

A man with curly hair and a mustache is shown in profile, facing left. Overlaid on his torso is a stylized anatomical diagram of the human respiratory and circulatory systems. The lungs are light blue, the heart is red, and the ribcage is represented by white dots. The background is dark with faint, colorful illustrations of a DNA helix, a jet airplane, and a highway sign with the number 20.

D tour

A FILM BY JIM GRANATO

DISCUSSION GUIDE

Pat Spurgeon has big dreams to make it as an indie rock musician. Just as his career is about to take off, he suffers an incredible setback when one of his kidneys begins to fail. Follow Pat on his emotional search for a living organ donor. But can he balance his health with a rock n' roll lifestyle?

FROM THE FILMMAKER

Pat Spurgeon and I have been good friends for more than a decade. We have worked on music and film projects together in the past, but nothing quite like what D TOUR has become.

Before this project started I knew a little about Pat's history. I knew he had a kidney transplant in 1994 and that it was a huge undertaking, especially for a 25-year-old college student and aspiring musician. A few years later I befriended Pat, and like many other organ recipients, he never really talked about it. Of course he carried on with his life, pursuing his goals like the rest of us. I never thought about how Pat would have to go through that again. And after the next transplant, he will have to go through it again... and again... for the rest of his life.

Pat found out in early 2006 that it was time to go down that road again. His 1994 transplanted kidney still had some function left, but it was inevitable that he needed a new one. This time he more than just talked about it; he felt the urge to share his story with others.

Pat called me just before starting dialysis and asked if I wanted to make "a video" about his experience through this elaborate process. The "hook" was that he was going to stay with Rogue Wave and continue touring and performing on dialysis! Pat wanted to show others who may be in the same predicament that you can go through this and live your life the way you want to. The original idea was to do a 10-minute piece that showed Pat going through dialysis, finding a donor and finally, a transplant. Almost three years later, I've ended up with about 80 hours of footage.

With the driving force of music behind him, Pat strives to share his exclusive outlook and experiences with an audience that may have not had the opportunity to think about the importance of organ donation, and what one person goes through in dealing with a rigid health care system. I certainly learned a lot along the way.

Jim Granato
Director & Producer



THE FILM

Pat Spurgeon is a drummer with Rogue Wave, an indie rock band in the San Francisco Bay area. He's passionate about his work and determined to not let anything stand in the way of his passion—not even a serious medical condition. Pat was born with just one kidney, which began deteriorating when he was in junior high school. At age twenty-five he had a transplant and that kidney also began to lose function. D TOUR chronicles Pat's experience coping with his condition, his fierce resolve to go on with a "normal" life, and the ultimately positive, but uncertain, outcome.

As a young man living in Bloomington, Indiana, Pat had very little income and no health insurance. When he became very ill with what he thought was flu, his mother brought him back to the Bay Area. Tests showed that his kidney was failing and Pat was put on dialysis. A year later he received a transplant, but after fifteen years that kidney also began to fail. At age 41, Pat was faced with the possibility of having his dream of touring with a rock band vanish. Dialysis again became part of his daily regimen, raising the question of whether he could—or should—continue touring. Pat insisted that with peritoneal dialysis, which, unlike hemodialysis, didn't require being hooked up to a machine, he could travel and carry on with normal activities. After much soul-searching and discussion, the band members made a business decision to keep Pat on, making adjustments in their travel arrangements, with a focus on Pat's health.

On tour with the band, Pat performed his dialysis twice a day. In the film he demonstrates how he prepares the equipment, explaining the importance of keeping the tube connections to the fluid bags absolutely sterile. With so much time devoted to "doing a 'D'", as he called dialysis, Pat began referring to the band's tour as the "D tour."

Dialysis does not cure kidney disease, and Pat was put on the national registry list to receive a kidney if and when one became available. With a twenty to one chance of receiving a kidney from a matching donor, the wait was expected to be six years. Finding a living donor could shorten the wait and Jill, whose husband Evan was one of the band members, became Pat's first potential donor. Based on her blood type, she was found to be a match. She underwent a battery of tests and set a date with Pat for the transplant operation, but a final x-ray revealed a stone in one of Jill's kidneys and the surgery was cancelled.

