

Testimony

Of Elizabeth M.P. Rubin

Before the Information Policy, Census and National Archives Subcommittee

Of the House of Representatives on Oversight and Government Reform Committee

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Good afternoon. My name is Elizabeth Rubin and I am here to represent transplant recipients and patient advocacy groups. To start out, I just want to tell you how glad I am to be here, or for that matter, anywhere! Were it not for the miracle of transplantation, I would have gone to the "Great Beyond" over 15 years ago, at the age of 36 years old. Up until the time I learned that my liver was failing and that I would need a liver transplant, I thought I was in tip-top shape, enjoying life to its fullest and taking my good health for granted. And, even after I had been informed that I was ill, I ignored the diagnosis and continued to pursue all of the activities that were part of my life at that time. I had just had a second daughter, and I had a four year old as well. My husband and I lived a comfortable life in the suburbs of Philadelphia, where he was employed as a business manager for an oil company, and I was working part-time as a legal assistant for a major law firm in the city. When my gastroenterologist gave me what he could of a diagnosis – he couldn't really determine what exactly was wrong because all of the tests for hepatitis and known liver diseases came back negative – I did not take it seriously; in fact, I denied it, and continued to swim 100 laps every day, and, as I said, do everything else as usual. Finally, my gastroenterologist had to call my husband and tell him just how seriously ill I was, adding, "you need to get her to a hospital that can handle this, like Pittsburgh, immediately". So, we did, and within five days, I was listed for a liver transplant, entering into that cavern of the unknown, because in those days, there wasn't that much published information on what to expect while waiting or going through a transplant. I spent close to five months in Pittsburgh, four of them in and out of the hospital, waiting a total of seven weeks for a transplant and spending the remainder of the time trying to get my body to accept the foreign organ.

A lot has changed since then. Fifteen years ago, there were not very many hospitals that did transplants, and the surgery was still considered to be risky. The results were quite depressing to look at: although the percentages varied depending on the organ transplanted, many patients did not even survive the first year, and the percentage of those surviving five years was not much more. Some patients didn't make it because the original disease they had attacked their transplanted organ; others were not as good at following their post-transplant instructions; and still others could not reach the point where their immune systems accepted the 'foreign' organ. Immunosuppressive drugs were still in their infancy: the options were cyclosporine and Prograf, or FK506, as it was first called, which was still in experimental form (not approved by the FDA). In fact, those patients who were given the latter were the test cases. As I went through the transplant process, I felt a little like an explorer breaking new grounds: I ignored the statistics, and decided that if I followed doctors' orders and took charge of my

life, I would be able to break all of the records and live a long life, despite this hiccup. After all, the diagnosis that I was finally given for my liver failure was Cryptogenic Cirrhosis, which had no real cause and therefore should not repeat itself in my system. But there were some complications along the way, and it was not until my fourth year post-transplant that things started to level off and I could finally rest a little easier. Talk about a lesson in mortality!

When I was listed for transplant, there were approximately 30,000 patients on the transplant waiting list; now there are over 97,292. [UNOS as of 9/24/07] This is both a positive and a negative sign of what has occurred in the transplant world: positive, because improvements in medical technology have made it possible for more patients to be listed for transplant, but negative because the number of donors has not increased at the same pace as the number of candidates. What has been done to encourage people to donate has been quite successful: for example, the increase in donor awareness and education activities has publicized the subject of organ and tissue donation, and we can assume that it has helped convince people to sign up to be organ and tissue donors. I am a firm believer in the power of speech, and like many other transplant recipients, I spend a lot of time telling people about my transplant experience and explaining why they should seriously consider signing up to be organ donors. Other efforts to increase the number of donors include the broadening of regulations allowing individuals to become donors, the development of state registries at such places as drivers license centers, and the establishment of living donor programs. But none of these efforts have done enough: the number of organ donors is not keeping pace with the number of patients on the waiting list.

This is the topic for discussion at this oversight hearing before the Subcommittee on Information Policy, Census, and National Archives. Although it is important to review what has been done to strengthen organ donor programs, it is crucial for us to spend our time today discussing what can and must still be done to improve the system. I am honored to have been asked to appear before you. As a member of the Board of Directors of TRIO (Transplant Recipients international Organization), including past president, and as a transplant recipient myself, I feel as though I represent the heart of the transplant community. For those of you not familiar with TRIO, we are a non-profit international organization committed to improving the quality of lives touched by the miracle of transplantation through support, advocacy, education and awareness. TRIO has been in existence for over twenty years. Our goal is to help individuals who are suddenly thrust into the world of transplantation, as patients, potential donors, and/or friends or family of patients or donors, so that they may learn to navigate the system and subsequently work with others to advocate for the rights of the transplant patient. Although some of our members are candidates for transplant or newly transplanted, many are individuals who have been 'out' for an extended period of time. We are proof that "Transplantation Works"! Some of our members have had their transplants for over 15 years, and they are still living quality lives. Most of our members come to us through our website or through word of mouth, although we do speak to patients in waiting rooms and put brochures in medical offices and other locations where potential members may appear. Our members do a lot of grass roots work, getting out the word of organ donation into their home territories and into their larger communities as well. Some of them work with their OPO's, and many of them work within local TRIO chapters organizing educational seminars, donor celebrations – both living

and anatomical -, and participate in athletic events such as the U.S. and International Transplant Games. All of these activities raise awareness of the success of transplantation and the need for more organ and tissue donors. In addition, some of our members have gone beyond their communities to join UNOS patient committees, and one of our members is currently serving on the Transplant Roundtable. We are constantly looking for opportunities to spread the word of organ donation and to improve the public face of transplant. We know how important it is to present a positive and accurate story on transplantation: what is presented in the media definitely has an impact on the decision to donate or not. TRIO has recently taken on the task of monitoring media presentations on the subject of organ and tissue donation in advertising, film and TV production by joining a group called Donate Life Hollywood. The efforts of TRIO members and other patient advocacy groups over the past decade have improved the rate of donation. However, they have not done enough to stem the shortage. The increase in the OPTN waiting list of transplant candidates far exceeds the increase in donor numbers every year. We are at a crossroads in the world of transplantation: the technology exists to make it possible for many illnesses to be treated by a transplant, and technology has also made the decision to donate and the carrying out of those wishes simple and straight forward.

