

Iowa Department of Public Health



Report to the General Assembly: 2017 Anatomical Gift Public Awareness Annual Donation and Compliance Report

**Iowa Department of Public Health, in conjunction with the Iowa Donor Network
and the Iowa Lions Eye Bank • November 2017**

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Introduction

In 1996, the Iowa Legislature created the Anatomical Gift Public Awareness and Transplantation Fund. County treasurers seek contributions to the fund when Iowans register or renew motor vehicle registrations. In 2004, an organ and tissue donation awareness license plate was created for Iowa motorists. A \$35 charge for the plate plus \$10 renewal fee, in addition to the normal fee, is provided to the awareness fund.

Iowa is served by a single organ procurement organization, the Iowa Donor Network (IDN), and one eye recovery agency, the Iowa Lions Eye Bank (ILEB). Through a contract with ILEB, IDN serves as Iowa's human tissue (eyes, bone, skin, tendons and heart valves) referral agency. ILEB conducts cornea recovery, processing, evaluation and distribution services. Both organizations cooperate closely with Iowa hospitals, hospice and emergency medical services, as well as the public, to promote and accomplish organ, tissue and eye donations.

Iowa Code Chapter 142C.17 requires the Iowa Department of Public Health (IDPH), in conjunction with any statewide organ procurement organization, to submit an annual donation and compliance report.

Organs, Tissues, and Eye Donors

The number of Iowa organ and tissue donors for January through September of each year is as follows:

Year	<i>Organ Donors</i>	<i>Tissue Donors</i>
2017	39	600
2016	40	636
2015	58	757
2014	59	800
2013	62	783

The number of eye transplant and research donors, January through September:

Year	<i>Eye Transplant Donors</i>	<i>Eye Research Donors</i>
2017	763	180
2016	781	161
2015	793	158
2014	700	143
2013	753	338

Organ, Tissue, and Eye Donors

Consistent with requirements of the Centers for Medicare and Medicaid Services (CMS), IDN receives a referral call on every death in Iowa hospitals. Not every referral results in a donation; consent for donation and medical suitability must also be considered.

On average, *each tissue donor* provides enough transplantable tissue for up to 75 people. Eye donations for transplant decreased by 2.3 percent this year and research donations increased by 11.8 percent. In 2017, Iowa imported six corneas for transplantation (no change over last year) and imported 99 corneas for research and training, a 61.2 percent decrease over research imports in 2016. Even though eye donation has slightly decreased, the demand for corneal transplants is also increasing in Iowa. On average, *each eye donation* provides sight to two people and provides additional tissue for up to eight scleral patch grafts for eye traumas and glaucoma shunt surgeries. Eyes donated to research by Iowans are used to develop new transplant techniques and potential treatments for blinding eye disease by ILEB and the University of Iowa Wynn Institute for Vision Research (WIVR). ILEB is pursuing groundbreaking research through the philanthropically funded Cornea Research Center, focused on the metabolic functioning of ocular tissue with a goal of identifying tissue that will most successfully restore sight. WIVR makes research tissue from Iowans available to their programs: Carver Family Center for Macular Degeneration; Glaucoma Research; Pediatric Genetics; Center for Bioinformatics and Computational Biology Visual Rehabilitation/Disability; Program in Stem Cell Biology; and the VA Center for Prevention and Treatment of Visual Loss. Through the generous gift by Iowans of ocular tissue for research, the precious goal of eliminating blinding eye disease will be a reality in the future.

Medicare Rules

In August 1998, the Health Care Financing Administration (now CMS) promulgated regulations designed to increase organ tissue and eye donation. The rules, part of the Hospital Conditions of Participation for the Medicare and Medicaid Programs, require "a hospital to have an agreement with the Organ Procurement Organization (OPO) designated by the Secretary of the Department of Health and Human Services (DHHS), under which the hospital will contact the OPO in a timely manner about individuals who die, or whose deaths are imminent in the hospital. The OPO will then determine each individual's medical suitability for donation. The hospital must also have an agreement with at least one tissue bank and at least one eye bank to cooperate in the retrieval, processing, preservation, storage and distribution of tissue and eyes, as long as the agreement does not interfere with organ donation. The final rule requires a hospital to ensure, in collaboration with the OPO with which it has an agreement; the family of every potential donor is informed of its option to donate organs or tissues or eyes, or not to donate."