Another friend, Heather, offered her kidney, but she was not a perfect match. To help raise awareness of Pat's needs and to defray the costs of a transplant, Pat's bandmate Zach organized a benefit concert. A kidney had become available, however, through the registry and Pat received a kidney from a deceased donor. This time, unlike after his first transplant, Pat decided to contact the donor's family to thank them—a sensitive task, since it would serve to remind them of the misfortune that enabled him to receive a healthy organ.

In a tragic twist of fate, Evan was killed in a house fire and his kidneys and other organs were donated. Bittersweet scenes of Jill meeting with the recipient families underscore the recipients' gratitude and Jill's sense of closure after Evan's death.

The film ends with a meeting between Pat and the family of the young man whose kidney he received. Through tears and hugs, they form a bond based on feelings of peace and gratitude.



INDIVIDUALS FEATURED IN D TOUR

Pat Spurgeon – musician; drummer for Rogue Wave

Pat's bandmates

Zach Rogue

Gram LeBron

Evan Farrell

Daniel Handler – benefit concert emcee

Ben Gibbard – singer/songwriter, “Death Cab for Cutie”

Jane Daley – Pat's mom

Jenna Feldman – Pat's girlfriend

Jill Nielsen-Farrell – wife of Evan (band member); potential kidney donor

Heather Ramsay – potential kidney donor

Dr. Deborah Adey – UCSF transplant nephrologist

Dr. Glenn Chertow – Pat's dialysis doctor

Megan Shaughnessy – California Transplant Donor Network

Jennifer McGehee – California Transplant Donor Network

BACKGROUND INFORMATION

Definitions

Kidneys - two bean-shaped organs that filter wastes from the blood. The kidneys are located near the middle of the back, below the rib cage. They create urine, which is delivered to the bladder through tubes called ureters.

For graphics showing the internal anatomy of the kidney, see <http://en.wikipedia.org/wiki/Nephron> and <http://en.wikipedia.org/wiki/Glomerulus>.

Renal - refers to the kidneys; “renal function” and “kidney function” mean the same thing and are used interchangeably

Nephrology - the branch of medicine dealing with the study of the function and diseases of the kidney. A doctor who treats patients with kidney problems is a *nephrologist*.

Nephrons - tiny structures that are the working units of the kidneys. Each kidney is made up of about 1 million nephrons, which remove wastes and extra fluids from the blood.

Glomerulus – the main filtration unit of the nephron, consisting of a network of blood capillaries, where blood passing through the kidneys is actually filtered.

Glomerulonephritis, or **glomerular nephritis** – a renal disease characterized by inflammation of the *glomeruli*, or small blood vessels in the kidneys. This is also referred to as nephritis and nephrotic syndrome.

Acute *glomerulonephritis* develops suddenly, sometimes after a throat or

skin infection. Sometimes, you may get better on your own. Other times, your kidneys may stop working unless the right treatment is started quickly.

Chronic *glomerulonephritis* may develop without symptoms over several years and often leads to complete kidney failure.

Dialysis - the process of cleaning wastes from the blood artificially. The two major forms of dialysis are hemodialysis and peritoneal dialysis. In *hemodialysis*, an artificial kidney (hemodialyzer) is used to remove waste and extra chemicals and fluid from the blood via a blood vessel in the arm or leg. Access (entrance) is created by minor surgery to the arm or leg.

In *peritoneal dialysis*, the blood is cleaned inside the body using a plastic tube, or catheter, that is surgically inserted in the abdomen. During the treatment, the abdominal area (peritoneal cavity) is slowly filled with dialysate through the catheter. The blood stays in the arteries and veins that line the peritoneal cavity. Extra fluid and waste products are drawn out of the blood and into the dialysate.

What causes kidney failure?

