# REPORT TO THE IOWA GENERAL ASSEMBLY

# ANATOMICAL GIFT PUBLIC AWARENESS ANNUAL DONATION AND COMPLIANCE REPORT

## FOR THE CALENDAR YEAR 2012

# **Submitted by**

**Iowa Department of Public Health** 

in conjunction with

**Iowa Donor Network and Iowa Lions Eye Bank** 

#### 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 one organ procurement organization, the Iowa Donor Network (IDN), and a single 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 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 donors for January through September of each year is as follows:

Year	Number of Organ Donors
2012	53
2011	46
2010	50
2009	43
2008	47

The number of tissue donors, January through September:

Year	Number of <i>Tissue</i> Donors
2012	784
2011	491
2010	390
2009	412
2008	300

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

Year	Number of Eye Transplant Donors	Number of Eye Research Donors
2012	762	353
2011	762	269
2010	737	368
2009	621	260
2008	506	274

#### Organ, Tissue, and Eye Donors

Consistent with requirements of CMS, the Centers for Medicare and Medicaid Services, the Iowa Donor Network 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 50 people. It is projected that approximately 34,000 people will receive transplantable tissue needed for life-saving and life-enhancing procedures each year.

On average, *each eye donation* provides sight to two people and provides additional tissue for up to six scleral patch grafts for eye traumas and glaucoma shunt surgeries. In the past few years, corneal transplant surgical techniques have advanced and now provide options that improve visual outcomes in a shorter period of time. For example, through standard transplant techniques, 13% of patients achieve 20/40 vision or better in one year. This compares to 35% in three months using a technique that transplants only the back 1/3 of the cornea. The Iowa Lions Eye Bank, using the corneal grafts preparation technique they pioneered last year, were able to help surgeons in Iowa and in the U.S. restore more vision faster with less rejection. Patients who had this new type of surgery gained 20/30 vision or better within one week of transplant with virtually no rejection. Transplants are being performed earlier and more frequently than before, saving sight earlier and decreasing the trauma and loss of productivity of Iowans who are losing sight. Even though donations are increasing, they do not keep up with the demand in Iowa. In 2012, Iowa imported 41 corneas for transplantation, a 32% increase over the corneas imported last year and again this year did not import eyes for research.

Eyes donated to research by Iowans are given to the University of Iowa Institute for Vision Research (IVR). The IVR makes available the research tissue from Iowans to their units: Carver Family Center for Macular Degeneration; Glaucoma Research; Pediatric Genetics; Center for Bioinformatics and Computational Biology; Non-profit Genetic Testing; Visual Rehabilitation/Disability; Program in Stem Cell Biology; and the VA Center for Prevention and Treatment of Visual Loss. This is the most efficient and effective way to utilize the precious gift of answers through research contributed by generous Iowans to the goal of eliminating blinding eye disease.

#### **Medicare Rules**

In August 1998, the Health Care Financing Administration (now CMS, the Centers for Medicare and Medicaid Services) 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."

#### **Contributions**

Contributions provided through county treasurers and the license plate program to the Anatomical Gift Public Awareness and Transplantation Funds totaled \$79,091 in fiscal year 2011. This is \$7,776 more than provided in fiscal year 2011. This revenue represents a steady rate of \$0.026 per capita (based on estimated 2010 population of 3,046,355 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**

Payment from the Anatomical Gift Public Awareness and Transplantation Fund totaled \$111,056 in Fiscal Year 2012. This included public awareness activities, organ transplantation procedures and related patient costs, and support of the donor registry. Of these payments, individual transplant recipients and donors were reimbursed \$51,622. Administrative costs totaled \$131.

#### **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 centralized database and automated system to make organ, tissue, and eye donor information available to family members and physicians seven days a week, twenty-four hours a day. IDN launched the Iowa Donor Registry (<a href="www.iowadonorregistry.org">www.iowadonorregistry.org</a>) on March 18, 2002. To date, more than 1.7 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.

As of November 2012, 68% of all Iowans are registered donors. This outpaces most states and the national average of 48% of all Americans 18 years and older.

#### Iowa Donor Registry Appropriation

During the 84<sup>th</sup> General Assembly (2012), Senate File 2336 appropriated \$50,000 to be directed to IDN through IDPH for upgrades and data cleansing of the registry. To date, bids have been requested by IDN to redesign the donor registry to ensure compatibility across all digital platforms that operate the internet. This work is in progress.

In addition, IDN has set aside monies to offset the costs of obtaining a list of deaths occurring in Iowa from the Vital Records Bureau in IDPH to ensure the registry data is upto-date, much like drivers license records are cleaned after someone has died.

### **Summary**

Organ, tissue, and eye donation programs continue to serve a significant number of Iowans. As of November 2012, more than 625 Iowans are waiting for lifesaving organ transplants. This number is higher than the number waiting at this time last year. 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.