



# *Organ Donor Leave Advocacy Guide*



Your Resource on  
State Organ Donor Leave Legislation





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## **THE ISSUE**

### ***Organ Donor Leave***

In 1999 Congress passed legislation granting federal employees 30 days paid leave if they serve as organ donors. The leave does not affect annual or sick leave which the employees may have already accrued. Some states have begun to replicate the legislation, making such leave available to state employees. Wisconsin, for example, enacted organ donor leave legislation in May 2000, granting state employees 30 day paid leave to facilitate living organ donation. Maryland followed suit, enacting donor leave legislation in October. The states of Delaware, New York, Texas, and Virginia have had legislation introduced addressing state organ donor leave.

The National Kidney Foundation's position is that other states should move forward with adopting organ donor leave legislation as a means of:

- ◆ **Enabling more people to serve as living organ donors**
- ◆ **Enhancing the well-being of living organ donors**
- ◆ **Providing a positive example for private industry to begin to offer the same benefit to employees.**





## THE MESSAGE

To my friends at the National Kidney Foundation around the country,

Many of you who know me from the U.S. Transplant Games know that I am a proud donor dad. I gave a kidney to my daughter. I am thrilled to have played a major role in her recovery. But since her transplant, I have had the opportunity to speak to others in similar situations and I know that so many people struggle with the decision to become a living donor because of the hurdles they face.

Often there are financial hardships and, of course, there is needed time for recovery. Recognizing this, the federal government passed legislation granting federal employees 30 days paid leave when they serve as organ donors.

I join all of you at the National Kidney Foundation in urging state legislatures to enact similar legislation for state employees, so that others might be inclined to offer the “gift of life”.

Together we can make a life-saving difference. I can pass on a bit of truth I learned from my former career. There is nothing like teamwork for achieving success. Good luck to you as you embark on this important mission.

Sincerely,

Oscar Robertson

*Oscar Robertson scored more than 26,000 points and won an Olympic gold medal during his 14-year NBA career as one of the greatest all-around players in basketball history.*





## THE IMPACT

What a **powerful message** it would send about the **importance of organ donation** if states provided a tangible demonstration that they **valued employees** who gave the “**gift of life**” and wanted to ensure that each of them had adequate time to recover from surgery.

Individuals from all walks of life might be more inclined to become organ donors, and private industry might follow the example of state government, granting their employees such leave. The size of the workforce in each state suggests the impact such legislation might have: there are 4,732,608 state employees nationwide.

Imagine the impact if each of them were a potential organ donor!





## THE CALL

**The NKF** is issuing a *call* to you and your Affiliate volunteers. We are asking that you take the issue of organ donor leave to your state legislators and encourage them to enact legislation which would grant state employees who are organ donors 30 days paid leave for recovery from surgery.

It is important to realize that the efforts of the “ordinary citizen” account for a great deal in the public policy arena.

Grassroots advocacy provides us with great power, and when that strength is used to fight for one’s convictions, policy can be influenced, even transformed.





## **THE STRATEGIES**

### **Understanding Grassroots Advocacy**

The call has been issued and you have responded. How do you go about accomplishing the task?

You use grassroots advocacy, the goals of which are to influence the legislative process and the programs and policies of administrative agencies.

One tool used in grassroots advocacy is a network, an ongoing **organized** system of recruiting, training, and motivating individuals to use their political power to influence legislation.





## **THE STRATEGIES Back to the Basics**

### **Identify the issue**

Make sure you understand the issue so you can explain it to legislators in simple language.

### **Recruit volunteers to carry the message**

Build a network of volunteers who can advocate on behalf of your issue. For the National Kidney Foundation, that group is our Renal Representative Network, At the center of the Network are volunteers from around the country who have agreed to lobby on behalf of issues that have an impact on kidney patients, transplant recipients and their families.

### **Work with Coalitions**

There are usually other groups concerned with the same issues. Seek them out. Work collectively to influence legislation. There is power in numbers.

### **Identify a champion or champions with political power**

An ally in the state legislature, state department of health, or another prominent state employee or elected official can help keep the issue at the forefront.





## COMMUNICATE YOUR MESSAGE

Make legislators and their staff aware of your issue. Get as many different individuals as possible to phone, write, visit or e-mail.