Iowa Administrative Rules

On November 16, 2016, Iowa Administrative Rules 641.122 went into effect. The new rules outline practices for the distribution of funds through competitive grant opportunities. Hospitals, non-profit agencies, and state agencies may apply for funds for projects that increase public awareness and encourage Iowans to register as donors.

Contributions

Contributions provided through county treasurers and the license plate program to the Anatomical Gift Public Awareness and Transplantation Funds totaled \$101,707 in Fiscal Year 2017 (through December 12, 2017). This is \$2,743 more than provided in Fiscal Year 2016, and

a rate of \$0.032 per capita (based on estimated 2016 population of 3,134,693 per the U.S. Census Bureau). County treasurers, IDN, ILEB and IDPH continue to explore ways to increase awareness of the contribution opportunity and contributions to the fund.

Community Grants

Payments from the Anatomical Gift Public Awareness and Transplantation Fund totaled \$68,255 in Fiscal Year 2016. That total included administrative expenses, public awareness activities, and organ transplantation procedures and related patient costs. Of these payments, individual transplant recipient and donor reimbursements totaled \$66,514, with IDPH administrative costs totaling \$1,741.

Donor Registry

Chapter 1052, Acts of the 2000 General Assembly, authorized the director of IDPH to contract for the establishment of a statewide organ and tissue donor registry. The contract provides for a secure centralized database and automated system to make organ, tissue and eye donor information available to family members and physicians seven days a week, 24 hours a day, as well as to increase public awareness of the program. IDN launched the Iowa Donor Registry (www.iowadonorregistry.org) on March 18, 2002. To date, more than 1.6 million Iowans have registered their intention to become organ, tissue and eye donors upon death. In 2007, the Revised Uniform Anatomical Gift Act was passed by the Legislature requiring the Iowa Department of Transportation (DOT) to provide the Iowa Donor Registry a listing of every Iowan who marked “yes” to donation on a license, permit or identification card. DOT provides monthly downloads to the Iowa Donor Registry as legal consent for donation according to Iowa law. This important legislation increased the number of registrants in the Iowa Donor Registry from an average of 2,000 entries per month to over 30,000 per month. Through digital efforts, IDN has also seen an increase in the number of Iowans registering online. On average, 230 people register online per month and that number is expected to double in the next two years.

As of November 2017, 69.8 percent of adult Iowans are registered donors. This outpaces most states and the national average of 52 percent of all Americans 18 years and older. This number decreased in 2015 due to the removal of duplicates from the state registry. IDN has worked with the state DOT office to gather driver’s license numbers to prevent duplicates moving forward.

Iowa Donor Registry Appropriation

During the 2017 87th General Assembly, the \$150,000 appropriated by House File 653 was reduced to \$100,000 in order to accommodate IDPH department-wide budget reductions. This decrease did not adversely impact IDN’s ability to provide secure access to the database on a 24/7 basis, but did preclude a small number of public awareness campaigns.

The monies for the database allow IDN to determine whether a donor or prospective donor has made, amended or revoked an anatomical gift. The Registry is also able to compile donation information received by the state DOT, county treasurers and the Iowa Donor Network.

Summary

Organ, tissue and eye donation programs continue to serve a significant number of Iowans. As of November 2017, 698 people in Iowa are waiting for lifesaving organ transplants. New corneal transplant techniques are being performed earlier in the course of a blinding eye disease, increasing the demand for corneal tissue. Researchers are utilizing eye tissue more effectively to find cures for blindness. Efforts to increase public awareness and acceptance of organ, tissue and eye donation must continue and should be fostered by every practicing nurse, physician, social worker, paramedic, law enforcement official, hospital administrator and funeral director in Iowa. The Iowa Donor Network, the Iowa Lions Eye Bank, and the Iowa Department of Public Health will continue to promote organ, tissue and eye donation, and explore ways to increase public awareness of the opportunity to donate.