

Your Choice First!

A Presumed Consent Policy for Organ Donation.

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Gene therapy and other cures for chronic diseases are being researched, but organ transplant remains the only lifesaving treatment for many patients with end stage heart, kidney, liver and lung diseases. With transplants from animals, cloned organs, and true artificial organs also many years away, we currently have an organ donation crisis in the United States! The waiting list for organ transplant is nearing **97,000***! Each day **77** people receive an organ transplant in the United States, but another **19** people on the waiting list die because not enough organs are available**!

When faced with a decision at the time of a tragic event, many people do not consent to donation of their loved one's organs or tissue, simply because they don't know their loved one's choice. Our current "opt-in" system requires people to state they want to be a donor by signing a donor card, marking their Driver License as a donor, or registering with an Organ Donor Registry. Federal "Required Referral" law requires hospitals to routinely refer to the Organ Procurement Organization (OPO) any patients that face impending death. There are many states with "First Person Consent" or "Donor Designation" laws requiring acceptance of completed donor cards or donor designation on a driver license as all the proof of consent needed for donation. Even with our state and federal governments having spent billions of dollars on educating our public on the need for donation, this system has failed miserably!

Implementing an "opt-out" system of Presumed Consent is the fastest and least expensive way to lessen the shortage of organs for transplantation with no harm to anyone. This policy is currently being explored for adoption in many countries including the United States, United Kingdom, Australia, and Canada. Presumed Consent is already in place in Austria, Belgium, Bulgaria, Czech Republic, Denmark, Finland, France, Greece, Hungary, Italy, Latvia, Luxembourg, Norway, Poland, Portugal, Singapore, Slovak Republic, Slovenia, Spain, Sweden, and Switzerland***.

The way Presumed Consent works is that everyone is considered to be an organ donor unless they "opt out" of the system. Our current system with the United Network for Organ Sharing (UNOS), our regionally located OPO's, and the existing transplant centers can be utilized continuing their current roles. We would still need the OPO's to provide procurement coordination and donor family services and UNOS could be utilized to maintain a confidential "opt out" registry to verify a potential donor's wishes while continuing their current mission. Making a choice remains the most important part of this policy as no one should be ridiculed for their choice and every one is entitled to have their choice honored.

Presumed Consent Policy in the US should be implemented with these four areas of integral capabilities:

1) Notification, Education, and Awareness- Every adult will need to be formally notified of the law and given an opportunity to state their choice. We have to have a mechanism ongoing to notify and educate our people as they become adults. We have to be able to verify that people have been made aware of the law. We certainly don't want anyone to be forced to be a donor just as much as we want everyone to be a donor.

We have to educate the general public, our lawyers, our doctors and all medical staff. Why can't we have a required course in every high school, every college, and every medical school? Why shouldn't a training or certification program be part of every nurse, doctor, lawyer, public servant/clerk/official? That's why we have the myths and the misinformation now- lack of education.

We need ongoing awareness programs- especially in secondary schools, churches, and all public facilities and activities.

2) A Central Registry- The most reasonable is a national "opt-out" registry. In Europe only 2% opt out of the program, so it would be easier and less expensive to track those that opt-out than those that opt-in. This registry would have to be able to maintain 100% accuracy, 100% confidentiality, and 24/7 accessibility. UNOS already maintains the transplant candidate list, why couldn't they be adapted for this purpose also. Or, at state level, existing Organ Donor Registries could be used or we can create registries in states that don't have them.

3) Program management- As an extension of the OPO's, we need a Dr. or at least a nurse in every hospital with over 150 beds to coordinate and manage the program. This person would be responsible for monitoring the patient population so they can identify in a timely manner a potential donor, provide donor family services, coordinate procurement actions, and administer the education program in their hospital as well as their local community. We have to have a system that provides legal protections for all involved. I believe that's a major failure of the program we have now- Doctors, Hospitals, and OPO's are afraid of being sued if someone takes offense.

4) Oversight- We would have to guard against abuses. We don't want a system that promotes "death mongers" and we don't want a system that allows any one person or part to be ignored or fail.

*As reported by United Network for Organ Sharing (UNOS),
www.unos.org

**As reported by US Dep't of Health and Human Services,
www.organdonor.gov

***from Presumed Consent and Other Predictors of Cadaveric Organ Donation in Europe; 04/16/03, North American Transplant Coordinators Association

David W. Courtney was diagnosed with COPD at the age of 40, and subsequently identified as having Alpha-1 Antitrypsin Deficiency, the underlying cause of his COPD. He is a disabled veteran and is currently pursuing lung transplant through the Veterans Administration. David is the Vice President and Director of Public Relations for The Presumed Consent Foundation, Inc.(PCF) www.presumedconsent.org . He also serves on the Board of Directors of the Alpha-1 Advocacy Alliance (A1AA) www.alphaladvocacy.org and the Fair Allocations in Research Foundation(FAIR) www.fairfoundation.org He leads the West Texas Alpha-1 Self Support Group, is past Chapter President of the Texas Panhandle Chapter, Transplant Recipients International Organization (TRIO) www.trioweb.org and is an active member of LifeGift Organ Donation Center's www.lifegift.org Volunteer Group. David served as a member of the Joint Commission on Accreditation of Healthcare Organization (JCAHO) Public Policy Roundtable on Organ Donation. He has presented PCF's proposed policy of Presumed Consent to meetings of the US Dep't of Health and Human Services, Advisory Committee on Organ Transplantation, the UNOS Ethics Committee, as well as many state and federal legislative committees and staff. David continues to campaign for Presumed Consent Policy in numerous patient advocacy, medical, legal, legislative and media forums.