The two most common causes of kidney disease are diabetes and high blood pressure.

Diabetes is a disease that keeps the body from properly using glucose, a form of sugar. If glucose stays in the blood instead of breaking down, it can act like a poison, damaging to the nephrons. Keeping blood glucose levels down with medication can delay or prevent diabetic kidney disease.

High blood pressure can damage the small blood vessels (glomeruli) in the kidneys, and the damaged vessels are then unable to filter wastes from the blood. Other causes include autoimmune diseases, infections and trauma. People with a family history of any kind of kidney problem are also at risk for kidney disease.

Dialysis and Transplant

When an individual's kidneys fail, three treatment options are available: hemodialysis, peritoneal dialysis and kidney transplantation. In some cases of acute kidney failure, dialysis may need to be only a short-term treatment. For end stage kidney failure, that is, the loss of about 85 to 90 percent of kidney function, dialysis becomes a life-long treatment unless an individual can receive a transplant.

A kidney transplant can provide a better quality of life because it allows greater freedom and often is associated with increased energy levels and a less restricted diet. Some people may not be able to receive a transplant because of other major physical or medical problems. For those who become transplant candidates, the wait for an available kidney is usually years long. There are currently more than 80,000 people on the waiting list for a kidney transplant.

The waiting list

In 1984, Congress passed the National Organ Transplant Act (NOTA), establishing the Organ Procurement and Transplantation Network (OPTN)



to regulate organ allocation and to increase the supply of organs available for transplantation. NOTA also made the selling of human organs a crime. OPTN is a public-private partnership that links all of the professionals involved in the donation and transplantation system, and it is administered by the United Network for Organ Sharing (UNOS). UNOS maintains an online database system, called UNet, for the collection, storage, analysis and publication of all OPTN data pertaining to the patient waiting list, organ matching, and transplants.

Shortening the wait

Donating a kidney. The only legal way to shorten the wait for a kidney transplant in the U.S. is to find a living donor. In addition to the donor programs sponsored or promoted by the National Kidney Foundation and other organizations, there are new approaches designed to increase the number of living donors.

Paired Donation. A friend or relative might be willing to donate a kidney to a loved one, but is not a good match. In paired donation one incompatible donor/recipient pair is matched to another pair in the same situation, so that the donor of the first pair gives to the recipient of the second, and vice versa. Several organizations now offer this option, and UNOS, which oversees the federal system of donation and transplantation, also has begun to develop a national system of paired donations.

Kidney Swaps. The idea is similar to paired donation, but instead of reciprocal donor/recipient partners, this system involves a chain of donors and recipients. A recipient's willing but incompatible donor gives a kidney to someone else with whom they are found to be compatible; that person's willing but incompatible donor then donates to someone else who is a good match, and so on. The donor chain, which starts with a Good Samaritan, or altruistic donor, theoretically can go on indefinitely.

The Internet. Web sites such as MatchingDonors.com help potential donors and recipients find each other, but using a service such as this is fraught with the same potential dangers and uncertainties as online dating and other online commerce. There is no oversight to guarantee the honest intentions of donors or the actual health of recipients, and many doctors are very wary of transplant arrangements made this way.

Other options. Other proposals to increase the amount of kidneys and other organs available for transplant include presumed consent and legalizing organ sales.

Presumed consent. This approach is followed by some European countries where the default position is that a deceased person's organs are available unless there are instructions to the contrary.

Sale of human organs. Proponents of this policy argue that developing a market for human organs is a rational and effective way to motivate

people to donate their organs, both while living and when deceased. Opposition to this idea is based primarily on ethical issues, particularly the potential exploitation of poor people.

Current research

Kidney research is taking place on several fronts:

Diet/nutrition - Recent studies show that intensive control of diabetes and high blood pressure can prevent or delay the onset of kidney disease.

Genetics - Researchers have located two genes that cause a type of disorder known as polycystic kidney disease (PKD). In order to develop PKD a person must have two defective copies of the *PKD1* gene. Researchers have found a gene in the roundworm that is identical to the *PKD1* gene. This new knowledge will be used in the search for effective therapies to prevent or treat PKD.

