



# Garet Hil, MBA: Entrepreneur, Kidney Donor, and Founder/CEO of the National Kidney Registry

In the heavily regulated field of transplantation, we have been inspired and (at times) surprised by your refreshing entrepreneurial approach. Would you mind sharing some of your educational and entrepreneurial experiences prior to getting involved in transplantation?

**GARET HIL:** When I was 17, I enlisted in the Marine Corps and shipped off to Parris Island. That experience inspired me to go to college. I completed my bachelor's degree at the University of Montana, then went to work for Electronic Data Systems as a systems analyst working on the Medicare claims processing systems. I left Electronic Data Systems to get my MBA at Wharton. After graduating from Wharton, I spent the next 2 decades doing startups and turnarounds in a variety of industries, but none in health care. Starting the National Kidney Registry was my first work in the healthcare industry since my early days at Electronic Data Systems. Looking back, it is clear to me that the healthcare industry is the most irrational industry that I have worked in, but it is also clear that the US kidney transplant industry is the most advanced in the world, which is why many international patients travel to the United States for living donor kidney transplants.

Donation got on your radar when your daughter suddenly lost her kidney function at age 10 and ended up on dialysis. What are some details of the early days of the Kidney Paired Donation (KPD) program you developed?

**GARET HIL:** When my wife and I started the National Kidney Registry (NKR) back in 2007, I was reading a lot about how KPD matching required massive computing capacity to handle what the scientist called an NP-Hard problem, which can have trillions of iterations. I was concerned about this because supercomputers are expensive and difficult to use. After making actual match offers for a few months, we realized that most match offers were being declined, so if we could prevent these declined matches we

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could use regular computers to do the matching. This was the genesis of our donor preselect system, which totally eliminated the need for a supercomputer.

One of the other major challenges in the early days was the HLA coding concept referred to as splits (eg, DQ3 can also be DQ7, DQ8, or DQ9). I thought it was a crazy way to organize antigen and antibody coding for computerized matching, and I could not believe it was being used for KPD and deceased donor matching. Thankfully, Mike Cecka was able to help us understand the HLA coding schema, and we pushed our Member Centers to higher-resolution tissue typing, which got rid of the splits and helped clean up our matching process. Ten years later, we have made significant progress, but we are still cleaning up the virtual crossmatching process and still striving for higher-resolution tissue typing.

The other experience from the early days that stands out is when we temporarily lost a kidney due to an airline mistake, which happens all too frequently with the airlines. When the kidney went missing, sheer panic ensued for about 2 hours before we found the kidney. The airline had put the kidney on a later flight and did not tell anyone. After that experience, we made it mandatory to use Global Positioning System (GPS) devices for all shipped kidneys. It still surprises me that GPS devices are not used for deceased donor organ shipments.

## You were not the first, but you are certainly the most successful in developing paired kidney exchanges. What is your recipe for success?

GARET HIL: To date, the NKR has facilitated over 3500 living donor transplants including the largest swap (35 deep chain completed over 6 wk). The NKR has become the largest paired exchange program in the world due to our capacity to rapidly innovate. Innovation has allowed us to overcome many of the complex barriers that were holding back the full potential of KPD. We were also very fortunate to have an experienced Medical Board that appreciated bold innovations, like implementing GPS technology, launching the Family Voucher Program, or providing lost wage reimbursement for donors. Importantly, our Board also protected us from our blind spots (ie, the lack of any clinical experience in our core team). Also, something that does not get a lot of attention in KPD, we created a revenue model in 2010 that took us from a charity to a feebased revenue model (like most nonprofit hospitals). There were about a dozen multicenter KPD programs when we

started, none of which had revenue models. Nearly all of them have gone out of business because they could not make the investments needed to keep up with the regulations and the rapid innovations in the KPD world.

#### You donated your own kidney in 2015 as part of the NKR's Advanced Donation Voucher Program. Can you share the details of your motivation and the success of this program?

**GARET HIL:** Our original business plan for the NKR included the concept of a kidney bank where a person could donate a kidney (ie, deposit) on behalf of a loved one who may need a kidney in the distant future (ie, withdrawal). This kidney bank concept became our current Advanced Donation Program. I was thinking about this because our youngest daughter, who was doing well after her transplant, could need a kidney in 30 years, but in 30 years, I would be too old to donate. Several of my Medical Board members advised me that, because I was the leader of the NKR, I should not be the first voucher donor, so I put the idea on the back burner for a few years.

