



**THE CENTER FOR
ETHICAL SOLUTIONS**
INNOVATIVE APPROACHES TO HEALTHCARE POLICY

QUICK FACTS ABOUT KIDNEY DISEASE AND THE ORGAN SHORTAGE

by

Sigrid Fry-Revere

(Last Updated April 2011 by Louise Flavahan)

The Center for Ethical Solutions is a non-partisan, non-profit, 501(c)(3), tax-exempt charity dedicated to educating the public on patient-care issues in medicine. The Center's financial statement (990EZ IRS annual tax filing) is available from the Center or upon written request from the Commonwealth of Virginia Office of Consumer Affairs.

TABLE OF CONTENTS

The Problem	3
What Kidneys Do and Why They are so Important	4
What Kidney Disease Does to a Person’s Body	4
Who is at Risk for Kidney Disease	5
What Causes Kidney Disease	6
How to Prevent Kidney Disease	7
How Do We Help People Who Already Have Kidney Disease	7
Why Transplants are so Much Better than Dialysis	7
Why Current Efforts to Solve the Organ Shortage Aren’t Enough	9
What are the Risks of Live Kidney Donation	10
What Can be Done to Encourage Live Kidney Donations	10
How You Can be Part of the Solution	12
Specific Ways You Can Help the Center	12

The Center for Ethical Solutions is a non-partisan, non-profit, 501(c)(3), tax-exempt charity dedicated to educating the public on patient-care issues in medicine. The Center’s financial statement (990EZ IRS annual tax filing) is available from the Center or upon written request from the Commonwealth of Virginia Office of Consumer Affairs.

The Problem

- The U.S. Centers for Disease Control and Prevention (CDC) has determined that kidney disease is the ninth leading cause of death in the United States. “In addition to reducing lifespan, [chronic kidney disease] substantially reduces quality of life, and yet is often not recognized as a serious health problem in the United States.” (CDC website, www.cdc.gov.)
- An estimated 26 million adults, or one in nine Americans, are estimated to have chronic kidney disease, and another 20 million are estimated as being at risk of developing the disease. (CDC, citing Journal of the American Medical Association, www.cdc.gov.)
- Over 10 percent of the population over the age of 20 has kidney disease. (CDC, www.cdc.gov.)
- There are 485,000 people in the United States with end-stage renal disease, that is, kidney disease so severe that their kidneys have failed and dialysis or a transplant are the only way to keep them alive. (National Kidney Foundation (NKF), www.kidney.org.)
- Over 88,000* or roughly 79.7 percent of people in the United States waiting for organs, need kidneys. (U.S. Department of Health and Human Services (HHS), <http://optn.transplant.hrsa.gov/data>. *As of April 5th, 2011.)
- The average wait in the United States for a kidney transplant is almost five years, but it can be shorter in some regions of the country or as long as ten years in others. (HHS, Organ Procurement and Transplantation Network, <http://optn.transplant.hrsa.gov/>.)
- Long wait times on dialysis are associated with poor transplant outcomes. (McGraw Hill Medical Text: Living Donor Organ Transplantation, 2008.)
- Approximately 15 people die daily waiting for a kidney that never comes. (HHS, Organ Procurement and Transplantation Network, <http://optn.transplant.hrsa.gov/>.)
- One person waiting for a kidney transplant dies every 90 minutes. (www.giftoflivingdonation.org.)
- The number of kidneys available for transplantation has plateaued despite continued efforts to increase donations and the efficiency of procurement and transplantation processes. (“Organ Donation and Utilization in the United States: 1998-2007,” Tuttle-Newhall et al., American Journal of Transplantation, 2009.)

The Center for Ethical Solutions is a non-partisan, non-profit, 501(c)(3), tax-exempt charity dedicated to educating the public on patient-care issues in medicine. The Center’s financial statement (990EZ IRS annual tax filing) is available from the Center or upon written request from the Commonwealth of Virginia Office of Consumer Affairs.

- By 2030 the number of people needing either dialysis or a transplant is expected to reach 2 million. (CDC, citing Preventing Chronic Disease, www.cdc.gov; also see www.nkdep.nih.gov.)
- In 2008, \$26.8 billion was spent by Medicare on people suffering from End Stage Renal Disease— this group represents only 1.3 percent of Medicare beneficiaries, but 5.9% of the Medicare budget was spent on their needs. (U.S. Renal Data System, www.usrds.org.)