Transplantation - New drugs are being developed to help the body accept foreign tissue. New techniques are also being developed to induce a person's tolerance for foreign tissue before receiving a transplanted organ, which will eliminate or reduce the need for immunosuppressive drugs after surgery.

Source: <http://kidney.niddk.nih.gov/Kudiseases/pubs/yourkidneys>



THINKING MORE DEEPLY

1. What is your impression of Pat Spurgeon? What words would you use to describe him?
2. Do you think it was a good idea for Pat to not have a back-up plan after learning he would need dialysis? Do you agree with him that not having a back-up plan "gives you the drive to keep going?" Why or why not?
3. Did the band have a choice about keeping Pat as a member once they learned about his condition and need for daily dialysis? What issues were involved in their decision?
4. Why do you think the band made a business decision to let Pat join them on tour, when they could have made the opposite decision, also for business reasons?
5. What health insurance reforms are needed so that people like Pat can get the care they need?
6. What is the responsibility of the health care system in providing screening and other basic services that might detect kidney problems and other conditions before they become serious?
7. Do you think Jill's decision to donate her kidney to Pat was a responsible one, in light of the fact that she has two young children? Explain your reason.
8. What about Heather's decision to give Pat her kidney? Do you agree with her family that she was being irresponsible? Why do you think they felt this way?
9. In your opinion, should people be encouraged to donate kidneys or other organs? Why or why not? Why are some people opposed to doing this, even after death?
10. Has seeing this film changed your attitude about living organ donation? How about deceased organ donation? Explain.



SUGGESTIONS FOR ACTION

Together with other audience members, brainstorm actions that you might take as an individual and that people might do as a group. Here are some ideas to get you started:

1. Consider becoming an organ donor. In many states, you can sign up to be a donor through the Department of Motor Vehicles. The U.S. Department of Health and Human Services coordinates organ procurement and allocation activities through its Health Resources and Services Administration (www.hrsa.gov). Donate Life America (<http://donatelife.net>) provides state-by-state information on how to become an organ, eye or tissue donor.
2. Volunteer your time with an organization devoted to helping people with kidney disease. Check with the American Diabetes Association (www.diabetes.org/support-the-cause/volunteer-with-us.jsp) to find out what events or programs in your area need volunteer support. Or join a Kidney Walk sponsored by the National Kidney Foundation; a listing of events is at www.kidney.org.
3. Organize an information fair that focuses on prevention of kidney disease. Work with the local medical community to provide speakers, brochures, and other information. In conjunction with the fair, reach out to local schools to provide workshops or information sessions on the importance of exercise and a healthy diet in preventing diabetes and high blood pressure, the two main causes of kidney disease.
4. If you are currently receiving medical care for a kidney problem or for a condition related to kidney disease, find out if you are a candidate for a clinical trial to test a new drug or procedure. By participating in a clinical trial, you can play a more active role in your own health care, gain access to new research treatments before they are widely available, and help others by contributing to medical research. For information about current studies, visit www.ClinicalTrials.gov.
5. Weigh in on the funding of health care in the U.S. Contact your representatives in Congress, write a letter to the editor, or start a blog about the issue.
6. Work with a local civic organization to sponsor a health care debate. Invite medical professionals, elected officials, business owners, insurance industry representatives, the insured and the uninsured to participate. Make an effort to include a wide range of voices, and invite local media to cover the event.
7. Consider volunteering for your local organ procurement organization. A list of organizations is available at www.aopo.org.

For additional outreach ideas, visit www.communitycinema.org. For local information, check the web site of your PBS station.

RESOURCES

www.roguewavemusic.com – Rogue Wave's web site contains information on the band's music and tours, a gallery of photos, videos and more.

