CHAPTER ONE

WHAT ARE WE TRYING TO DO HERE?

For as long as I can remember, I've wanted to be a doctor. When my exploits as a ten-year-old on the Little League baseball diamonds of the Midwest signaled that playing centerfield for the Yankees was not in my future, being a doctor seemed the next best thing. How cool to be able to fix those who were sick or injured. I signed up.

I was fortunate to study medicine at the Johns Hopkins School of Medicine. At Johns Hopkins, a cadre of world-class mentors relentlessly emphasized two things: the constant pursuit & mastery of medical knowledge and the continuous awareness of the responsibility of practicing medicine. This responsibility includes many components: ethics, honor, and integrity, but chief among these components is 'caring' for the patient. The patient must always be the primary focus of all our efforts. The patient is a human being with hopes and fears, dreams and hurts. The patient is a human being that deserves another human being on the other end of the doctor-patient relationship. Treatment protocols and algorithms alone will never be sufficient to satisfy the entirety of human needs and suffering.

At the same time I was learning to become a physician, I was also learning to become a patient. Diagnosed with Type I diabetes as a youth, I was introduced early to my role as a patient. I've been a patient longer than I've been a physician. Being a doctor and a patient simultaneously has been a profound and humbling experience. I learned that the exact words I was trained to use as a physician to give confidence and certainty to my patients often engendered only fear and uncertainty when delivered to me as the patient. The view is definitely different on each side of the relationship.

I've spent my life caring for patients. I coach and mentor people with kidney disease, particularly those considering transplantation. I've experienced kidney disease from both sides of the scalpel. I know the burden. I know the challenges. Just like you, I live with those challenges daily. Decades in the patient care system as both the healer

and the patient have impacted me mightily. The twin perspective is distinctive and worth sharing. That is why I write.

What will you get here? Two things: Education & Encouragement. The information herein is the distillate of a lifetime of facts, experiences, opinions, and faith. Now I will share it with you.

In all of medicine, education is critical to patient outcomes. The more that our physicians know, the better we patients will do. The more we patients know, the better we patients will do. Everyone knows that. That's why educational materials are everywhere. Experience has taught me this deluge of health information has some significant limitations. You may have already experienced these limitations yourself. In any event, the information presented here will be different. I have seen and experienced those educational materials that work and those which fall short. I pledge to give the information I wish I had had early on in my transplant journey. I will present it in the style I found most helpful to my patients and me.

What exactly does that mean? First, education must be delivered and consumed in digestible portions. You can't take a shower under Niagara Falls. Psychologists say most of us can only hold three or four things in our minds at once. No wonder we are easily overwhelmed by well-intended directives delivered by those who care for us. What overwhelms us can also discourage us. The goal is not to present everything. The goal is to present enough.

Education must be consistent. It's not helpful if advice for one aspect of our lives directly conflicts with advice on another. The goal here is to remain internally consistent. We'll resolve notable conflicts whenever they arise. Education requires a No- Internal-Conflict Zone.

Another huge issue in medical education is the 'standard of truth.' 'Truth' is a complicated topic. There are as many definitions for 'truth' as there are people. In just a moment, we will discuss 'truth' in detail. For the moment, let's just say that physicians generally require that data meet the highest standard of proof before passing it along to their patients. Accumulating sufficient data to meet that highest standard of proof can take a lot of time. Some of us don't have a lot of

time. Some of us don't have a lot of patience. What do we do in the meanwhile?

This book will present information on all the treatment options we can find. We will assess the data in support of each of them. We will examine the risks and the benefits. We will learn what is known, what is not known, and everything in-between.

My personal and professional journey has given me a front-row seat on what works and what doesn't. That is how the information will be presented to you. You will hear some biases coming through the words. That's just fine. I'm not your doctor. You're not my patient. I'm just a teacher and cheerleader sharing opinions on every option available to us kidney patients. Notre Dame's famed football coach Lou Holtz once said, 'I give opinions, not advice.' That's me too.

NOTE: we never do ANYTHING without the advice and consent of our personal physician. First, we have to know our options. Then, we need to understand the pros and cons of each option. Finally, in concert with our physician, we can each assess the risk-benefit analysis for each of us. At the same time, we will evaluate our ability to meet the burden of any intervention. Naturally, before we accept any burden inherent in our care, we want to know that that burden matches our individual goals in life, our fears, our dreams, and our hopes.

Information in the form of personal risk:benefit analysis is more easily digested than a collection of delivered directives on glossy laminated handouts. A personalized risk:benefit analysis means the individual patient is now involved. We want involved patients. Involved patients get better care. Better care leads to better outcomes. The best possible outcomes are our goal here. Individual motivation results when we find information digestible, understandable, unfiltered, and personalized. Vince Lombardi, Hall of Fame Green Bay Packer head coach, famously said: 'Coaches who can outline plays on a blackboard are a dime a dozen. The ones who win get inside their players and motivate.' Mr. Lombardi has perfectly summarized our goal here. We're aiming high.

My life view says we are all playing on a far grander stage than the one immediately before us. All of us are gifted with a single finite life to live. This earthly life is the only one we get. The legacy we will ultimately leave is the one we write every day. We get only one chance to write our legacy. With this reality, it is critically important we get our battle plan right. Each of us greets each day with the challenge of kidney dysfunction. Our battle with kidney disease will be only one portion of our legacy. Our kidney affliction does not define us. Our valor in the battle against it will.

Suppose this book can result in just one individual seeing kidney failure as an opportunity rather than a misfortune. In that case, this writing will have been a success. Simply put, how well we address the challenge of kidney failure laid out in front of us can be a large part of our legacy. That is why education and encouragement are such vitally important starting places.

So, our goal is to 'de-mythologize' an abundance of information. Information, to be valuable, needs to be effective. It needs to be digestible, practical, and personalized to be effective. You're in the right place if you're on board with that.

Happily, there's a lot of good news to be had. Remarkable changes are happening in the world of kidney disease. Kidney function steadily declines in all of us as time passes. New drugs are becoming available that slow the inexorable downhill course of kidney function. These drugs promise better outcomes for kidneys and hearts, the two organ systems intertwined with kidney health and outcome. New data validate the benefits of traditional recommendations for diet, exercise, blood pressure control, & mental health. Research continues. More good news is on the way.

We need to get the word out. People can't use what they've never heard of. We can't benefit from what we've never tried. No one benefits from treatments we've never been offered. Each of us must be the number one advocate for our own situation. We only advocate well when we know what questions to ask. The key is information. At the same time, I warn you. Some of the pharmacology chapters can be tough sledding. They don't all have to be read word-for-word your

first time. A basic rule of life, however, is that if one wishes to be taken seriously, it is always a good idea that one knows what they are talking about.

Finally, we close out the housekeeping details with two additional warnings. First, I will occasionally add opinion and personal bias to what is written here. Trust me; I will always give notice when I move beyond the facts. Second, I am an unabashed Christian. I don't apologize for my faith. I similarly respect wherever your faith currently resides. That debate is for another place. Here I will occasionally show where my faith has provided me immense strength and peace on my journey. Regardless of where we all start, I sincerely wish that same peace for everyone.

Let's get to work.