The Kidney Sellers

A Journey of Discovery in Iran

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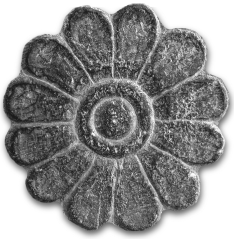
For Steve and Maurie
I wish they had lived to see the book they helped inspire.

For Ian
If love could have saved you, you would have lived forever.



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Solving the Organ Shortage, project
www.ethical-solution.org/projects/sos

True intellectuals have the fortitude to change their minds when faced with new evidence.

—Penn Jillette

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A Few Words about This Book

This book is nonfiction, based on true accounts and authentic research. From November 14, 2008, to January 1, 2009, I traveled to six different Iranian cities to explore the market for human organs. I interviewed hundreds of people, including physicians, nurses, the administrators who run and operate transplant and hemodialysis ("dialysis"* for short) units, clergy, government officials, the staff of the non-governmental organizations (NGOs) that arrange paid transplant matches, and of course the kidney sellers and recipients themselves. I collected over 100 hours of filmed interviews and over 200 transplant stories, primarily from those who had sold their kidneys or were in the process of arranging such a sale. Later, in August 2011, Simin Golestani (an intern at the Center for Ethical Solutions, which I run) traveled to Tehran to visit family and to do follow-up telephone interviews with the kidney sellers and recipients I had interviewed.

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I could have written an academic monograph, but I was sure my material would interest more than just academics. I wanted readers to share in my journey of discovery and to experience the drama of the stories of the kidney sellers and recipients I'd met. To that end, I decided to write a nonfiction adventure with only a few vestiges of the original academic book I'd planned. I limited the number of footnotes to minimize interference with the flow of the narra-

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* There are basically two types of dialysis used to keep end-stage renal disease patients alive: hemodialysis which usually cannot be done at home and peritoneal dialysis which usually is done at home. Throughout this book I use the word "dialysis" to refer to both types of dialysis interchangeably.

tive but kept some detailed analysis, references, and further-reading resources in a Notes section at the end of the book.

Another issue I faced when deciding on the format of this book was how to accurately portray the very personal stories of the people I'd met without violating their privacy or putting their safety at risk. What would happen if the Iranian government took issue with my book? Almost every kidney seller and recipient I interviewed signed a consent form allowing me to use their personal information, including their image, in the documentary film I was making or in a book should I decide to write one. Nonetheless, I want to take at least one important precaution to protect them while still staying true to their personal narratives—I've changed the names of all the donors and recipients described in this book, as well as the names of any medical or administrative personnel who hesitated about being recorded. All other details described are accurate and based on taped interviews or Dr. Bastani's and my notes. I have not used fictitious names for other Iranians or the Americans interviewed because they fully understood my project and participated willingly, if not enthusiastically, in talking to me about their lives.

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A less significant problem I faced writing this book is that I had to decide how to translate certain Farsi/Persian terms integral to understanding my experience in Iran. I have tried to use phonetic versions of Farsi pronunciations where obvious English translations weren't available in a language dictionary. For example, "institution" or "association" doesn't adequately communicate the distinct nature of the non-governmental non-profits that arrange kidney sales in Iran, so I used the phonetic transcription of the term commonly used in Iran for such organizations and italicized it—"*Anjoman.*"

One word in particular caused me difficulty because its Farsi transliterations have potentially confusing associations in English. The Farsi word for "bread" is phonetically spelled "noon" or "nun." I decided not to use either but instead went with the Indian word "naan." Most English speakers are familiar with Indian flatbread, and the word "naan" will conjure up a more accurate image of what Iranian bread is like than "noon" or "nun."

I had yet a different problem when it came to choosing aliases for some of my Iranian interviewees. I didn't want to simply give everyone a Persian name. Instead I gave each person a name that reflected the cultural origin and spelling of their given names. For example, you might see both "Muhammad" (the typical Arabic transliteration) and "Mohammad" (the typical Farsi transliteration) or both “Sara” (a Farsi or Arabic version of the Biblical name “Sarah”) and “Zahra” (a common Arabic name of different origin). You will also see Turkish and occasionally Western names and spellings of names. I understand that Iranian parents, like parents all over the world, don’t necessarily give their children names that reflect their heritage, but this way at least the aliases I’ve chosen reflect the same degree of name diversity that existed among my interviewees.

