an impressive ability to adapt to the changes in our life situation. Others may not, and may stay away. We need to allow our families and friends room to grieve for the loss of our health and the impact it has on them. We may develop new support systems that we never had before — we just need to be open to new opportunities. We have learned that our care partners will need support, too.

Couples

Intimacy may be a struggle even for lifetime companions. We may fear that our partner will desert us. Some of us have felt guilty that we cannot be the companions we want to be. Emotions, medications and illness can affect sex drive. We may lose our sex drive due to physical or psychological pressures, or both. We may feel jealous of our healthy partner and feel angry and guilty that we cannot live up to our own expectations of partnership.

Be gentle with yourself and your spouse or partner. Be aware of unrealistic expectations you may have for yourself or your mate. Try to remember that you are both doing the best you can. The physical changes that accompany our illness can generate distressing feelings. Because these changes affect our body image, we may need special support in this area from our partners. We should talk to our partner about how we feel and what we need, including what kind of physical contact we want. A therapist, psychologist or psychiatrist was a great help to some of us.

Some of us were hit by illness before we started a family. We may wonder if we will ever be a mother or father. Many of us, both male and female recipients of all organs, have gone on after transplantation to have biological children. We have also adopted children. Others of us have built extraordinarily rich, satisfying lives without children.

responsibility on them; they still need time to be kids. Let children know they are loved and will continue to be taken care of, even though family members may be sick, upset or tired.

When a child is the candidate

As all parents know, children have unique needs when they are ill. Children experience stress and strong emotions, and at times feel set apart from their friends and classmates. Teenagers feel acutely self-conscious about their physical changes, let alone the added embarrassment of medical exams and tests. At an age when teenagers are striving for independence, it is hard to need assistance, to be different, and not be able to participate in all school and extracurricular activities.

Knowing what to expect is helpful for adults as well as children. Visit the transplant hospital, perhaps with the child at one point, to see where things are located, learn about procedures, and meet with the personnel so a familiar face can be found when the time comes. Some pediatric transplant centers have child life specialists who can help. Discuss what to expect with the whole family. Find out what family support is available, such as a support group, or a meeting with the transplant coordinator or team.

Children need help to express their emotions. Talk directly to your child to learn what their worries might be. He or she may be anxious about feeling pain, embarrassed by procedures, or frightened that the transplant won't work. It is important that the child have an opportunity to express feelings so that they

don't come out in harmful ways, such as refusing to take medicine. Let children and teenagers make as many decisions and do as much for themselves as is appropriate for their age. Taking charge even of small things (watering and caring for a plant, for example) can bring them a sense of well-being and a needed sense of control.

Focus on other parts of life, too. Plan family outings and talk about school and friends. Keep things as normal as possible, which may include continued discussion about curfew time!

Stress and our emotions

Waiting is as stressful for our loved ones as it is for us. Some feelings are a reaction to loss, some to the uncertainty of the future or our current physical health. It is possible to experience many different feelings in a short period of time, or at the same time, and to not always know why you are feeling the way you do.

Not all of our stress is purely emotional. Chemical abnormalities and fatigue associated with illness have effects on our thoughts and perceptions. Severe heart disease may diminish blood flow to the brain. Kidney failure results in anemia and fatigue. Chronic liver and kidney diseases can cause waste products to build up in the body and interfere with mental functioning and alertness. The medications we take can affect our moods and thinking.

False alarms

To those around us, our anxiety can seem out of control at times. For example, some of us have had our pager go off by mistake, creating excitement followed by disappointment. It is not uncommon to be called and think, "This is it!," only to find that final testing showed that the organ was incompatible, or that it is a better match for someone else. This is tremendously disappointing. It takes some work to accept that waiting time is random and cannot be controlled.

Be aware that when your transplant coordinator calls, he or she will say, "We may have a *potential* organ for you..."

Living Donation

What is living donation?

Living donation takes place when a living person donates an organ or part of an organ to be transplanted into another person. Living donation can result in positive outcomes for the recipient and the living donor in carefully selected situations. Living donation has increased because there are not enough organs from deceased donors for people on the waiting list. Living donation has all the risks of major surgery for the donor. The living donor can be a family member, such as a parent, a child (over 18 years of age), a brother or a sister. Donation can also occur between two individuals who are not biologically related. A living unrelated donor could be a good friend, spouse or coworker. The donation may even come from a stranger, in which case it is called a non-directed donation.

What organs can come from living donors?

The most commonly donated organ is a kidney. People usually have two kidneys. One healthy kidney is all that is needed to live a normal life. It is also possible to transplant part of a lung (two donors are needed for every lung recipient), liver, intestine or pancreas from a living donor.

What are the advantages to the recipient of living donation over deceased donation?

An organ from a living donor can have a number of advantages for the recipient over a deceased donor organ. First, the living donor organ is in excellent condition. The kidney usually functions immediately and there is less chance of rejection, leading to better long-term results. Second, the transplant can be scheduled when most appropriate, avoiding the usual lengthy waiting time for a deceased donor organ. Risks to the donor organ itself are minimized because it has only a short journey from the donor's body to the recipient.

Who can be a living kidney donor?

A donor must be in excellent health and have kidneys that are normal, both functionally and anatomically. High blood pressure, diabetes, some forms of cancer, or certain infectious diseases such as AIDS or hepatitis B would be contra-indications for donation.

The decision to donate must be voluntary and free from emotional duress or family pressure. The donor needs to have all the information necessary to make an informed, educated choice. If the donor meets the criteria for donation, there will be tests to check for compatibility. These tests could include cross-matching and tissue typing as well as physical and psychological examinations.

