



National Kidney Foundation Position Statement on Increasing Organ Donation and Transplantation in the United States (Adopted January 17, 2009)

The Board of Directors of the National Kidney Foundation has addressed the urgent need to increase the number of organs available for transplantation in the United States. After extensive research and discussion with constituents and experts, the Board adopted a comprehensive action plan, rather than focusing on any single tactic, to solve this problem and ***END THE WAIT!***

This ***END THE WAIT!*** initiative is a roadmap to implementing tested and proven actions that will end the wait for kidney transplants in ten years.

These recommendations will eliminate barriers, institute best practices across the nation, improve the transplant system, totally cover the cost of donating an organ, reduce regional and ethnic disparities and increase living and deceased donation throughout the United States.

The National Kidney Foundation Board of Directors is making these recommendations to address the fundamental problem facing Americans in need of a kidney -- the shortage of organs and resulting long wait for a transplant. This is a comprehensive program focused on a commitment to do what patients really need done.

A collaborative framework must be created. A big picture approach will be needed throughout the transplant community and in Congress. These recommendations call for action on the part of transplant programs, organ procurement organizations, professional societies, government agencies, patient organizations and the government.

Comprehensive legislation must be crafted to meet the larger goal to *End the Wait* rather than making small changes or single issue amendments in existing laws. These initiatives will complement the National Organ Transplant Act (NOTA) and the Uniform Anatomical Gift Acts (UAGAs), not amend them.

NKF's initiatives fall into four broad areas:

1. *Improving outcomes of first transplants, reducing the need for second transplants*
2. *Increasing deceased donation, a source not fully tapped*
3. *Increasing the number of living donors, the largest potential source*
4. *Improving the system of transplantation and donation throughout the United States*

This task is complex and challenging, well beyond the scope of any single organization. But by collaborating, the kidney community can come together around this goal and succeed in ending the wait for a kidney transplant.

Background

The National Kidney Foundation's mission has included increasing and improving transplantation for decades. NKF was involved in passage of Uniform Anatomical Gift Acts (UAGA) in all 50 states. It led the effort to have drivers' licenses legally indicate a person's decision to be an organ donor. It advocated for the National Organ Transplant Act of 1984 (NOTA) and other legislative efforts to help patients get transplants. NKF continues to carry out programs in education, research and services to fulfill this mission.

NKF has always responded to requests from the transplant community and our patient constituents to evaluate and comment on proposals to improve organ donation. In 2003, the NKF Board of Directors actively supported the provisions of NOTA and the UAGA's that kept financial considerations out of the donation process. That Board action came up for routine review after five years and became a major agenda item for the organization during the past six months. The Board devoted most of its time at two meetings to these issues and scheduled final determination of the NKF position for January 17, 2009.

This time, however, the Foundation took a different approach. Rather than reacting to events, single issues or proposals from outside, it decided to meet the core challenge head on. The NKF Board determined that what our patients need is a broad-based NKF-led initiative to end the long wait for a transplant that has subjected too many patients to deteriorating health, poor quality of life and even premature death.

So, NKF is committing itself to actions that will ***END THE WAIT! In Ten Years***

This is a major Board commitment that will reach out to the entire NKF organization as well as our constituents, the transplant community, federal and state government agencies, Congress, organizations, concerned individuals and the public. This will be a difficult, complex and expensive initiative. It is too large for NKF or any single group to do alone. Yet it can, and must, be successful.

Our efforts will begin immediately and will continue for years. After the first five years, there will be a thorough evaluation of progress at which time other strategies can be considered.

The *END THE WAIT!* Initiative

The principle behind this initiative is that a large collaborative commitment will end the wait for a transplant. By working together and focusing on the big picture and real needs of our patients, we will have a dramatic impact on the health of transplant recipients, donors and those who will have only a brief wait for the organ they need.

Rather than focusing on single issue tactics, these broad based actions will achieve the common goal that everyone agrees on – ending the wait for a transplant. It uses proven and tested strategies, each of which is already successful in some areas and which

should now be implemented everywhere. (The full list of NKF's Recommendations is attached and is available on the NKF website www.kidney.org)

We can improve the outcome of first transplants, reducing the need for a return to the waiting list. We should pay for immunosuppressive drugs for the life of the recipient. The loss of a transplant is one of the leading reasons for starting dialysis. Reducing that problem will make more kidneys available. We can improve the health of recipients, transplant them earlier when their condition is better, educate them about their options and ask them sooner, "Do you have a donor?"

We can also increase the number of organs available from deceased donors. We can improve the care of donor families in hospitals and support them while they are with their loved one. We can increase the use of proven techniques such as extended criteria donors and donation after cardiac death throughout the country. And, we can make sure that donor families don't incur any additional costs because of the donation, including extra funeral costs.

Increasing the number of living donors is vital to meeting our goal. Living donors and potential donors should receive state-of-the-art care and never suffer financially because of their donation. We can cover all the costs of donation, including lost wages. We can track donor outcomes and make sure they have health care coverage and life insurance for anything that happens related to the donation. And, a program of matched donation should be available throughout the United States.

Living donors and potential donors are our constituents, too. NKF will establish a Living Donor Council to support their needs. They should always have the best information about the donation process to help them make decisions that are right for them.

We also can improve the American system of organ donation and transplantation. Many challenges are resource-based. We can increase the number and skills of people working in transplant programs nationwide to reduce the time it takes to complete the living donation process. All potential living donors should have access to laparoscopic nephrectomy.

Summary

This can be done. It won't be easy but the goal is worth the effort. We can End The Wait! We can leave existing laws as they are and write new ones that address the whole problem. We can have a dramatic impact on the health of all our patients and our country.

The National Kidney Foundation will commit itself to leading the effort. If the community responds and reaches above individual priorities and single issues, the goal can be met. The challenges are many and the work will be hard. But, it's the only way to do what our patients need us to do:

END THE WAIT!