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Finally, the adventure I have to share is not only interesting because it took place in a far away country that Americans rarely visit, but also because the United States is struggling with a problem Iran seems to have solved.* This book provides both the data and the context for understanding the Iranian solution to its kidney shortage. I also provide valuable insights into the ethical complexities of living organ donation as understood by those who participate in Iran’s kidney market. I do not claim to know how to solve the U.S. organ shortage, but I do know that there are notable lessons to be learned from Iran’s more than 25 years of experience with legalized compensated kidney donation. I hope that sharing my discoveries will result in a better understanding of both the Iranian and U.S. systems of organ procurement. I also hope that this book can serve as a window into the lives of the remarkable people I met both in the United States and Iran. I could never have anticipated the things in store for me or the way they would move me.

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* Other countries such as Singapore and Saudi Arabia have more recently begun compensating living donors but, as yet, neither has succeeded in eliminating its kidney shortage.

Prologue: A Personal Journey

Haaj Khanoom, "one who has been on a pilgrimage." It was an expression of respect from a young man at the Vakil Bazaar in Shiraz, struggling to pass me with a wooden flatbed cart overflowing with cooking pots. He was right. I was on a pilgrimage—a pilgrimage not to Mecca or Jerusalem, but to Iran—in search of a solution to a serious medical ethics problem: How can we solve the U.S. organ shortage? How can we save the more than a hundred thousand Americans who need organs right now? Might Iran, of all places, hold clues to the solution?

In Iran scarcely a week, I was starting to feel comfortable—maybe a little too comfortable, given what would happen to me later that day at the Vakil Bazaar. But things hadn't started out that way. In the beginning, the thought of going to Iran seemed preposterous. An American woman doing research and filming without permits in one of the most repressive, anti-American regimes in the world? Although my fear of going to Iran was significant, my compulsion to find an answer to the organ shortage ran deeper. There was little anyone could do to dissuade me from traveling to find the truth about Iran. Were the rich exploiting the poor? Was the government forcing people to sell their kidneys? Were drug addicts selling their kidneys to support their habits, or worse, forcing relatives to do so? Were kidney sellers dying for lack of post-operative care? And were the desperately poor selling their kidneys only to find themselves in more debt than before?

In graduate school I studied the problem of organ allocation, but the topic isn't merely academic to me. Not long after completing my doctorate in philosophy (specializing in patient-care ethics), I experienced firsthand the fear of losing a loved one to kidney disease. My son Ian, at just 10 months old, was diagnosed with kidney cancer. Surgeons operated and removed his left kidney. They told me the functioning of his good kidney would need to be monitored closely and that Ian would probably need dialysis and a kidney transplant by the time he was a teenager. While my life has taken many turns since then—clinical ethics, food and drug law, health law, teaching, consulting, and writing on many different topics related to patient-care ethics—never has the intractable organ shortage been far from my mind.

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In 2007 I began studying the merits of compensated organ donation* for the Cato Institute, where I was the director of bioethics studies. I set out to explore certain searching questions: Does prohibiting compensated organ donation violate a donor's right to self-determination and self-ownership? Would paying donors beyond reimbursement for transplant-related expenses cause exploitation, offend human dignity, or degrade the medical profession? And how does one weigh such countervailing concerns? To help explore these questions, I organized a Cato forum where leading experts** debated compensated organ donation. At the event, which was held on February 21, 2008, I was astounded to learn that each speaker had strong opinions on Iran and its system of legalized kidney sales, but none had ever been there.

When I researched the issue further, I realized no Westerner had ever gone to see what organ procurement was like in Iran. Numerous articles and reports had been written about the Iranian system, including the one I had edited for Dr. Hippen, but no one had done a comprehensive firsthand examination of the Iranian system of compensated kidney donation. No one had interviewed actual or potential kidney sellers. Iranians had conducted some regional studies that involved donor and recipient interviews, but no national studies, and no studies had been done by Westerners.

I left my job at Cato because—among other reasons—the Institute's administration didn't want me to continue researching Iran's kidney market. I suspect this was because it was politically risky to suggest that Iran might be doing

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* See the Notes section at the end of this book for a discussion of the appropriateness of using "donation" terminology in situations where money is exchanged.