### **Tips on Phoning:**

- ◆ Ask for the staffer who handles health care issues
- ◆ Introduce yourself and identify the nature of your call
- ◆ Be concise

### **Tips on Writing:**

- ◆ Write as an individual constituent
- ◆ Cover only one subject; be as specific as possible
- ◆ Ask the legislator to do something specific
- ◆ Indicate your thanks and reiterate your most important message
- ◆ Indicate that you expect a response

### **Tips for Visiting:**

- ◆ Make an appointment; indicate the subject you would like to discuss
- ◆ Thank the legislator for his or her previous support (if applicable)
- ◆ Get to the point of the meeting; be brief; ask for specific action
- ◆ Leave written materials behind pertaining to your issue.

### **Tips on E-mailing:**

- ◆ Be brief
- ◆ Use e-mail for issues that need prompt attention, such as a request to vote a specific way on a bill under consideration.





## USE THE MEDIA

Aim for coverage of your issue in local newspapers and on television broadcasts. To be effective, you will need to vary your approach. You can recruit a patient or volunteer to write letters to the editor, appear on local TV and radio as guests or experts or be the focus of a human interest story you are pitching to the newspaper. Here are some tips for working with the media.

- ◆ Compile a press list of print and electronic media in your state. Call each outlet and identify a contact person who writes about legislative and/or health issues. Make sure you have his or her correct phone, fax and e-mail and, of course, the spelling of his or her name. Also ask how and when they prefer to be contacted so you don't make the mistake of calling someone at 4 p.m. when he is on deadline and absolutely hates phone calls but loves e-mail. Read the newspapers and watch the broadcasts you plan to target so you know what type of coverage is realistic to expect and also so you become familiar with the beats of individual reporters.
- ◆ Prepare a news release that spells out your issue in a timely way. Try to tie it to some local news so the media have an "angle" or reason to run it at a given time. Make sure it reaches the media with enough lead time prior to the date you want the information published or broadcast. Follow-up with a phone call.
- ◆ In letters to the editor, focus on one issue. Cite relevant article(s) and include titles and dates when they appeared. Make a direct appeal, asking readers to contact their legislators.
- ◆ In an interview, speak about your cause in a conversational style, similar to addressing a friend. Try to refer back to the points you want to convey.
- ◆ Submit a story for the evening new. Make sure it has a visual element, otherwise it will not be interesting for TV.





### **Use the Media (continued)**

- ◆ Hold a press conference.
- ◆ Talk shows help you reach a broad audience and provide a way for you to support particular policies, refute common fallacies, and most importantly, educate and inspire citizens to take action. Call talk shows, respond to the issue being discussed or suggest your issue as a possible subject for the station to address; offer to provide an expert guest.
- ◆ Pitch a story to the major daily newspaper for feature coverage of your issue. Wrap your pitch around a personal story of a family or patient who can illustrate the point you are trying to make about living donation. Good human interest will always sell. As the old adage goes, “people respond to people.” Start your pitch off with a personal anecdote and then lead into a brief explanation of the issues.





## **THE APPROACH**

### **For the media and government**

#### **Use statistics**

The number of people on the transplant waiting list is currently 74, 570. Of those, some 47,902 are waiting for kidney transplants.

#### **Develop draft legislation**

Ask the NKF Office of Scientific & Public Policy for help. Use the Wisconsin Act as a model. Find a legislator to introduce the bill.

#### **Point to the views of constituents**

Document numbers of constituents who would support such legislation.

#### **Use research or conduct research to answer potential questions**

For example, 25% of potential living organ donors do not donate because of concerns about unreimbursed expenses related to organ donation (missed time from work).

#### **Build a coalition**

Seek support from the union representing state employees in your state.





## **THE FACTS About Organ Donation**

- ◆ 16 people **die every day** because of the shortage of available organs.
- ◆ More than 74,000 people nationwide are waiting for organs, yet only 21,692 received a transplant last year because of the shortage of suitable organs.
- ◆ Of the over 74,000 people waiting for organ transplants, more than 47,000 are waiting for needed kidneys.
- ◆ The number of people on the transplant waiting list continues to increase. In 1988, there were 13,943 people on the waiting list for a kidney transplant. By 1999, that number had increased to 46,489.
- ◆ The death rate due to the shortage of available organs continues to increase. In 1988, 743 people died waiting for a kidney transplant. By 1999, the number of deaths had increased to 3,046.
- ◆ The increase in the number of living organ donors has tripled within the last decade.





