



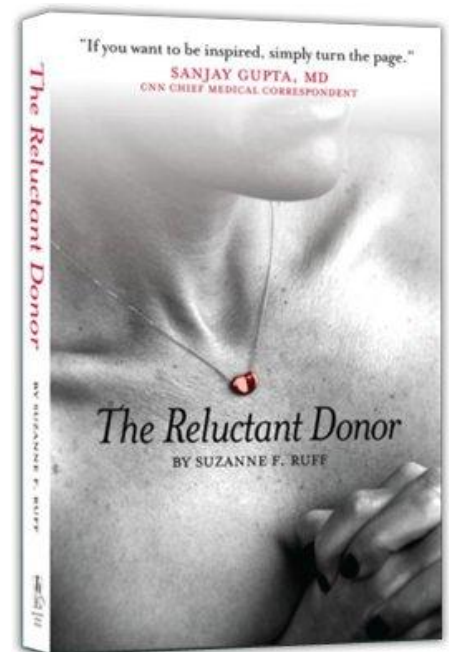
Suzanne Ruff, Author of The Reluctant Donor

She is On a Mission to Spread the Word About the Importance of Organ Donation

The last time you renewed your driver's license, did you check the box that says "Organ Donor?" Suzanne Ruff hopes the answer is yes. She has volunteered in many states to raise awareness about organ donation.

"My family would have pretty much been wiped off the face of the Earth if it weren't for the generosity of organ donors," she said. Her mother and two sisters, as well as several aunts and uncles and cousins have all needed kidney transplants to save their lives. Her family carries the gene for Polycystic Kidney Disease (PKD), a hereditary disease for which there is no cure.

Those who inherit PKD develop fluid-filled cysts on both kidneys. Over time, these cysts grow and multiply, causing the kidneys to increase sometimes dramatically in size. More than 60 percent of people with PKD will develop kidney failure and be forced to depend on dialysis or a transplant to live.

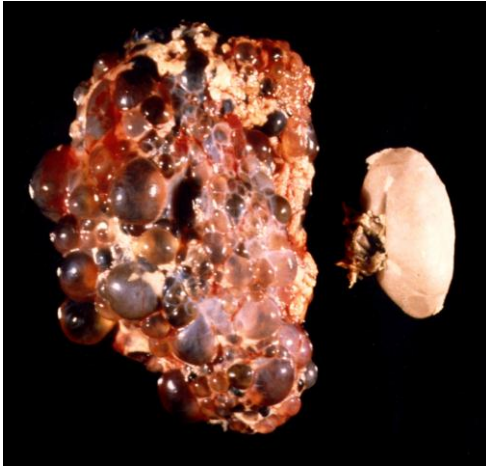


While Ruff's mother and sister, Janice, received their transplants from strangers, when her other sister got sick, something inside her told her she should be the donor. Ruff was the only one of the sisters that was not sick. "Right after learning that JoAnn had collapsed and was in the hospital, I called her up and offered to donate one of my kidneys," said Ruff, "even though JoAnn and I were not getting along at the time."

During the 10 months that lapsed between the day she made the offer and the day of the surgery, Ruff considered backing out several times. She kept her emotions in check through prayer and by journaling, eventually going through with the surgery on Oct. 19, 2004.

More than eight years later, both women are doing great, and celebrating the publication of Suzanne's book about their journey. Together they are spreading the word to end this disease. A portion of the proceeds from ***The Reluctant Donor*** (Beaver's Pond Press, \$14.95) goes towards kidney disease research.

"This story is not so much about me as it's about those amazing siblings of my mother, and my mother, who taught my sisters and I how to handle this disease. I want anyone that's diagnosed with PKD now to know what it was like, to see how much progress has been made and to have hope," said Ruff.



PKD Kidney vs. Normal Kidney

Ruff's sister, JoAnn, wants people to know how deeply touched she has been by the selfless act that saved her life. "In the morning as I take my pills I drink my water and say, 'This one is for Suzie, the name of my kidney, then I say this one is for me. Now go do your work because I promised Suzanne I would take good, good, good care of you because you're taking good care of me,'" she said.

The Reluctant Donor (Beaver's Pond Press, \$14.95) is also an eBook and is available for purchase through Amazon.com, www.thereluctantdonor.com, www.beaverspondbooks.com, Barnes and Noble and at select independent bookstores.