General

www.kidney.org/atoz/atozItem.cfm?id=39 – Web site of the National Kidney Foundation; contains a Q & A about dialysis and a complete menu of information about kidney health.

www.nlm.nih.gov/medlineplus/dialysis.html – Medline Plus is the National Institute of Health's web site of medical information. This section contains information on dialysis, kidney health and clinical trials being conducted by the National Institute of Diabetes and Digestive and Kidney Diseases.

<http://kidney.niddk.nih.gov/kudiseases/pubs/transplant/#hope> – The National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC) is a service of NIH. This site explains the steps involved in kidney transplants, including donor information, and maintains a list of organizations providing patient support.

<http://kidney.niddk.nih.gov/Kudiseases/pubs/yourkidneys> – This section of the NKUDIC provides a clear explanation of the kidneys and how they work, why they fail and what treatments are available.

http://www.ucsfhealth.org/adult/medical_services/organ_transplants/kidney/index.html – The University of California, San Francisco (UCSF) Medical Center has performed more kidney transplants than any other institution in the world. The web site offers information on specialized transplant services, donor procedures and patient education.

www.kidney.org/news/newsroom/fs_new/25factsorgdon&trans.cfm – This fact sheet maintained by the National Kidney Foundation provides a variety of numerical information on organ donation and transplantation.

Organ donation

www.unos.org/data/about/viewDataReports.asp – The web site of the United Network for Organ Sharing (UNOS) lists a variety of data on organ transplants and waiting list numbers nationally, by region and by state.

www.transplantliving.org/livingdonation – Transplant Living provides comprehensive information on being a live organ donor.

www.nepke.org/ – The New England Program for Kidney Exchange is a service that arranges kidney exchange, paired donations and kidney swaps.

www.paireddonation.org/ – Founded by Dr. Michael Rees, a transplant surgeon at University of Toledo Medical Center, the Alliance for Paired Donation has pioneered the system of matching incompatible donor-recipient pairs.



www.thenead.com – Never Ending Altruistic Donor offers the option of altruistic or Good Samaritan kidney donations, which can begin a cascading chain of donors.

www.organdonor.gov – The official U.S. Government site for organ and tissue donation.

www.donatelife.net – Formerly the Coalition on Donation, was founded by the transplant community in 1992 to educate the public about organ, eye and tissue donation.

Ethical issues

www.scu.edu/ethics/publications/iie/v1n2/kidneys.html – “Kidneys for Sale” by Claire Andre and Manuel Velasquez is a brief article from the Markkula Center for Applied Ethics at Santa Clara University that lays out the pros and cons of developing a market for human organs.

www.cato.org/pub_display.php?pub_id=8780 – This Cato Institute policy paper advocates the regulated sale of organs from living donors.

Health care reform

www.commonwealthfund.org - The Commonwealth Fund is a private foundation that promotes a health care system with better access, improved quality, and greater efficiency, particularly for society's most vulnerable, including low-income people, the uninsured, minority Americans, young children, and elderly adults. The Fund supports research, publications, charts and healthcare score cards that can be explored on its web site.

www.cnn.com/2009/HEALTH/06/18/ep.health.reform.basics/ - In a Q & A format, this CNN web site presents the main issues in the current health care debate in the U.S.

D TOUR WILL AIR NATIONALLY ON THE EMMY AWARD-WINNING PBS SERIES *INDEPENDENT LENS* IN NOVEMBER 2009. CHECK LOCAL LISTINGS.

D TOUR was produced by Jim Granato. The Emmy Award-winning series *Independent Lens* is jointly curated by ITVS and PBS and is funded by the Corporation for Public Broadcasting (CPB) with additional funding provided by PBS and the National Endowment for the Arts.

ITVS COMMUNITY is the national community engagement program of the Independent Television Service. ITVS COMMUNITY works to leverage the unique and timely content of the Emmy Award-winning PBS series *Independent Lens* to build stronger connections among leading organizations, local communities and public television stations around key social issues and create more opportunities for civic engagement and positive social change. To find out more about ITVS COMMUNITY, visit www.pbs.org/independentlens/communitycinema.

