Prior to Matthew’s death, he had discussed organ donation with us and had put the sticker on his license. This made our decision to proceed with organ donation much easier. We are very proud of Matthew for the life that he lived and the gift he gave at his death.

Kim, donor mother
**methods**

**PRA AND CPRA**
For kidney and pancreas transplant recipients prior to December 2007, PRA at the time of transplant is the value of the most recently recorded PRA. If that value is missing, we use the peak PRA value known at the time of transplant. In 2004, the OPTN Recipient Histocompatibility form changed the PRA collection method from overall PRA to Class I and Class II PRA. From 2004 through 2007, we use the maximum of the Class I and Class II values. From December 2007 through October 2009, we incorporate Calculated PRA (CPRA) if the value is greater than zero. In this time frame, we use the maximum of measured PRA and CPRA. From October 2009 to present, we use the maximum of CPRA, measured PRA, and allocation PRA. A similar approach is used for PRA and CPRA among kidney and pancreas candidates.

For liver, intestine, heart, and lung transplant recipients, PRA at the time of transplant is the value of the most recently recorded PRA. If that value is missing, we use the peak PRA value known at the time of transplant. In 2004, the OPTN Recipient Histocompatibility form changed the PRA collection method from overall PRA to Class I and Class II PRA. In these years, we use the maximum of the Class I and Class II values.

**GRAFT FAILURE**
Unless otherwise specified, “graft failure” refers to graft failure due to any cause, including death and re-transplantation. For kidney failure, this also includes return to maintenance dialysis. “Graft survival” similarly refers to the absence of all-cause graft failure.

**HALF-LIFE**
Graft half-life and conditional half-life estimates were computed using a “period” method, which is different from the method previously used. In the past, conditional half-life estimates relied on the rarely-true assumption of constant hazard after the first post-transplant year, and extrapolated the survival curve to its half-life based on that early hazard. The “period” method constructs a survival curve until the half-life differently. If the half-life of a cohort in a given year is observed, then the survival curve is constructed using the Kaplan-Meier method based on the observed data of this cohort.
Otherwise, we construct the survival curve using the data from the cohort for the observed part and “borrow” data from earlier cohorts for the rest. For example, the 2007 half-life estimate for kidney graft survival is based on observed and borrowed data. For patients transplanted in 2007, we have observed 4-year survival data through 2011. We extrapolate this 4-year survival curve to its half-life by using the observed 5th year failure rate of the 2006 cohort as the 5th year failure rate of 2007 cohort, the 6th year failure rate of 2005 cohort as the 6th year failure rate of 2007 cohort, and so on. Conditional half-life estimates are similarly computed, but limited to patients with one year of graft survival.

ALIVE WITH FUNCTION
For a given year and organ type, counts of recipients alive with function include all recipients of that organ, transplanted prior to June 30 of the given year and with no evidence of graft loss or death. Multi-organ recipients are counted once per organ. A heart-lung recipient, for example, is included in the counts of heart recipients and of lung recipients alive with function. A kidney-alone recipient who is transplanted in January, 2000, and who loses graft function in November, 2010, is counted as alive with function every year from 2000 through 2010. Recipients who are lost to follow-up are assumed alive with a functioning graft until evidence, usually a death date, contradicts this assumption.

RATES BY SUBGROUP
When rates are shown by subgroup (i.e., sex, race, primary cause of disease), numerator and denominator are computed exclusively within those groups. For example, for pre-transplant mortality by race group, the numerator for each race group is the number of deaths in that race group during the interval described. The denominator is the total waiting time within each race group in that same time interval. When a characteristic is subject to change over time (i.e., age, PRA), the subgroup variable is updated to use the first known value in a given interval, unless otherwise noted. For example, a wait-list candidate who is 34 on January 1, 2001, will be included in the 18-34 age group in 2001, but if still listed in 2003, that patient will be included in the 35-49 age group.
Acute rejection  The host recognizes the graft as foreign and mounts an immunological attack on the graft tissues. Most acute rejections occur in the first year.

Allocation  The process of determining how organs are distributed. Allocation includes the system of policies and guidelines, which ensure that organs are distributed in an equitable, ethical and medically sound manner.

Allocation analysis  Review of the allocation of an organ to determine whether the allocation policies were followed. The analysis is performed by the OPTN contractor through the peer review process of the OPTN Membership and Professional Standards Committee.