The following are my suggestions for how we should tackle the organ donor shortage. For anatomical donors, there are five areas in which I recommend we concentrate our efforts. First of all, we should continue to expand the criteria for viable donation. We have already expanded the age range – when I was transplanted, the cut-off age was 70 – but we also need to continue the research necessary to determine what other categories of potential donors may be acceptable. Perhaps we should push for the use of “extended donors” and cardiac death to be totally accepted.

Secondly, we should push for individual registration with state registries in all states of this country. It has already been proven that the number of donors has increased in the states where registries exist, but not all states have passed laws in favor of these registries. This should become a nationwide practice and maybe there should even be a national database so that when you are traveling all OPOs in the country could know your wishes even outside of your home state where today you might be registered (today, only the region's OPO can access their own state registry if it is even in place). Furthermore, I recommend that individual registries override family objections to donation, that they be considered legal contracts, just like voter registration.

In addition, regulations need to be standardized across the United States with regard to the integration of organ donation responsibilities among hospital staff, OPOs and state registries so that viable organs are not wasted and organ procurement outcomes improve. The Organ Donation Breakthrough Collaborative has already proven that this will increase the percentage of organ donors. As stated in the Memorandum prepared for this Hearing, “During the program’s first year, the 95 hospitals participating in the Collaborative achieved a 14.1% increase in donation, as compared to an 8.3% increase in donation at non-Collaborative hospitals.” [page 4]

Another recommendation is that we seriously examine the possibility of Presumed Consent as a law of the land. Today there are enough countries using this approach to provide the data to determine whether this would be feasible in the U.S. If it is deemed possible, then there would be a need to enlist technology to allow for online opting out using a national data base as the security to assure people that

their organs would not be taken if they did not want them donated. If Presumed Consent is not deemed feasible in this country, then we should dedicate some time and funding to finding acceptable methods of offering incentives to people who are considering signing up to be organ donors.

Finally, I suggest that more effort and funding be put into educating the public on the need and reasonableness of organ donation, perhaps even rewarding organizations that do this, with grant money and formal acknowledgement of their efforts. We have already seen the Internet as a major force for general education. The UNOS web site as it is continually evolving is an excellent example of technology's use to provide public access to a wealth of information and reports that both patients and the general public need to make such decisions about donation and in choosing health care providers for transplantation. In addition, education in the form of 'advertising' is evident in today's grass roots initiatives driven by desperate families using websites and billboards to seek a donation of organs to save their loved ones' lives, but we could eliminate the controversy of individuals doing that and make it a full public press to benefit all patients, leveling the playing field as today's UNOS registry process does already in the area of listing patients.

For living donors, I have a few recommendations. In cases where living donation is possible, usually involving kidneys and partial livers, such donations are considered to be preferable to deceased donor organs due to the viability of the organ being donated. In many cases, these donor organs come from relatives who are more likely to be biologically compatible to the recipients. Occasionally, a relative comes forward who is willing to donate but is incompatible with the transplant candidate. Among new programs aimed at increasing the use of living organs to decrease the organ shortage, some OPTN members have established directed donation programs for the donation of kidneys in these circumstances. There are two such directed donation programs now: the "list" or "paired" programs. These two programs have been found to be quite successful in that they make use of more offered and therefore available organs. In the "list" program, a willing kidney donor who is incompatible with the transplant candidate he had intended to donate to will donate to another candidate from the waiting list with whom he is compatible. Meanwhile, his intended recipient will then be granted priority on the waiting list when a kidney that is compatible becomes available. In the "paired" program, two living donors deemed incompatible with their intended beneficiaries will be matched up with patients in which both donors are compatible, thereby providing each patient with a new organ. These two programs should be universally accepted at all transplant centers; regulations should be established and followed, thus removing the question of preferential treatment.

Another suggestion for living donors is to offer each and every one of them a certain amount of health and life insurance. I would also recommend that, as part of the follow-up, living donors be treated to long-term care. Even though transplant surgery has become less risky, signing up to be a living donor still requires one to go through unnecessary surgery, which may cause problems during or after the surgery.

I would like to add one more recommendation, which, although it may not directly impact upon the number of organ donors, would impact upon the longevity of the lives of transplant recipients. For years, we have been advocating for lifetime immunosuppressive coverage. It is time to push through the bill promoting this in Congress! It is economically short-sighted to be pushing for improvements in

the U.S. organ donor program, if we are not also concerned with the fact that transplant recipients are dying because they cannot afford to pay for their transplant medications once their 18/36 month coverage runs out. If they don't die, they may be fortunate to receive a second transplant, which is also stupid when there is already such a shortage of organs.

I congratulate this committee for scheduling this hearing to discuss potential opportunities to strengthen and improve our nation's organ donor programs and awareness activities. I am honored to have been invited, and I hope that some of my recommendations will be considered. I hope that discussions such as these will continue, so that those of us living in the world of transplantation can help to continually update and improve the procedures and regulations by which transplant candidates live or die.

Finally, I hope all of those involved with this hearing will sign up to become organ donors if you have not already done so, and tell your family!

Thank you.