What Kidneys Do and Why They Are So Important

- Kidneys filter almost 200 quarts of blood every day and make approximately two quarts of urine; through which excess chemicals, drugs, toxins, minerals, and other impurities are eliminated from the body. (NKF, www.kidney.org.)
- Kidneys release hormones that regulate blood pressure and make red blood cells. (NKF, www.kidney.org.)
- Kidneys promote strong bones by producing an active form of vitamin D and helping to metabolize calcium. (NKF, www.kidney.org.)
- Kidneys regulate water retention and the amount of sodium, potassium, and phosphorus in the blood. (NKF, www.kidney.org.)
- Kidneys regulate the acidity of the blood. (NKF, www.kidney.org.)

What Kidney Disease Does to a Person's Body?

- Kidney disease causes wastes to build up in the blood stream making the person feel sick and weak. A person may become tired, have trouble concentrating, have a poor appetite, trouble sleeping, muscle cramps at night, dry skin, itchy skin, puffiness around the eyes, frequent urination — especially at night —, and swollen feet and ankles. (NKF, www.kidney.org.)
- Kidney disease causes urea, nitrogen, and creatinine to build up in a person's blood, while proteins and albumin, that are supposed to remain in the blood, are accidentally spilled into the urine. (NKF, www.kidney.org.)

The Center for Ethical Solutions is a non-partisan, non-profit, 501(c)(3), tax-exempt charity dedicated to educating the public on patient-care issues in medicine. The Center's financial statement (990EZ IRS annual tax filing) is available from the Center or upon written request from the Commonwealth of Virginia Office of Consumer Affairs.

- A person with kidney disease may develop complications like high blood pressure, anemia, weak bones, poor nutritional health, and nerve damage. (NKF, www.kidney.org.)
- A person with kidney disease is at an increased risk of heart and blood vessel disease. Heart and blood vessel disease can lead to heart attacks and strokes. (NKF, www.kidney.org.)
- People with chronic kidney disease have 10 to 30 times the rate of cardiovascular disease than people without kidney disease. (CDC, citing *Preventing Chronic Disease*, www.cdc.gov. Also see asn-online.org.)
- As the disease progresses, kidneys fail, requiring either dialysis or a kidney transplant to keep the person alive. (NKF, www.kidney.org.)

Who is at Risk for Kidney Disease?

- Anyone at any age can get kidney disease. (NKF, www.kidney.org.)
- High-risk ethnic groups include African Americans, Native Americans, Hispanics, and Asians and Pacific Islanders. (NKF, www.kidney.org; CDC, www.cdc.gov.)
- Obese people are at risk of kidney disease. (CDC, www.cdc.gov.)
- People who are sixty years of age or older are the age group at highest risk of developing chronic kidney disease. (CDC, www.cdc.gov.)
- Approximately one-third of people with diabetes will develop chronic kidney disease. Forty-five percent of people who start treatment for kidney failure each year have developed kidney failure due to diabetes. (NKF, www.kidney.org.)
- Almost 26 million Americans (8.3% of the population) have diabetes; another 79 million are estimated to be pre-diabetic. (American Diabetes Association (ADA), www.diabetes.org.)
- About 30 percent of people with Type 1 diabetes (juvenile onset), and 10 to 40 percent of those with Type 2 (adult onset), eventually suffer from kidney failure. (NKF, www.kidney.org.)

The Center for Ethical Solutions is a non-partisan, non-profit, 501(c)(3), tax-exempt charity dedicated to educating the public on patient-care issues in medicine. The Center's financial statement (990EZ IRS annual tax filing) is available from the Center or upon written request from the Commonwealth of Virginia Office of Consumer Affairs.

- The usual span of time between the onset of diabetic kidney injury and kidney failure is five to seven years. If a person's kidneys fail, only dialysis or a transplant can keep that person alive. (NKF, www.kidney.org.)

What Causes Kidney Disease?

- Two thirds of all kidney disease is caused by diabetes or high blood pressure (also called hypertension). (NKF, www.kidney.org.)
- Kidney disease is also caused by glomerulonephritis, a disease that causes inflammation and damage to the kidneys' filtering system. Glomerulonephritis can happen suddenly, such as after a strep throat infection. (NKF, www.kidney.org.)
- Many types of kidney diseases are inherited. For example, polycystic kidney disease is an inherited disease that causes large cysts to form in the kidneys that damage surrounding tissue, and Fabry Disease causes a fatty substance called GL-3 to build up and do damage to various organs including the kidneys. (NKF, www.kidney.org.)
- Congenital malformations (ones which occur while a baby develops in the womb) can cause kidney disease. (NKF, www.kidney.org.)
- Lupus and other immune system diseases can cause kidney disease. (NKF, www.kidney.org.)
- Obstructions caused by kidney stones or an enlarged prostate can cause kidney disease. (NKF, www.kidney.org.)
- Kidney disease can also be caused by the overuse of analgesics, or pain-relieving medicines, especially aspirin, acetaminophen (Tylenol), and non-steroidal drugs like ibuprofen, ketoprofen, and naproxen (Aleve). Taking too many of these drugs can cause irreparable damage to the kidneys. (NKF, www.kidney.org.)
- Physical injury to the kidneys can cause kidney disease. (NKF, www.kidney.org.)
- Repeated urinary infections can cause kidney disease. (NKF, www.kidney.org.)