In 2014, Judge Howard Broadman approached University of California Los Angeles with the exact same idea. He was in his early 60s and wanted to donate on behalf of his 4-year-old grandson, who was doing well at the time, but could need a kidney in 10-20 years. Howard donated his kidney in December of 2014 and became first voucher donor. Once Howard's voucher donation was successfully completed, I began the workup process at Cornell and became the second voucher donor. Since then, we have organized about 200 voucher donations, which have facilitated over 500 KPD transplants.

#### What role do Good Samaritan donors play in NKR and what other initiatives is the NKR currently working on?

GARET HIL: Good Samaritan donors allow the NKR to start domino chains, which were pioneered at John's Hopkins in the 2000-2007 timeframe. These domino chains are significantly more effective in finding matches in a KPD program compared with the original closed-loop matching approach, which does not utilize Good Samaritan donors. Many years ago we started providing life/disability insurance and prioritization for a living donor kidney to our Good Samaritan donors. We have since added lost wage reimbursement, travel and lodging reimbursement, legal support and coverage for uncovered complications to better protect and support our Good Samaritan donors. Recently, we made all of these protections available to all NKR donors (ie, paired donors and advanced donors). We are now providing these protections to non-NKR donors at transplant centers through our Donor Shield product.

#### You authored a book called Finding a Kidney: and Getting the Most Out of Your Transplant. Can you share any feedback you have received?

**GARET HIL:** The feedback from the book has been great. Many patients have found a living donor based on the principles taught in the book. I am in the process of writing another book based on what we have learned since the original book was published, which should be out within the year. We also recently launched a new system that provides personalized websites at no cost to patients to enable them to tell their story and help find a living donor. These customized websites, we call them microsites, are integrated with our automated donor intake systems, making it very easy for transplant centers to screen donor candidates who come through the personalized websites.

#### Kidney transplantation and the care of patients with end-stage renal disease (ESRD) have received recent attention with the Presidential executive order. Is paired kidney exchange playing a role in this context in making kidneys more available?

**GARET HIL:** We are very excited about the President's recent executive order, and I believe it will lead to many more living donor transplants. Kidney paired exchange will play an important role because 1 in 3 donors are generally incompatible with the intended recipient. So, as more living donors come forward, because of executive order policies such as donor lost wage reimbursement, KPD will facilitate transplants for at least 1 in 3 of these new cases. Additionally, we have had discussions with Department of Health and Human Services officials and are working to clarify that the cost of our Donor Shield product (which provides lost wage reimbursement and travel/lodging reimbursement, etc) can be reimbursed via the Medicare cost report. This will increase the number of living donors who come forward because many potential donors cannot afford the time off work and the travel costs related to kidney donation surgery, and most ESRD patients are not in a position to reimburse these donor costs.

The success of paired kidney exchanges has largely eliminated the need for complex and burdensome treatments for patients who have an incompatible living donor. The significance of this achievement is most obvious in countries in which paired kidney exchange is not an option. Do you engage in international outreach activities to support paired kidney exchange programs in countries that do not have those opportunities?

GARET HIL: Since 2013, the NKR's desensitization rate has dropped by about 80% as our volume has grown and sensitized patients have been able to find clean matches through NKR swaps. We have also eliminated ABO-incompatible transplants at most of our Member Centers. Additionally, NKR outcomes are better than the typical living donor transplant in spite of the more challenging cases that we are handling. This success has attracted many international patients with incompatible donors to the United States to participate in NKR swaps.

We recently hosted an international paired exchange conference with leaders from Canada, Australia, and Saudi Arabia to share ideas and best practices. We are working to publish an annual international KPD report to share information related to each country's paired exchange activity. I believe this will help accelerate the development of paired exchange internationally.

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## What is your future vision for the National Kidney Registry?

**GARET HIL:** As we continue to see NKR outcomes exceed the outcomes of direct donation transplants, more compatible pairs will participate in NKR swaps. I see a future where direct donation will become a thing of the past and the majority of living donor transplants will be organized through the NKR so that the patients get the best possible match and have the best possible outcomes. We will eventually integrate the NKR process with kidney/stem cell transplant

technology, eliminating immunosuppression medications and extending transplant longevity (ie, kidney for life). Additionally, I expect that in the not too distant future, all living donors in the United States will be protected by Donor Shield.

### You are a powerlifter, a triathlete, and a family man. How do you balance professional and private life?

**GARET HIL:** For me, the key is to be very organized, wake up early, and most importantly, to have a spouse who is very supportive.