How will living donation affect the kidney donor?

Most living donors tell us, the recipients, that they feel good about the decision to donate. Everyone is different. Anyone choosing to undergo the surgery should be prepared for a variety of outcomes afterwards. The living donor should be psychologically stable and prepared to handle negative outcomes from the surgery, should they occur. These outcomes include: medical or psychological complications for the donor; death of the recipient; loss of the transplanted organ; the experience of pain by the donor; a change in the relationship between donor and recipient; depression; and more. These possible outcomes are why a potential living donor will be evaluated by a psychologist, psychiatrist or social worker. Though rare, as in all major surgery, there is a risk of serious medical complications and death to the living donor.

People can live normal lives with only one kidney. In fact, some people are born with only one. A donor, who has been evaluated thoroughly and cleared for donation, can usually participate in normal activities after donation.

Donors are encouraged to have good long-term medical follow-ups with their primary care doctor. People with one kidney may be at an increased risk of developing high blood pressure. Certain career choices may be limited – for example, some branches of the military, police and fire departments do not accept individuals with one kidney. Donors

who are thinking of getting pregnant should consult with their doctor first. Pregnancy after donation is possible, but not recommended for at least six months to a year afterwards.

What is the recovery period for kidney donors?

The length of stay in the hospital varies, depending on the individual's rate of recovery and the type of procedure performed (traditional open nephrectomy vs. laparoscopic). After leaving the hospital the donor will typically feel tenderness, itching and some pain as the incision continues to heal. Generally, heavy lifting is not recommended for approximately six weeks following surgery. It is also recommended that donors avoid contact sports in which the remaining kidney could be injured. It is important for the donor to speak with the transplant staff about the best ways to return to physical fitness as quickly as possible, and when the donor can resume normal activities, return to work, travel etc.

What testing is required to determine whether someone can be a kidney donor?

Potential donors will have blood, urine and radiology testing to determine suitability for donation. A full physical examination and psychological examination will be required. Time will be allotted to ask questions and address any concerns that may arise. Before surgery, special x-rays will be taken of the donor's

kidneys, including an intravenous pyelogram (an x-ray image of a part of the kidney after injection of a dye into a vein), and/or renal arteriogram, or CT scan testing to check the anatomy of the kidney. Some transplant centers may use MRI (magnetic resonance imaging) or MRA (magnetic resonance angiogram) to generate images of the kidneys or arteries. Testing also includes a full cardiac evaluation. Additional blood testing will determine the quality of match between the donor and the recipient.

What if the potential donor decides not to donate?

The decision to become a living donor must be voluntary and made without pressure. Individuals have the right to decide whether donation is right for them.

Likewise, some individuals with kidney failure may decide they do not want the transplant or may choose not to consider a living donor. The decisions of the potential donor and recipient must be respected. Possible donors may change their mind at any time during the evaluation process without fear of embarrassment or repercussions.

It is quite normal for a potential donor and their family to have fears and concerns about potential complications. This might be felt by some as reluctance to donate, yet it is a natural reaction to major surgery. The donor should be encouraged to speak openly with the transplant team about these

fears. All conversations between the living donor and the transplant team, including those with the recipient and others, are kept confidential. The results of medical testing are also kept confidential.

How do I ask someone to be my living donor?

This depends on you and your loved ones. All families are different. Many of us who were in need of a transplant found that our family members or friends asked us. Others found that asking someone we loved to donate was too hard.

Others of us were able to overcome our fear of talking to our loved ones about living donation when we learned more about transplantation and donation. Instead of asking directly, we took the time to educate our families and friends about transplantation and donation. Sharing as much factual information as we could, along with sharing our thoughts about our progress, our options, our hopes and dreams helped us and our families think about whether living donation was an option. Some of us found a friend or family member to “champion” the cause for us and take the lead in talking to and educating friends, family and acquaintances about our need for a kidney. This was very helpful and relieved the pressure of having to ask someone directly. However, feeling free enough to talk about our need for a kidney in regular conversations was important in getting the word out and making other

people comfortable asking us questions about donation. We found that if we could mention it, we could manage the conversation that followed.

The issue of buying and selling organs may come up. This practice has been illegal in the United States since 1984, when it was outlawed by the National Organ Transplant Act (PO 98.507).

With the increasing need of organ transplants, some have risked traveling to unregulated parts of the world to receive an organ. A person must consider the risk of complications and unknown quality of post-operative care in an unregulated environment along with ethical concerns regarding the origin and circumstances surrounding the recovery of the organ that became available. Another compelling concern is the continuity of post transplant medical care upon return to your home community.

Desensitization

Desensitization is a procedure currently being provided at a limited number of transplant centers. It allows a recipient to be able to receive a kidney from a donor of an "incompatible" blood type. Until recently, a transplant recipient could only receive an organ from a living donor who had a compatible blood type. An organ from a donor with an "incompatible" blood type would be perceived by the recipient's immune system as foreign and would be vulnerable to attack by the recipient's natural antibodies.

In desensitization, the recipient undergoes plasmapheresis, a process involving the removal of the plasma portion of the blood that contains harmful antibodies, and the administration of a medication to prevent their production. The patient is then ready to undergo transplant surgery where, in addition to receiving a donor organ, the patient's spleen, home to the harmful antibodies, is removed using minimally invasive surgical techniques. In some cases, spleen removal can be avoided through the use of a new drug that creates similar effects. Post-transplant, the recipient undergoes additional plasmapheresis treatments before being discharged from the hospital. The transplant recipient will then take the same immunosuppressive medications as patients receiving a compatible kidney.