** The panel included four top authorities in the field: Dr. Francis Delmonico, professor of surgery at Harvard Medical School and former member of the board of trustees for the United Network for Organ Sharing (UNOS), a staunch critic of the Iranian system; Dr. Arthur Matas, professor of surgery and director of the renal transplant program at the University of Minnesota, known for his studies on altruistic donation and possible alternatives; Dr. Benjamin Hippen, clinical associate professor of transplant nephrology at the University of North Carolina at Chapel Hill School of Medicine, author of a recent paper on kidney selling in Iran; and Dr. Samuel Crowe, Ph.D., deputy director of The President's Council on Bioethics, known for his defense of professionalism in medicine.

something right—after all, President George W. Bush had called Iran a member of the Axis of Evil. I argued that I didn't know what I would find: For all I knew, Iran would be just as guilty of mishandling its organ shortage as it was of mishandling its relationship with some of its Middle East neighbors. But the Cato administration was adamant that it would hurt the Institute's reputation as a serious Washington player to even consider finding anything positive about Iran—regardless of the truth. Consequently, I created my own think tank, the Center for Ethical Solutions, and initiated the Solving the Organ Shortage (SOS) project. A team of scholars was formed to study the worldwide organ shortage. I wanted answers, and it looked more and more as if I would have to go to Iran to get them.

Dr. Delmonico, whom I'd met organizing the Cato event, mentioned that the next biannual Middle East Society for Organ Transplantation (MESOT) conference was scheduled to be held in Shiraz, Iran. I contacted MESOT organizers and was invited to join the conference as a speaker in November 2008. This left me little more than eight months to figure out how to get from attending a conference in Iran to researching the Iranian system of organ procurement.

I hardly knew where to begin, but like many things in life, a fortunate coincidence saved the day. My friend Alison Griffin, the daughter of the former head of NASA Michael D. Griffin, happened to remember an Iranian engineer who used to visit the house when she was a little girl. She contacted her father, who introduced me to Professor Assefi, who in turn passed on my note of inquiry about Iran to his physician daughter, Nassim. Before I knew it, I was getting emails from Iranian expats all over the United States and even Europe who were interested in hearing more about my research and eager to help arrange interviews and come along as translators.

Of those who contacted me, I decided Dr. Bahar Bastani would be the best choice to accompany me on my trip: Firstly, he was a nephrologist—a kidney specialist—who taught in the Department of Internal Medicine at St. Louis University. Secondly, he could set up a lecture tour of several major cities in Iran where he knew hospital staff would be interested in learning about recent developments in transplant medicine and perhaps even about transplant ethics in the United States. And best of all, he could arrange to have directors of the programs where we would speak cover our travel expenses from one city to the next. In exchange for our lectures, hospital administrators would also give us access to their transplant wards and clinics and would introduce us to the *Anjomans* (the non-profit organizations that arrange living donor matches—the "kidney brokers," so to speak). At all these locations we could interview actual kidney sellers, but the *Anjomans* had the added advantage of also providing us access to potential sellers who were at various pre-transplant stages of the donation process. Dr. Bastani's plan worked perfectly. Before we even left for the MESOT conference, he had us lined up to visit major university hospitals in six different cities, each for a week or more.

I returned from Iran with 211 firsthand accounts from kidney sellers, donors, recipients, and their families. Over a period of more than two years, American-Iranian volunteers (mostly U.S. college students) graciously helped translate over 100 hours of video that corresponded with my photos and Dr. Bastani's and my notes. After reviewing the material, I realized that there were no simple answers to what was going on in Iran or to solving the U.S. organ shortage. The truth lies in the stories of the people I met: the desperate, willing to help each other, but afraid because their lives, financial well-being, and health were at stake; and the courageous who set up a donor-compensation system in defiance of what the rest of the world was doing.

I learned that the Iranian system, unlike kidney markets in the rest of the world, has laws in place that protect the basic rights of compensated donors. For example, in Iran, kidney sellers are guaranteed at least a modicum of informed consent, and there are mechanisms in place to help ensure compensated donors are paid the money they are promised. As a result, selling a kidney in Iran is less risky and more socially acceptable, and there is a waiting list to donate, not a waiting list to receive a kidney as there is in other countries.

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This book tells the stories of the Iranians I met, along with my story of discovery in a land where the government can be hostile toward foreigners and almost everyone is leery of an American with a camera. I hope the pages that follow will help Americans overcome their preconceptions about the U.S. organ shortage and their misconceptions about what Iran has done to solve its kidney shortage. No debate over compensating kidney donors is complete without some insight into the stories of those who have bought and sold kidneys in the only country in the world where such transactions are legal. I have done my best to present an honest, unbiased account of the truth, unaffected by political or social agendas. If I have accomplished my goal, then this book should go a long way toward banishing the uninformed imaginings, both good and bad, over what caused the organ shortage in the United States and what solved it in Iran.