PKD Facts

- It is the most common genetic disease - more common than Down syndrome, cystic fibrosis, muscular dystrophy, sickle cell anemia, hemophilia and Huntington's disease - **combined**. Combined!
- Afflicts 650,000 Americans suffer from it.
- 12.5 million people worldwide have PKD.
- Of the more than 116,000 waiting for an organ transplant, over 90,000 are waiting for a kidney transplant.
- If one of your parents has PKD, you have a 50% chance of inheriting the disease.
- PKD equally affects men, women and children. Age, race or ethnic origin does not matter. It does not skip a generation.
- There are two hereditary forms of PKD - ADPKD (autosomal dominant) and ARPKD (autosomal recessive).



Praise for...The Reluctant Donor

"As soon as I started reading *The Reluctant Donor* I knew I had found a special book that would restore my faith in my belief about the goodness of everyday people. This book is a 60-year long epic journey of triumphs and tragedies of a beautiful and inspiring family. Even more than that, though, it is a story of unbridled love one sister had for another, and how that love was tested. If you want to be inspired, simply turn the page."

— **Sanjay Gupta, MD, *CNN Medical Correspondent***

"What would you do if you had to face the thing that terrified you the most? Suzanne Ruff found that you come out stronger when she donated a kidney to her sister. Ruff, who lives in Minneapolis, tells the story in this beautifully written, gut-wrenching memoir. Ruff's family was devastated by polycystic kidney disease (PKD) for generations. "The people I have loved most had kidneys that failed," she writes. "My mother had the disease. Her mother, my grandmother, had the disease. My two uncles. My two aunts. All are deceased, as are two of my cousins who had the disease ... now both of my sisters have the disease." Ruff did not inherit PKD and knew she had to donate a kidney to one sister, with whom she had had some arguments. But she didn't make her decision without anguish and fear. She wept, raged at her husband, prayed, whined. But she did it with the help of her family, including her patient husband, who kept saying, "Just for today you aren't going to donate a kidney" in the weeks leading up to the surgery. Ruff effortlessly weaves together her emotions and family background with just enough information about PKD to make clear its seriousness without overwhelming the reader with biology. Ruff is a member of the National Kidney Foundation's Living Donor Council Executive Committee, and her book is sure to make readers do some soul-searching about whether to be organ donors."

— **Mary Ann Grossman, *Pioneer Press newspaper review***

"*The Reluctant Donor* is the story of a ticking time bomb in one family's DNA, a generations-long battle with kidney disease. With heart and humor, Suzanne shares her family's trials and triumphs, and challenges us all to think deeply about what is most important in our lives. This wonderful book is a testament to the gift of organ donation and its power to transform the donor as well as the recipient."

— **Jeff Richert, *Volunteer Coordinator, LifeSource***

"Suzanne Ruff may have given one of her kidneys to her sister, but she's poured her heart and soul into this book. It's a compelling story of the struggle between fear and faith, with love casting the deciding vote."

— **John DeDakis, Author, *Fast Track***



Suzanne Ruff Biography

Suzanne Ruff who grew up in a large Irish Catholic family in Chicago., comes from a family that has been plagued by kidney disease for generations. In her lifetime, she has lost her mother, several aunts and uncles and cousins to Polycystic Kidney Disease (PKD), the most common of all life-threatening genetic diseases. Both of her sisters inherited the disease. She did not.

When her younger sister fell ill shortly after their mother's death in 2003, Ruff decided to do something about it. She had always been afraid of doctors and needles, but says with God's help she found the courage to save JoAnn's life by donating a kidney.

In the months leading up to the surgery, which took place on Oct. 19, 2004, Ruff spent a lot of time journaling, and just recently published a book based on her notes and memories. Her hope is that ***The Reluctant Donor*** (Beaver's Pond Press, April 2010, \$14.95) will find its way into the hands of others who are facing a difficult life-and-death decision, and help them find the courage they need to get through it.



Her family has been active with the Polycystic Kidney Disease Foundation since its founding days in 1982. The PKD Foundation is a source of information for newly diagnosed patients with PKD and helps fund research to find a cure.

Suzanne Ruff is a member of the National Kidney Foundation's Living Donor Council Executive Committee. She is currently working as a freelance writer for Charlotte Observer. She has written stories for the , *Chicken Soup for the Soul* books. : *Grieving & Recovery* and *Say Hello to a Better Body*.

Ruff is a sought after speaker on organ donation. She has addressed many hospitals, organizations, associations, book clubs and libraries across the country, including Regions Hospital & LifeSource, St. Paul, MN; Transplant Grand Rounds University Transplant Center at University of Texas Durham; UPMC Tissue Typing Lab, Pittsburgh, PA,; Renal Round Table, American Nephrology Nurses Assn. (ANNA); The Renal Network, Inc., and Christ Hospital, Oak Lawn, IL.