The Center for Ethical Solutions is a non-partisan, non-profit, 501(c)(3), tax-exempt charity dedicated to educating the public on patient-care issues in medicine. The Center's financial statement (990EZ IRS annual tax filing) is available from the Center or upon written request from the Commonwealth of Virginia Office of Consumer Affairs.

- Kidney disease can also be caused by tumors that originate or spread to the kidneys. (HHS, <http://optn.transplant.hrsa.gov/>.)

How to Prevent Kidney Disease

- In most cases a healthier life-style can help prevent or slow the onset of chronic kidney disease. For example, weight loss and exercise have been shown to prevent or delay the onset of Type 2 diabetes (the number one cause of kidney failure). (CDC, www.cdc.gov.)
- Early diagnosis and treatment can prevent or slow progression of the disease in some cases. For example, controlling high blood pressure in the early stages of chronic kidney disease can prevent progression towards kidney failure. (CDC, www.cdc.gov.)

How Do We Help People Who Already Have Kidney Disease?

- In most cases early detection, compliance with treatment, and a healthier life-style will help slow, and sometimes prevent, the progression towards kidney failure. (NKF, www.kidney.org.)
- Continue research on how to cure the underlying illnesses that lead to kidney disease and kidney failure. (CDC, www.cdc.gov.)
- Provide people with the best treatment options available should their kidneys fail. (CDC, www.cdc.gov.)

Why Transplants Are So Much Better than Dialysis

- “Kidney transplantation remains the preferred therapeutic option for patients with end-stage renal disease (ESRD), since survival and health-related quality of life are better after kidney transplantation than after dialysis therapy.” ([New England Journal of Medicine](#), 2009.)

The Center for Ethical Solutions is a non-partisan, non-profit, 501(c)(3), tax-exempt charity dedicated to educating the public on patient-care issues in medicine. The Center’s financial statement (990EZ IRS annual tax filing) is available from the Center or upon written request from the Commonwealth of Virginia Office of Consumer Affairs.

- A dialysis machine is an artificial kidney. It cleans the blood of certain toxins just as kidneys do, but even the most effective form of dialysis is only a stop-gap, keeping a person alive, but not healthy. A normal kidney filters 120 ml of waste per minute from the blood, but four hours of dialysis, three times a week, only filters about 10 to 15 ml of toxins per minute from the blood. (Handbook of Dialysis, 2006.)
- Because dialysis accelerates the progression of cardiovascular disease, time spent on dialysis is directly related to a higher risk of heart attack and poorer transplant results. (McGraw Hill Medical Text: Living Donor Organ Transplantation, 2008.)
- Kidney disease patients who receive transplants die at half the rate of those on dialysis waiting for a transplant. In 2010 over 4,700 people died on dialysis waiting for a kidney that never came. (HHS, Organ Procurement and Transplantation Network, <http://optn.transplant.hrsa.gov/latestData/rptData.asp>.)
- Dialysis patients, on average, spend more than twice the number of days in the hospital each year than transplant patients — 13.1 days a year for dialysis patients, only 5.3 days a year for transplant patients. (United States Renal Data System, www.usrds.org.)
- “As little as 6 to 12 months of pre-transplant dialysis was associated with 37% increase in long-term graft loss [transplant failure] compared to preemptive transplant.” (McGraw Hill Medical Text: Living Donor Organ Transplantation, 2008.)
- Most transplant patients resume their normal lives. (What constitutes normal, depends in part on how long they were on dialysis before getting their transplant). (McGraw Hill Medical Text: Living Donor Organ Transplantation, 2008.)
- Dialysis patients spend anywhere from 12 to 50 hours a week hooked up to a dialysis machine, depending on the type of dialysis they are using. (McGraw Hill Medical Text: Living Donor Organ Transplantation, 2008.)
- Dialysis patients end up too weak to do many of their normal daily activities — traveling becomes tedious, intimate relationships fall apart, and they suffer uncomfortably of thirst, fluid retention, and the dietary restrictions they must follow. Many patients, at least at first, experience, headaches, cramps and stomach upset. Only a little more than one tenth of people on dialysis work either full-time or part-time. (NKF, www.kidney.org; McGraw Hill Medical Text: Living Donor Organ Transplantation, 2008.)