Non-directed donation

Immunosuppressive medications, which keep the recipient's body from rejecting the donor kidney, have been improved so much over the years that a genetic link from donor to recipient is no longer necessary to ensure a successful transplant. Therefore, strangers who wish to donate a kidney for altruistic reasons are accepted as suitable donors for kidney transplant by some transplant programs. A stranger who wishes to donate a kidney is advised to contact a nearby transplant center that has a non-directed donation program. The non-directed donor will go through the same extensive medical testing and rigorous psychological exam as any living donor. If the donor is accepted, the transplant team will choose a candidate from the waiting list who would best be suited for the kidney.

We encourage people considering non-directed donation to familiarize themselves with what is involved with living donation by visiting www.livingdonors.org. Some Web sites attempt to match recipients with non-directed donors. Instead, we encourage non-directed living donors to work with a transplant center to find the most appropriate recipient. It is important for the transplant center to be involved and notified if the recipient advertises on the Internet or in any advertising campaigns. The center's role is to evaluate potential donors and, if approved for donation, find an appropriate recipient for the organs. This process helps protect donor and recipient confidentiality and ensures that potential living donors fully understand the risks and processes involved. We have concerns that commercial advertising for donors via Web sites or billboards can create undue competition among transplant candidates and can give an unfair advantage to those who have the resources to advertise. Regardless of how recipients and donors are matched, we feel it is important to involve the transplant center in the process.

For some transplant centers, non-directed living donors can kick off the first of many transplant operations that can result from one non-directed donor's gift of a kidney. The transplant program arranges for the non-directed donor to give the kidney to a candidate who has a living donor who isn't a match. Then, that living donor (who didn't match their family or friend) is paired up with another candidate who has their own living donor who didn't match, who is then paired up with another — and

so on. This is a form of “paired exchange” and this method can result in a chain reaction allowing many transplant operations to occur from one selfless gift.

Paired exchange or donor chains

Sometimes a loved one may want to donate a kidney, but has a blood type that is incompatible with the recipient. For example, someone with type A blood wishes to donate to a type B recipient. This incompatible pair may be able to enroll in a paired exchange system through a transplant center. In this system, matches for compatible pairs of donors and recipients are identified. Your intended donor will donate to someone else, participating in a donor swap or chain that includes a compatible donated kidney for you. These exchanges can be 2-way or can include a long chain of donors and recipients. They may involve multiple transplant centers and even multiple states, though in most cases these days, donors are able to donate the kidney at the same facility as their intended recipient, and their kidney is shipped to their actual recipient's transplant center. If the recipient from one pair is compatible with the donor from the other pair, and vice versa, some transplant centers may arrange for two simultaneous transplants to take place. This allows two transplant candidates to receive organs and two donors to give organs, even though the original recipient/donor pairs were unable to do so with each other. As with every potential donation, both donors and candidates are carefully evaluated and tested medically and psychologically to assure that the benefits outweigh

the risks. Surgeries can take place at the same or different hospitals. It can be advantageous if the surgeries take place at the same hospital, although this may mean extra travel and housing costs for one donor and recipient pair.

What are the risks associated with kidney donor surgery?

The surgery involves the same level of risk for the donor as any other major surgery. The risks associated with surgery and donation will be discussed in detail during the evaluation process.

Traditional living donor kidney surgery has been the standard surgery since living donation began in 1954. It requires an incision in the donor's side to remove the kidney, its blood vessels and ureter.

Laparoscopic donor surgery began in 1996. The operation most often requires four small incisions in the donor's abdomen, though there are several different options for laparoscopic technique. In most cases, surgical instruments are inserted into the smallest incisions and the kidney is removed through the fourth incision. Scarring is less pronounced; donors typically feel less pain and experience a shorter hospital stay and recovery.

Laparoscopic surgery, though less invasive, is still major surgery. Advantages of this surgery for living donors over the traditional nephrectomy are: minimal surgical scarring, and a generally quicker return to

full activities and work. While this is a suitable option for some, like any major surgery, it involves risks and may not be appropriate for some living donors or transplant recipients. Both laparoscopic and traditional open nephrectomy surgeries carry risks. Again, it is important to discuss the associated risks with a doctor. Visit www.livingdonors.org for detailed information.

Live liver donation

Transplanting a piece of the liver is possible because the liver can regenerate itself in both the donor and recipient after transplantation. Donating a section of liver is riskier than kidney donation. The liver donor must undergo extensive examination and testing to determine excellent physical and psychological health. Radiological imaging of the liver is done to assess the anatomy, liver volume and size. A liver biopsy may be performed. Adult-to-adult live liver transplant is still relatively rare and carries a higher risk to living donors, compared to kidney transplant. We strongly recommend talking to a transplant center about their experiences and success rates with this procedure.

Live lung donation

Live lung donation involves two adult donors, one giving the lower right lobe and the other giving the lower left lobe to an adult or pediatric recipient. The potential donors' lungs must be the right size and volume. For adults, donors should be at least

as tall as the recipient. Ideally, donors should not be overweight and should be non-smokers. Potential donors receive a series of exams and tests including chest radiography, pulmonary function testing, ventilation-perfusion and CT scans, and a cardiac stress test. Again, donating a lung is riskier than live kidney donation and the risks and benefits should be discussed with the transplant team.

What is a donor advocate?

A donor advocate is a person appointed by the hospital whose job it is to help make sure the potential donor is a volunteer, feels well-informed and prepared, and can advocate for their interests. This person could be a nurse, a social worker, or even a chaplain.