Suzanne and her sister were featured in a multi-part story on the front of the Chicago paper(it was a four part series on one newspaper)at the conclusion of the kidney transplant.. She has since made appearances on Fox News Minneapolis MN , *Good Morning, San Antonio* and *NBC Chicago*.

After living in eight major cities during their marriage, Suzanne and her husband, Bill, now live in Mooresville, N.C. They have two daughters, Rachel and Colette. Her North Carolina license plate reads K-I-D-N-Y D-N-R.

Her website is www.thereluctantdonor.com. To see video go to: http://www.nbcchicago.com/on-air/as-seen-on/What_Do_You_Know_About_Polycystic_Kidney_Disease_Chicago-130522858.html



On-Air Introduction

Suzanne Ruff is a living kidney donor, but she is more than that-- she is a storyteller. She says it's because she's Irish! The author of the inspiring, poignant, funny and powerful award-winning book *The Reluctant Donor*, Suzanne is also a free lance writer for *The Charlotte Observer* and has been published in the *Chicken Soup for the Soul* books – *Grieving and Recovery* and also the *Chicken Soup for the Soul* Harvard Medical School series: *Say Hello to a Better Body*.

Suzanne serves on the Executive Committee of the Living Donor Council of the National Kidney Foundation and volunteers with the PKD Foundation. She works tirelessly to tell others how organ donation has saved her family. There have been six kidney transplants to six different people in her family because of a genetic disease. Suzanne was the only one in her family not to inherit the disease. She was named after her grandmother – who died of kidney failure before Suzanne was born. Sadly, that grandmother died in the 1940's while a doctor in the Netherlands was experimenting with the concept of dialysis.

Today, Suzanne is making a difference for many people beside her family, 19 of which have been afflicted with PKD. She is one of the nation's greatest advocates for organ transplant and she is a sought-after speaker across the country.



Questions for Suzanne Ruff

1. What is PKD and how prevalent is it?
2. The title is "The Reluctant Donor." Why were you reluctant?
3. I understand you're the only one in your immediate family who didn't inherit the disease. How does that make you feel?
4. How is your sister doing now?
5. Now that the book is out, what are you hoping it will accomplish?
6. How did the past and your big Irish Catholic family affect your decision to become a living donor?
7. Why do you think PKD is such a little known disease when it affects so many?
8. Has your life changed since you became a donor?
9. Has your health changed since you became a donor?
10. You mention that follow up care for the recipient is better than for the donor; what would you like to see for the donors?
11. How can the medical field learn about living organ donors?
12. What advice do you have for living donors?
13. What advice do you have for each living donor's doctor?
14. How much hope do you have that a cure for PKD will be found?
15. Why do you think there should be studies done on living donors?
16. Who would fund those studies?
17. Do you think living donation will continue?
18. Why do you think it is important for future generations to know about today's living donation?
19. Why do you think organ donation is the great "unifier?"
20. What are some of the reasons people do not become organ donors?
21. What do you believe is the greatest gift you can give a person?



She's on a Mission to Find a Cure for the Disease that Has Devastated Her Family

By Rachel M. Anderson, Freelance Writer

There are a lot of causes worth fighting for, but none as important to Suzanne Ruff of Mooresville, N.C., than finding a cure for PKD. "I have lost eight close family members, including my mother, to Polycystic Kidney Disease," she says.

PKD, the most common of all life-threatening genetic diseases, is a condition in which fluid-filled cysts develop on both kidneys. Over time, the cysts grow and multiply, causing the kidneys to increase dramatically in size.

According to statistics posted on the PKD Foundation's website (www.pkdcure.org), more than 60 percent of people with PKD will develop kidney failure and be forced to depend on dialysis or a transplant to survive. An estimated 600,000 Americans and 12.5 million newborns, children and adults worldwide are currently battling the disease. PKD affects more people than Down syndrome, cystic fibrosis, muscular dystrophy, sickle cell anemia and Huntington's disease combined. There is no treatment. There is no cure.

Ruff says her earliest memory of PKD is from when she was about 5-years-old. "I remember my mother being sad when she told me that my grandmother had died of kidney disease and I was named after her," she says.

There wasn't much talk about the disease again until she was about 12 and her mother's beloved sister, the nun Sister Mike, was diagnosed. Then when she was 19, her mother's brother, Jack, fell ill. "It was at that point that we learned the disease was hereditary, and I remember being terrified," she says. "I was engaged and didn't know if my husband would marry me, didn't know if I should have children, didn't know if I was going to have a short life."