## **THE EXAMPLES**

### **THE FEDERAL LAW**

- ◆ **Public Law 106-56, the “Organ Donor Leave Act.”** Signed into law on September 24, 1999, the Organ Donor Leave Act grants Federal employees who serve as organ donors 30 days paid leave.

### **THE WISCONSIN LAW**

- ◆ **1999 Wisconsin Act 125.** As of May 24, 2000, state employees in Wisconsin who serve as organ donors will receive 30 days paid leave which is separate from their annual or sick leave.

### **THE MARYLAND LAW**

- ◆ **Chapter 221, Statute 9-1106.** As of October 1, 2000, state employees, including temporary employees, in Maryland who serve as organ donors will receive up to 30 days paid leave which is separate from their annual or sick leave.

**Will your state be next in making lives better?  
Will your state support living organ donors?**





## THE LEGISLATION

### 1999 Assembly Bill 54

Date of enactment: **May 9, 2000**

Date of Publication: **May 23, 2000**

### 1999 WISCONSIN ACT 125

AN ACT **to amend** 111.93 (3) and **to create** 230.35 (2d) of the statutes; relating to: paid leaves of absence for state employees for the purpose of serving as bone marrow and human organ donors.

**The people of the state of Wisconsin, represented in the senate and assembly, do enact as follows:** [Section 1 concerns collective bargaining agreements.]

**SECTION 2.** 230.35 (2d) of the statutes is created to read:

230.35 (2d) (a) In this subsection:

1. "Bone marrow" has the meaning given in s.46.34 (1) (a).
  2. "Human organ" has the meaning given for vascularized organ" in s. 157.06 (1) (L).
- (b) An appointing authority shall grant a leave of absence of 5 workdays to any employee who requests a leave of absence to serve as a bone marrow donor if the employee provide the appointing authority written verification that he or she is to serve as a human organ donor.
- (c) An appointing authority shall grant a leave of absence of 30 workdays to any employee who requests a leave of absence to serve as a human organ donor if the employee provides the appointing authority written verification that he or she is to serve as a human organ donor.
- (d) An employee who is granted a leave of absence under this subsection shall receive his or her base state pay without interruption during the leave of absence. For purposes of determining seniority, pay or pay advancement and performance awards and for the receipt of any benefit that may be affected by a leave of absence, the service of the employee shall be considered uninterrupted by a leave of absence.
- (e) For employees who are included in a collective bargaining unit for which a representative is recognized or certified under subch. V of ch. 111, this subsection shall apply unless otherwise provided in a collective bargaining agreement.





## **WORKING WITH YOU**

### **NKF Office of Scientific and Public Policy**

This brochure is a tool, a guideline. These tactics have been proven effective, but it is up to you to determine which mix of approaches will get the job done in your state.

Keep in mind that you are not acting alone. NKF's Office of Scientific & Public Policy, (800)889-9559, is available to assist you.

If you want state specific data such as the number of state employees or the number of people on the transplant waiting list, contact the Washington D.C. office (800)889-9559 and ask for Shaun Hill, Legislative Advocacy Director, or e-mail [shaunh@dc.kidney.org](mailto:shaunh@dc.kidney.org).

For information on contacting your state legislature, view the Government Relations page on NKF's website, [www.kidney.org](http://www.kidney.org). Under "State Legislative News and Information" click on Contacting Your State Legislatures.





## **The Mission and Goals of the National Kidney Foundation**

The Mission of the National Kidney Foundation is to prevent kidney and urinary tract disease, improve the health and well-being of individuals and families affected by these diseases, and increase the availability of all organs for transplantation.

### **Goals**

- Supporting Research and Research Training
- Continuing education of Health Care Professionals
- Expanding Patient Services and Community Resources
- Educating the Public
- Shaping Health Policy
- Fund Raising