Ideally, the donor advocate is in a position to veto the transplant if it could cause unacceptable risk to the donor.

Who pays for living donation?

The costs of living kidney donation, including those associated with donor evaluation and surgery, are usually paid for by the recipient's insurance. There are some exceptions (such as when a donor work-up is repeated at a second transplant center within a certain time frame), so it is important to check with the transplant center financial counselor. Travel and lodging expenses are not covered, but may be reimbursable under a 2007 Federal Grant

program managed by the “National Living Donor Assistance Program.” [www.livingdonorassistance.org] This program allows transplant centers to file an application on the donor's behalf. Donors whose employers offer benefits may be eligible for sick leave. Living donors who are family members of the recipient and work for a large employer may be covered under the Family Medical Leave Act (FMLA). Many federal employees are eligible for 30 days paid leave. Some states allow live organ donors to deduct up to \$10,000 in expenses from state income tax.

It is worthwhile to check with an accountant and to review the laws in your state that impact living donation.



“We found maintaining a positive and independent attitude wasn’t always easy. Nor did it make a transplant happen any sooner. However, it helped make our lives more productive, enjoyable and meaningful while we were waiting.”

—Gerard Migliore, kidney recipient



“Our families saw us at our worst and although we had to remember that they loved us, some days they may not have liked us at all.”

— Brenda Dyson, kidney recipient

Will donors be able to obtain insurance coverage after donating?

We are aware of some kidney donors who have reported having to wait after donating to obtain insurance coverage because their donation was considered to be a pre-existing condition. Lung and liver donors face more obstacles. Future insurability must be evaluated by each potential living donor.

Some living donors who do not receive insurance benefits through a large employer have reported difficulty obtaining health and life insurance after the operation. Pre-existing condition limits or delays in coverage, high premiums and denials have been reported by some living donors who are purchasing insurance on their own, or who work for small employers. It is important for potential donors to be aware of their risk factors regarding employment and insurability and to talk it over with the transplant program social worker or living donor advocate.

We encourage living donors to contact the National Kidney Foundation regarding their experiences obtaining insurance.

Are transplants from living donors always successful?

Although transplantation is highly successful, and success rates continue to improve, problems can occur, sometimes without warning. Sometimes the kidney is lost immediately due to rejection or surgical complications. Over the long term, the original disease that caused the recipient's organ to fail may recur. Our immunosuppressive medications leave us susceptible to infections and new diseases. Transplantation is not a cure, but a treatment option. It is reported that at one year after the surgery, 95 percent of transplants performed between living donors and recipients are successful.

For more information about living donation, visit www.livingdonors.org

Deceased donation

Deceased donors

Some of us have struggled with the knowledge that our donor organ came from a grief-stricken family willing to donate a loved one's organ at the time of death. This painful awareness is balanced by the hope that the donor organ will provide us with a chance for a new beginning. We have found that donor families are not unlike our own families. The gift of a donor organ is a family's choice and families often feel comforted by the knowledge that their loved one was able to help others through donation.

A survey conducted by the National Kidney Foundation of 500 donor families found that nine out of ten believed donation was a positive experience. Excellent success rates are reported for transplants of vital organs. At one year, 90 percent of kidney transplants from deceased donors; 84.3 percent of living liver transplants; 83 percent of deceased liver transplants; 87.7 percent of heart transplants; 78.4 percent of pancreas transplants; and 77.2 percent of intestinal transplants were still functioning well.

Due to the critical organ shortage in our country, some recipients benefit from accepting organs from older donors, also called "expanded criteria donors" as opposed to the younger "standard criteria donors."

During your transplant evaluation, or at another time well in advance of your transplant operation, you can discuss this possibility with your physician or surgeon.

Expanded criteria donors are not an option for all candidates, but may be considered for those who face a substantial risk to their health by remaining on the waiting list. In general, an organ from an older donor can increase life expectancy by adding several years to what would have been a candidate's life expectancy without a transplant.

Expanded criteria organs are usually from older donors, but may be from younger donors who have some risk factors, such as high blood pressure, cancer, infectious disease, or a history of smoking, drug or alcohol use. The definition of an expanded criteria donor varies between hospitals and transplant programs, so you should talk to your doctor about your options. There is an expectation from the transplant team that these organs, if offered to you, will work well, despite the risk factors. However, with any organ transplant, there are risks and unknowns.

In an effort to increase the number available for transplantation, some liver candidates decide to accept a donor liver that has been divided into two sections — thus saving the lives of two candidates. This usually reduces time on the waiting list.

The transplant evaluation

Your evaluation is a snapshot of one moment in your life. Most of us don't like tests or being evaluated under any circumstances. When we are not feeling well, and the outcome can mean life or death, the evaluation is likely to provoke anxiety. The transplant evaluation is a thorough medical examination consisting of a chest x-ray, blood tests, cardiac (heart) and pulmonary (lung) exams. It is a time to ask questions, obtain information and meet the transplant health care team. It is a time for you to call upon your inner strengths and to activate your social support system. The evaluation gives you an opportunity to demonstrate to yourself and the health care professionals that you have the resilience and fortitude to weather the rocky road of the transplant journey.

A few of us were evaluated by several transplant centers before we found one that was right for us. Most of us went to the transplant center referred by our specialist or one that was approved by our insurance company.

Some of us found that the evaluation gave us a chance to think about issues that we had not thought of before, but until we actually went through the transplant process, we couldn't understand the depth of how it would change our lives both physically and mentally.