The Center for Ethical Solutions is a non-partisan, non-profit, 501(c)(3), tax-exempt charity dedicated to educating the public on patient-care issues in medicine. The Center’s financial statement (990EZ IRS annual tax filing) is available from the Center or upon written request from the Commonwealth of Virginia Office of Consumer Affairs.

Why Current Efforts to Solve the Organ Shortage Aren't Enough

- Solutions such as those that help prevent or stave off kidney failure should be pursued, but efforts should also be made to help the over 88,000 Americans on the organ waiting list for whom preventative measures are too late. (UNOS, www.unos.org.)
- Improving the efficiency of the existing organ procurement system will make a difference but not enough to solve the kidney shortage. There has been a kidney shortage since the 1970s and one of the goals of the transplant community and the government institutions that support them has always been to try to assure an adequate supply of organs for transplantation, but despite continued efforts and successes at improving system efficiency, the shortage continues to worsen. (“Organ Donation and Utilization in the United States: 1998-2007,” Tuttle-Newhall et al., [American Journal of Transplantation](#), 2009.)
- Roughly 2 million Americans die every year, but most are too old, too sick, or dead too long before they reach the hospital to allow their organs to be used. Only 10,500 to 13,000 Americans die under conditions that allow their organs to be used for transplantation. Even if we assume the higher number (remember everyone has two kidneys) that would make only 26,000 kidneys available for transplantation. Since over 60% of Americans already agree to donate their organs, the 40% increase created by having everyone donate would really only result in a 9,500 increase in the number of kidneys available for transplant – a number that could be improved slightly by improving organ retrieval and storage techniques, but not enough to provide kidneys for even a third of the over 88,000 currently waiting for a kidney. (HHS, Health Resources and Services Administration, www.hrsa.gov; [New England Journal of Medicine](#), 2009.)
- While it is important to pursue long-term solutions for reducing the number of people who suffer kidney failure, the only immediate way to help those currently in need of a kidney is to increase the number of people willing to donate a kidney while they are alive. (McGraw Hill Medical Text: [Living Donor Organ Transplantation](#), 2008.)

The Center for Ethical Solutions is a non-partisan, non-profit, 501(c)(3), tax-exempt charity dedicated to educating the public on patient-care issues in medicine. The Center's financial statement (990EZ IRS annual tax filing) is available from the Center or upon written request from the Commonwealth of Virginia Office of Consumer Affairs.

What Are the Risks of Live Kidney Donation?

- Normally people are born with two kidneys. Extensive long-term studies indicate that people who have donated one of their two kidneys are at no more risk of kidney disease than people with two kidneys, nor is there any indication that they are at any greater risk for other health problems. (New England Journal of Medicine, 2009.)
- In the last twenty years, there have been over 100,000 living kidney transplants in the United States, but no reports of deaths related to kidney donation with open surgery, but there have been some reported deaths related to the use of laparoscopic techniques. The risk of death for donors is commonly believed to be about 3 in 10,000 or .03%. (McGraw Hill Medical Text: Living Donor Organ Transplantation, 2008.)
- Almost all living kidney donations come from people who, after realizing that they can save or greatly improve the life of a friend or relative with minimal risk to themselves, agree to donate. But this pool of potential donors is limited because often relatives are at risk of kidney disease themselves and both friends and relatives are not always healthy enough to donate. (McGraw Hill Medical Text: Living Donor Organ Transplantation, 2008.)
- To date, of the 232,684 kidney transplants completed in the United States since January 1988, 45.3 percent were from live donors (54.7 percent were from deceased donors)*, but fewer than half a percent of living donations were from strangers who didn't direct that their kidney be given to a particular person.** (*U.S. Department of Health and Human Services (HHS): <http://optn.transplant.hrsa.gov/latestData/rptData.asp>; **McGraw Hill Medical Text: Living Donor Organ Transplantation, 2008.)

What Can Be Done to Encourage Live Kidney Donations

- Education campaigns are necessary to inform the general public of the need for live kidney donations and to help overcome the myths and misconceptions people have about kidney donation.
- Pilot projects should be developed to test, on a regional basis, how best to create incentives for live kidney donation.