Shortly after learning the disease was hereditary, Ruff, her mother and two sisters were all tested. She says her parents lied when they got the test results back and told their daughters no one in their immediate family had the disease, when in fact, their mother and her two sisters did.

"The lie," as Ruff refers to it became apparent a few years later when her mother collapsed and entered the hospital. She spent the next 10-years on dialysis before getting a kidney transplant. The same fate awaited her two sisters – first Janice and then JoAnn.

Ruff's mother and sister, Janice, had received their kidney transplants from strangers who had died, but by the time Jo Ann got sick, living donation had become more prevalent. "After JoAnn collapsed with PKD my daughter, Colette, who was 25-years-old at the time, quietly said to me that maybe she could give JoAnn a kidney. I thought, no! I should be the one to step up before my daughter. She has her whole life ahead of her."

Also weighing heavily on her decision, the knowledge that in 2003 there was a five to six year wait for JoAnn if she put her name on the waiting list. “Our mother was on dialysis for ten years and I couldn’t bear JoAnn going through that if I was a match, despite my fears,” says Ruff. But shortly after making the offer, she started having reservations. “I was scared to death of being operated on,” she remembers.

Journaling was one of the key ways Ruff was able to work through the terror she felt about being a living donor. Soon, page after page of thoughts and memories filled her notebook. Ruff originally thought her journal would be something she’d only share with her immediate family. However, after showing it to her daughter, Rachel, who was working as a producer for CNN’s Dr. Sanjay Gupta, at the time, that changed.

“She told me the story was really good and I should publish it. My husband told me the same thing and around that same time, my father came across a collection of letters I had written to my mom when she was alive,” says Ruff. In one of the letters, she had said to her mom, “I wish I had the courage you do.”

“It had been 20 years almost to the day of our scheduled transplant that I wrote ‘I wish I had the courage you do.’ I considered it a God Wink,” says Ruff, who explains a God Wink as a wonder, a coincidence, a miracle.

“I felt like I was being called to give the kidney,” she says. “But when I got that sign from above from my mother, it was like, Wow! This is really going to be an amazing legacy of my mother and her amazing siblings. I have to get this book published.”

The Reluctant Donor, (Beaver’s Pond Press, April 2010, \$14.95) was published just in time for Donate Life Month. Established in 2003, it’s a celebration of the tremendous generosity of those who have saved lives by becoming organ, tissue, marrow and blood donors. It’s also a time to encourage more Americans to follow their fine example.

“One of the best things about Suzanne’s book is it lets people suffering from PKD know they are not alone. There are options for dealing with it. They can be proactive researching and looking into what’s out there.

“I think ***The Reluctant Donor*** will do wonders for people just diagnosed, letting them know there is an entire community dealing with it and they are not alone,” says Dave Kappas, former central regional chapter manager for the PKD Foundation. The organization’s mission is to promote programs of research, advocacy, education, support and awareness in order to discover treatments and a hopefully a cure for Polycystic Kidney Disease.

“I hope Suzanne’s book will help people think about becoming a living donor by showing them that their lives will be the same as they were before, only enriched by the experience. I also hope it will bring awareness to this disease that my family has lived with for so long,” says Ruff’s sister, JoAnnVillanueva, who now lives in Charlotte, N.C.

Copies of ***The Reluctant Donor*** are available for purchase at Barnes and Noble Bookstores, Amazon.com, the publisher’s website: www.beaverspondbooks.com and via the author’s website: www.TheReluctantDonor.com. The title is also available as an ebook. A portion of the proceeds will fund kidney disease research.

About Rachel M. Anderson

Rachel is a freelance writer who lives in Minnetonka, Minn. She has written professionally for the Minneapolis Star Tribune, Minnesota Christian Journal and Tampa Tribune newspapers.



Promotion

Book

The Reluctant Donor (Beaver's Pond Press, \$14.95)

- Available for purchase through Amazon.com, www.thereluctantdonor.com, www.beaverspondbooks.com, Barnes and Noble and at select independent bookstores.
 - And as an ebook
-

Organ Donation

- ***Kidney, Organ Donation and PKD Resources***
 - Living Donation
 - LifeSource—www.life-source.org
 - United Network for Organ Sharing (UNOS) —www.UNOS.org
 - National Kidney Foundation—www.kidney.org
 - Polycystic Kidney Disease Foundation—www.pkdcure.org
 - <http://www.kidney.org/transplantation/livingdonors/index.cfm>
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Polycystic Kidney Disease Foundation

- PKD Foundation's website (www.pkdcure.org)
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Speaking

- To secure Suzanne Ruff as a speaker for your event, contact her at ruffsuzanne@gmail.com