Your transplant care team

You and your family are the most important members of the transplant care team. You can take an active role in your care by learning all you can and taking part in your treatment plan. It is important to work together with each member of your health care staff.

Your **Transplant Physician** is a doctor with advanced training in an area of medicine. This doctor will supervise your care before and after your transplant.

Your **Transplant Surgeon** has advanced training in surgery. The surgeon will meet with you before the transplant surgery to determine, with the help of other members of the medical team, whether transplant is the best treatment for you. The surgeon will speak to you about the risks and benefits of the surgery and answer any questions you may have about the surgery or about the follow-up care.

Your **Transplant Coordinator**, a registered nurse, is your link to the transplant hospital and will work with you and other members of your transplant team to coordinate your care. Coordinators facilitate all aspects of the transplantation process. Their responsibilities include: educating patients and families about various treatment options and answering any questions they may have, and coordinating post-transplant follow-up.

Your **Transplant Social Worker** provides you and your family with emotional support and practical suggestions to help you obtain benefits and the care you need at the psychosocial and financial levels.

Your **Financial Counselor** or **Insurance Case Manager** evaluates your insurance benefits and will assist with any billing and financial questions you may have.

Another integral part of your transplant care team is your **dietitian** who develops nutrition therapy for you before and after transplantation.

Your transplant center may have a specially trained **pharmacist** on staff, who will dispense your medications and answer your questions about how to take them.

Do I really need a transplant?

During the wait you will have good days and bad days. Some days you may feel so good you'll think you don't need a transplant. Other times you may be sick enough to be hospitalized in intensive care. At any time during the wait, you can always change your mind if you decide you do not want a transplant, even when you receive the call. However, since one can never know when or if the next call will come, most of us accepted the organ when we received notice that it was available.

None of us wanted to go through the trauma of surgery if it was not our best treatment option. If it wasn't, we enlisted the help of health care professionals to find other specialists to help us.

The list

Once you have completed your evaluation and are found to be a good candidate, you will need to add your name to a national computerized list of all candidates waiting for organs.

The list is maintained by a non-profit organization — the United Network for Organ Sharing (UNOS) — [www.unos.org] that is under contract to the federal government to maintain the list 24 hours a day, seven days a week, year round.

Visit the UNOS Web site at www.transplantliving.org for information about the listing criteria and maintenance of the list. Many factors contribute to whether or not an organ will be offered to you: your blood type; where you live (an organ must be safely transported the distance to the transplant hospital); in some instances your weight and size; and more. Different criteria will affect your place on the list and the length of your wait. Your transplant health care team can answer your specific questions. It is natural to wonder if the list is fair. To protect the access to organs for persons of all incomes, it is illegal to buy or sell organs. Celebrities are listed using the same criteria as the average citizen.

It is recommended that you put yourself on the waiting list even if you have a potential living donor. This is so you can hold a place on the list in case you end up needing a transplant from a deceased donor.

Multiple listing

Generally, deceased donor organs are offered locally, regionally, and then nationally.

The list may progress faster in some geographic areas than in others. Recipients having the physical ability, the family support and financial resources to travel, can look into being evaluated and listed at more than one transplant center in different regions of the country. This is called "multiple listing." Some transplant physicians encourage their patients to multiple list, if possible. It is important to multiple list in coordination and cooperation with your original transplant hospital. There may be insurance, financial and travel complexities that need to be arranged. The waiting time incurred at the first center where you listed can be transferred to a subsequent transplant center in another region if you wish to change centers later on rather than stay active on more than one list. Some of us found that our insurance would not pay for listing at more than one transplant center; we had to be prepared to repeat tests and exams and also pay out-of-pocket for evaluation, travel and other related expenses.

What helps

For many of us, information reduces the fear of the unknown. We learned not to be afraid to ask questions, no matter how “off-the-wall” they may seem. Many of us get information through reading and getting involved in our own care.

Some of us want our doctors to be direct and forthcoming. “Sugarcoating” the facts has never helped those of us who like to know what we have to deal with. Some of us overcame longtime fears about our health, learned how to put in our own dialysis needles, or researched everything on our disease.

Having the courage to share ideas with our doctors and working together with them on our care gave us emotional and physical strength.

We all need things to look forward to. For one man with a long hospital wait, a schedule of TV shows, particularly big sporting events, gave his days a rhythm. For another, getting shaved and dressed, even on the hardest days, was a morale boost. Do something every day. One woman makes herself sketch. For others, writing poetry, keeping up with current events, working on crafts or walking slowly, even in a limited way, was helpful. What brings us comfort may be the same thing that helped us before we became ill — or it may be a new discovery. That “something” may be different for each one of us. Seek it out. It will be worth the time and effort.

Planning ahead

Planning ahead is helpful for practical reasons as well as reducing anxiety. Issues we have already taken care of should not drain our energy or cause us worry. Many of us have found that we can limit uncertainty by taking charge of what we can do. Having our bags packed and ready to go when the call comes helps ease anxiety. We recommend including **money** for tolls and a **calling card or cell phone**. You may want to bring any **medications** you are currently taking and, if you are on peritoneal dialysis, your **supplies and equipment**. Bring a **list of any medications** you are on. Know your allergies and, most importantly, bring your **health insurance card**. You may want to keep a log of surgical tests, medical events and hospitalizations, and bring it with you.