The Center for Ethical Solutions is a non-partisan, non-profit, 501(c)(3), tax-exempt charity dedicated to educating the public on patient-care issues in medicine. The Center's financial statement (990EZ IRS annual tax filing) is available from the Center or upon written request from the Commonwealth of Virginia Office of Consumer Affairs.

- To allow for pilot projects, Congress would have to authorize a temporary exception to the National Organ Transplant Act of 1984, because the Act currently prohibits anyone from getting “valuable consideration” for a kidney donation. That means no one can be given a valuable gift or payment of any kind in exchange for donating a kidney.
- Pilot projects that test the feasibility of compensating kidney donors could also determine if repeal of the prohibition against “valuable consideration” in the National Organ Transplant Act could help cut Medicare costs. Estimates are that Medicare could save anywhere from \$58,600* to \$94,000** per end stage renal disease patient. (*based on data from “Kidney Transplantation as Primary Therapy for ESRD: A National Kidney Foundation/Kidney Disease Outcomes Quality Initiative Conference,” Abecassis et al., 2008. **based on data from “Payment for Living Donor (Vendor) Kidneys: A Cost-Effective Analysis,” Matas & Schnitzler, 2003.)
- If all 88,000 people currently waiting for kidneys had received a transplant before going on dialysis, then Medicare would have saved approximately 5.2* to 8.3** billion dollars. (*extrapolated from data found in “Kidney Transplantation as Primary Therapy for ESRD: A National Kidney Foundation/Kidney Disease Outcomes Quality Initiative Conference,” Abecassis et al., 2008. **extrapolated from data found in “Payment for Living Donor (Vendor) Kidneys: A Cost-Effective Analysis,” Matas & Schnitzler, 2003.)
- In general, the longer a patient is on dialysis before transplantation, the less chance there is that the transplant will be successful and the more expensive that person’s care becomes. (“Kidney Transplantation as Primary Therapy for ESRD: A National Kidney Foundation/Kidney Disease Outcomes Quality Initiative Conference,” Abecassis et al., 2008.)
- There are other possible savings such as fewer repeat transplants or returns to dialysis because living donor transplants last anywhere from 10* to 50* percent longer on average than deceased kidney transplants. (*“Kidney Transplantation as Primary Therapy for ESRD: A National Kidney Foundation/Kidney Disease Outcomes Quality Initiative Conference,” Abecassis et al., 2008. ** McGraw Hill Medical Text: Living Donor Organ Transplantation, 2008.)
- The money the federal government saves by encouraging live organ donation could be used to establish incentive programs to encourage even more living donation, to provide education for the prevention and better management of kidney disease and to pay for research programs to come up with even more long-term solutions for how to prevent or cure kidney disease. (United States Renal Data System, www.usrds.org; McGraw Hill Medical Text: Living Donor Organ Transplantation, 2008.)

The Center for Ethical Solutions is a non-partisan, non-profit, 501(c)(3), tax-exempt charity dedicated to educating the public on patient-care issues in medicine. The Center’s financial statement (990EZ IRS annual tax filing) is available from the Center or upon written request from the Commonwealth of Virginia Office of Consumer Affairs.

How You Can Be Part of the Solution

- Your support for the Center for Ethical Solutions will save American lives and families. Help us rescue kidney disease patients from dialysis – help us get them the transplants that will allow them to return to normal lives.
- Help the Center raise Americans’ awareness of the severity of kidney disease and the organ shortage.
- Help the Center get Americans involved in helping solve the organ shortage. By 2030 the number of people needing either dialysis or a transplant is expected to reach 2 million. (CDC, citing Preventing Chronic Disease, www.cdc.gov; also see www.nkdep.nih.gov.)
- Public awareness and efforts on all fronts to deal with this crisis is the only way to slow and hopefully reverse this horrible trend.

Specific Ways You Can Help the Center

- Go to the Center’s website www.ethical-solutions.org and sign up as a volunteer.
- Or, make a financial contribution either on-line at our website (www.ethical-solutions.org.) or by sending a check to the Center for Ethical Solutions at 40357 Featherbed Lane, Lovettsville, VA 20180.

The Center for Ethical Solutions is a non-partisan, non-profit, 501(c)(3), tax-exempt charity dedicated to educating the public on patient-care issues in medicine. The Center’s financial statement (990EZ IRS annual tax filing) is available from the Center or upon written request from the Commonwealth of Virginia Office of Consumer Affairs.