Make detailed plans for living arrangements if you have to move to another town for your transplant. If the transplant center is several hours away or in another state, have access to flight information. Find out how to arrange for a police escort, if warranted, from your home to the hospital. Pre-plan for child care. Set up a cell phone or pager system for family and friends involved in your plan. Know what to expect at the hospital; see where the intensive care unit (where you would wake up) is located. See the transplant floor. Since the medications you will need after transplant may not be in stock at your local pharmacy, or your pharmacy may not be a specialized Medicare-provider drug store able to bill immunosuppressants, arrange to have a pharmacy ready and willing to supply you with the medications

you will need. Your transplant coordinator or social worker can help you. If your transplant center offers an orientation program, we encourage you to attend.

Caring for yourself emotionally and physically

We all benefit from taking an active role in our health care. We need to pay attention to how we are doing physically and let health care providers know immediately if there are changes in our physical or emotional health and well-being. Sometimes we hesitate to speak up for fear of being “poked and prodded” if more tests are needed.

Exercise

As poor as we felt physically, some of us managed to stay in good shape or become more physically fit by swimming, stretching, and practicing tai chi or yoga. Some of us looked at the waiting time as if we were “in training”: We refrained from smoking, tried to maintain normal body weight and kept up an exercise program, even if it was all done from a sitting position!

Pacing yourself

Many of us found that we were able to do more if we paced ourselves over a longer period of time or broke down large tasks into smaller ones. Let your family know that there are times when you have to save your energy. Remind them that you don't love them less just because they get less of your time.

Relaxation

Learning relaxation techniques was a great help for those of us who could not control our worry. We found that a few visits to a psychologist specializing in stress management and relaxation techniques helped. Learning about breathing, imagery and bio-feedback taught some of us how to relax. It was amazing! Doing anything we find relaxing can help. For some of us this may be a relaxing bath or talking with a friend. Music and art also have therapeutic benefits.

Treating anxiety and depression

Never having considered psychotherapy before, some of us found it to be just what we needed. Antidepressant medications, prescribed by a psychiatrist in consultation with our transplant team, helped some of us, too. Though it is perfectly natural that we would be depressed given our situation, the medications helped some of us feel better.

Do not take over-the-counter or herbal antidepressant medications (St. John's Wort or others) without discussing them with your physician first. Some symptoms of depression such as fatigue and difficulty sleeping are often related to our illnesses. However, if symptoms such as hopelessness, despair and diminished self-worth ("Is my life not worth saving?") persist, it is important to let your health care team know. Antidepressant medication in combination with psychological counseling can help alleviate these debilitating symptoms.

Learning about addictions

Some of us found it easier to live a healthier life while we were waiting. It helped those of us with addiction problems take the time to learn about our addictions and treat them. After our transplant, many of us faced the same temptations we had before our wait began. We must prepare to live our lives in a way that negates the possibility of again picking up addictive habits. Addictions — even some “socially accepted” habits, such as tobacco and alcohol — can limit the life of our transplanted organs.

Support groups

Support groups can take away some of the loneliness. During our wait, many of us were introduced to a group of individuals who, like us, were waiting. Your transplant social worker can help you locate a support group near you. Support groups allow you to share practical tips and information about the waiting and transplant process. There are also Internet discussion and support groups for transplant recipients.

Hopeful thinking

It helps to not second-guess decisions. Trust your gut instinct and avoid the trap of wondering, “What if it doesn't work out? What if ...?” Instead, we learn to refocus our thoughts. Squelch the doubts, especially when you are not feeling well. Share your hopes and dreams with people you love, and look forward to special days and celebrations.

Telling our stories

Sometimes it is therapeutic to tell our stories. We can do this by talking to trusted friends or by writing in a journal. Photographs and scrapbooks can help us remember and reflect on joyous times. Putting feelings and stories into prose and poems can help. We found that sharing our stories publicly had the added benefit of encouraging people to talk with their families about organ and tissue donation and to sign their state donor registry (visit www.donatelife.net).

Spirituality

Many of us draw courage and hope from spiritual sources when times are difficult. There may be days when the uncertainty of illness makes life seem unreal and terribly wrong. We are not being punished or tested. Some of us feel calm and unafraid when we take strength from our beliefs. Faith may help us find moments of hope and peace in each day. Houses of worship can provide the social support to our families and to ourselves as well. Many have provided emotional support and practical assistance to congregants. And many are active in educating the community about organ and tissue donation.

Volunteering

You may want to volunteer some time while you are waiting for your transplant. You can get involved with the National Kidney Foundation, or your local organ procurement organization (OPO – the organization that procures a donor's organs for transplant), or by making others aware of the need for more organ and tissue donors. You can get in touch with your Members of Congress through the NKF's Take Action Network [www.kidney.org/takeaction].

Taking care of our caretakers

Our care partners can become physically and emotionally exhausted at times. We need to encourage them to take time for themselves so they can “recharge.” We need to encourage them to take care of their own health — to go to the doctor when they are sick and keep routine appointments.

It helps to be specific about what assistance we need from our care partners. One person let her family members know that making the bed each day was hard. This may seem like a small thing, but it meant a lot to her to see the bed made. It made the world seem less chaotic. Being able to do this made the family members feel good.

Learn to accept help. Accepting help was not easy for those of us who were independent before our illness. Some of us thought receiving help meant we were weak or accepting charity. We learned this was not so. If we give a smile, a thank you, a request

for assistance freely, we are giving our care partners a gift and helping them deal with their sense of helplessness.

Some days we may push ourselves beyond our limits. It may be hard for our families to watch us make demands on our bodies knowing that we will both pay for it later. Yet, we do not want to be nagged or treated like children. If you pay attention to your body and listen to others, you can learn how much you can physically do and when you need to stop.

What family and friends can do

Family members and friends can learn CPR and basic first aid. Others take this time to educate people about organ and tissue donation. Don't let your family and friends underestimate the value of simply being with you, even when declining health may drain your energy for conversation. Encourage family who live far away to write to you, and write back. We found it helpful to let trusted family members know where we kept records and other important information. Reviewing your finances and arranging for power of attorney with your bank will allow your household to run smoothly when you are hospitalized or otherwise unable to manage your finances.

After transplant

What to expect after a transplant

There is an old joke about a patient who asks his doctor, "Will I be able to play the piano after my surgery?" The doctor reassures him that of course he will. The patient responds, "Good, because I couldn't play a note before!"

People sometimes have unrealistic expectations about transplantation. Think about how you expect life to be after transplantation and talk over your expectations with family, friends and professionals to see if your expectations are realistic. It may help to talk with other candidates and recipients; however, your journey will be unique. Everyone reacts differently to surgery. Some people wake up after surgery and feel great; others struggle in the beginning and then do fine. Once again, we brace ourselves for the unknown.

Once you are home from the transplant surgery, the most important work begins: the follow-up. You will be carefully followed and your medications will need to be adjusted. This is done to watch for rejection. Over time, follow-up visits and blood tests are required less often. You should become familiar with the signs of rejection so you can report them promptly and be treated early.

What are immunosuppressants?

Immunosuppressants are drugs that suppress or lower your body's ability to reject a transplanted organ. These are also called anti-rejection drugs. Almost everyone who has a transplant must take these drugs every day as directed, for the life of the transplant. It is very important that you know the name of each drug you take as well as what it does. Anti-rejection medications have a large number of possible side effects because the body's immune defenses are lowered. These side effects may include changes in your mood or sleep patterns or gastrointestinal discomfort. Fortunately, these side effects are usually controllable for most people. You can work with your doctor and medications may be changed if side effects are intolerable. It is important to stay informed and read about each medication to understand these side effects and to realize that such changes may be a medication side effect.

Re-transplantation

Re-transplantation is no longer an uncommon occurrence. On one hand, most of us who have had more than one transplant were more prepared in many ways. We didn't fear the unknown. On the other hand, sometimes ignorance is bliss! The second time around can be more frightening when you know what could happen. However, surgical techniques and medications are always improving. Again, a range of emotions can leave us feeling overwhelmed. Those of us who are waiting again struggle with difficult feelings. Feelings of failure,

even though not logical, can burden us. Know that you are in good company. We need to remember that transplantation is a treatment, not a cure.

Informing your employer

When we are working and need a transplant, it is unrealistic to think we can fool everyone and no one need know. We are protected under the Americans with Disability Act and our employers should be able to make reasonable adjustments to our job, if feasible, when we need assistance. Many of us have been pleasantly surprised by the support we have received from employers and co-workers.

When should you tell? Give your employer enough notice to know when and why you may be in late or miss work. You may apply for the Family Medical Leave Act (FMLA). Under this law, you can take time off from work in 15-minute increments for up to 12 weeks for illness-related appointments, etc. Let your doctor know what your job entails and what physical demands are required. If you are unable to continue working, there may be other benefits available. Ask your supervisors and human resources professionals about these options. Transplant social workers can advise you about social security disability, job training and other benefits.

Preparing to return to work

Do you like the work you do or did (before transplant)? If so, the most direct path to employment is returning to your prior role with the same employer. In some companies, short-term disability is available, and in other instances you may be eligible for state disability, and have a job waiting for you when you return. But, not everyone is so fortunate. You may be out of work for too long and no longer have a job to return to, or, because of the transplant, you may no longer be suitable for your previous job responsibilities. If this is the case, now would be the time to take advantage of what is called a “forced sabbatical.” This time can allow you to reconsider your future, re-educate yourself and develop new skills. If you are collecting Social Security Disability Insurance, you can take advantage of work incentives which include innovative ways to get back to work, and can qualify you for funded state vocational job training and education. Volunteer work can help you gain experience and references in a new field.

Our best advice is to find something you are passionate about, and determine what you need to do to enter the field. It may help to talk with other transplant recipients who have transitioned back to work. Support groups can be a good place to find an organ recipient who can act as a mentor. Your transplant social worker can also help.

Some transplant programs also have vocational rehabilitation specialists and back-to-work programs.

Also, remember that perception is your reality. If you see yourself as disabled by your transplant, you are. At first, your transplant experience may come across to potential employers as a liability. It is up to you to educate them and turn that liability into an asset as many before you have already done. Let potential employers see you as someone who can overcome the lesser challenges of daily work life. If you see yourself as getting past this setback and moving on to be stronger, that will come across in your interviews. You can discuss benefits after you have been offered the job. You will need a good insurance plan that includes prescription drug coverage. Some states have special Medicaid programs for working people. Remember—you have a whole new life to live. Make it your best life yet.

Communication with donor families

If your organ was from a deceased donor, most transplant centers will provide basic information about your donor. You may also write to your donor's family. If the family is willing to receive a letter from you, your letter will be forwarded. Donor family members may also initiate correspondence. Some of us waited years after our transplant to write because we did not know what to say. A simple thank you is fine.

Some of us just sent a store-bought thank you card prior to leaving the hospital after our transplant. Some of us wondered how we would feel having another person's organ. Once it was transplanted, we came to think of it as our own.

We have heard from many donor families that receiving a simple letter from their loved one's recipient has meant a great deal to them.



“I became the person that I am because of what I’ve been through. Everything I have gone through helps me value and cherish life more.”

– Deborah Rodriguez, kidney recipient

End-of-life decisions

Talking about death with your family

Death is inherently difficult to talk about. It is tempting to avoid talking about it. However, talking about the possibility of death made us feel more in control and able to focus our energy on staying healthy. This is a time for all adult family members to talk about practical matters. What burial and funeral arrangements do we want? If we are able to preplan these arrangements, our families will have one less burden. Is our will in order? Have we given a loved one medical power of attorney or appointed a health care proxy? Have we discussed with our surrogate what type of care we want if we become critically ill? Do we want, if we are able, to donate organs or tissue at the time of our death? What are our loved ones' anxieties about life without us? Can we help prepare and comfort them? We found talking about death did not make it happen and it did not mean we had given up.

Keep living while waiting

All of us would benefit by living as if each day were our last. Perhaps we would die with fewer regrets if we told people that we love them, asked for forgiveness, if necessary, and thanked people we are grateful to.

Seize the opportunity to be the type of person you want to be. You will have the same personal problems after your transplant, so use this time to work on the conflicts in your life. Try to stay active and involved, and live as normally as possible.

Entertainment is important. Some of us who have dialysis or other treatments try to do this in a pleasant environment — we read books and magazines or watch a movie.

Look for ways to help others, no matter how insignificant your help may seem. Be generous in giving thanks. Have fun with people you care about. Listen to them. Never forget to laugh, especially at yourself. Humor is a wonderful weapon against depression. Live each day as fully as possible.

What if the transplant never comes?

Modern medicine is highly sophisticated and successful at keeping people alive until a donor organ is available. There are differences in waiting experiences depending on the organ you need transplanted. If you are waiting for a heart, liver, or lungs there are heart pumps (left ventricular assist devices), medication, stem cell transplants, and operations. For those patients waiting for a kidney transplant, you have the advantage of having access to dialysis, which not only keeps you alive but also allows you to continue to live a very productive and meaningful life.

None of us know when the call will come; some of us wait one day, and some wait years. One of the toughest things we have to do is maintain hope for a life-altering transplant, while at the same time being prepared for a life on dialysis, or in the case of those waiting for another organ, death. We do not know if the transplant will happen or if it will work. As we continue on our medical odyssey, death is no stranger to us. We experience the personal threat every day and the reality of it for our friends, and fellow transplant recipients who end their journey as we continue on ours.

All we can do is focus on living each day, and filling it with meaning as we continue to grow. None of us know how long our life will be, but we do have life — and as transplant candidates we are fighting for it each day.

We argue you are not “waiting” for a transplant but are “living” for a transplant.

We are all in this together. We are all partners in hope, holding one another's hands, with solidarity, compassion and strength.

Other sources of help

About NKF's Transaction Council

The transAction Council was established by the National Kidney Foundation in 1996 to ensure that organ transplant recipients receive the finest possible care. It is the largest group of transplant recipients in the United States and has international members as well. The transAction Council is “us”—candidates and recipients bringing each other information and educational materials such as this book on waiting for a transplant and the Transplant Recipients' Bill of Rights and Responsibilities.

The name transAction comes from “Transplant Recipients” + “Action.” Many of us who have joined the transAction Council are actively working with the National Kidney Foundation, the largest not-for-profit organization serving individuals with all types of organ transplants (not just kidney), striving to increase the number of organs available for transplantation. The transAction Council provides advice and assistance to transplant recipients and candidates. Our programs and services include educational symposia, national surveys, health and fitness programs and other support activities.

Membership in NKF's transAction Council is free and open to all individuals who have received a life-saving or life-enhancing organ transplant, transplant candidates, their families and friends, and the health care professionals who care for them. To join, go to **www.kidney.org/transplantation**.

END THE WAIT!

END THE WAIT! is a National Kidney Foundation initiative to end the wait for kidney transplants in the U.S. by eliminating barriers and disparities, instituting best practices across the nation, improving the transplant system, covering the cost of donating an organ, and increasing deceased donation. For more information, visit www.kidney.org/endthewait.



“While waiting, I didn’t count the days since there is no known target amount of days of when an organ will come.

I focused instead on making the most of each day — setting and achieving daily goals, no matter how big or small.”

—Jim Gleason, heart recipient

NATIONAL KIDNEY FOUNDATION RESOURCES

NKF Cares Patient Information Help Line

NKF Cares offers support for those people affected by kidney disease, organ donation or transplantation. Speak with a trained professional who will help answer your questions and listen to your concerns. Call toll-free at **855.NKF.CARES** (855.653.2273) or email us at **nkfcares@kidney.org**.

NKF Information Center

Call **800.622.9010** to receive information, answers to your questions, membership applications, or to find the phone number of the NKF local office. Visit **www.kidney.org** to access our online resources.

Take Action Network

The Take Action Network is a grassroots group of thousands of transplant candidates and recipients of all organs, as well as people affected by kidney disease and organ and tissue donation, who advocate for health care legislation and reform. Join online at **www.kidney.org/takeaction**.

ADDITIONAL RESOURCES

www.donatelife.net

Donate Life America is a not-for-profit alliance of national organizations and state teams across the US committed to increasing organ, eye and tissue donation.

www.transplantliving.org

The United Network for Organ Sharing (UNOS) Web site featuring statistics, resources for recipients of all organs and information about how to obtain a transplant in the United States.



“People would stare and I’m sure they were making their own conclusions about my health. I was extremely thin and I often heard people say things about girls with anorexia. If they only knew!”

— Kelly Helms, lung recipient



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