Allograft  An organ or tissue that is transplanted from one person to another of the same species: i.e. human-to-human. Example: a transplanted kidney.

Anti-rejection drugs (immunosuppressive drugs)  Drugs that are used to prevent and/or treat rejection of a transplanted organ.

Antibody  A protein molecule produced by the immune system in response to a foreign body, such as virus or a transplanted organ. Since antibodies fight the transplanted organ and try to reject it, recipients are required to take anti-rejection (immunosuppressive) drugs.

Antigen  An antigen is any substance that causes your immune system to produce antibodies against it. An antigen may be a foreign substance from the environment such as chemicals, bacteria, viruses, pollen, or foreign tissues. An antigen may also be formed within the body, as with bacterial toxins.

Biopsy  A tissue sample from the body, removed and examined under a microscope to diagnose for disease, determine organ rejection, or assess donated organs or tissues.

Blood vessels  The veins, arteries and capillaries through which blood flows in the body. Certain blood vessels can be donated and transplanted.

Brain death  Irreversible cessation of cerebral and brain stem function; characterized by absence of electrical activity in the brain, blood flow to the brain, and brain function as determined by clinical assessment of responses. A brain dead person is dead, although his or her cardiopulmonary functioning may be artificially maintained for some time.

Candidate  A person registered on the organ transplant waiting list. When an organ is offered on behalf of the candidate, he or she is then referred to as a Potential Transplant Recipient (PTR).

Cardiac  Having to do with, or referring to, the heart.

Cardiac death  Death defined as the irreversible cessation of circulatory and respiratory functions. Death is declared in accordance with hospital policy and applicable state and local statues or regulation.

Chronic  Developing slowly and lasting for a long time, possibly the rest of a person’s life. For example: chronic kidney failure.

Chronic Disease Research Group (CDRG)  A division of Minnesota Medical Research Foundation (MMRF). MMRF is the non-profit research subsidiary of Hennepin Faculty Associates, the academic medical group that staffs Hennepin County Medical Center, a teaching hospital in Minneapolis, Minnesota. The CDRG conducts research primarily focused in the areas of chronic kidney disease and organ transplantation. The MMRF-CDRG is responsible for the administration of the Scientific Registry of Transplant Recipients (SRTR).

Chronic rejection  Slow, continuous immunological attack of the host immune system on the transplanted organ usually resulting in progressive loss of organ function.

Cirrhosis  A disease of the liver in which normal, healthy tissue is replaced with nonfunctioning fibrous scar tissue and healthy, functioning liver cells are lost; usually occurs when there is a lack of adequate nutrition, an infection or damage caused by alcohol abuse.

Committees  The OPTN currently maintains approximately 20 standing committees, a fluctuating number of ad hoc committees (established by the President to address a specific issue as it arises), subcommittees and joint subcommittees (created and maintained by standing committees). Committees are comprised of professionals, at least one Patient/Public representative, Minority Affairs Committee Representative, Pediatric Committee Representative, and one or more SRTR representatives. Permanent Standing Committees also include representatives from each of the 11 Regions. HRSA’s OPTN Project Officer and Director of DOT, or their designees, serve as ex-officio non-voting members of all committees. Each committee is provided administrative, policy, analytic, clinical and technical support by one or more committee liaisons from the UNOS staff.
Corticosteroid A synthetic hormone used to reduce the body’s normal immune reaction to infection and foreign tissue, such as a transplanted organ. Prednisone is a corticosteroid.

Criteria (medical criteria) A set of clinical or biologic standards or conditions that must be met.

Cyclosporine A drug used to prevent rejection of the transplanted organ by suppressing the body’s defense system. Considered an immunosuppressant.

Deceased donor An individual from whom at least one solid organ is recovered or the purpose of transplantation after suffering brain death or cardiac death.

Deceased donor transplant The transplant of an organ from a deceased donor.

Department of Health and Human Services (DHHS or HHS) The department of the federal government responsible for health-related programs and issues.

Dialysis A mechanical process designed to partially perform kidney functions, including correcting the balance of fluids and chemicals in the body and removing wastes. See Hemodialysis and Peritoneal Dialysis.

Diastolic blood pressure The bottom number in the blood pressure measurement (80 in a blood pressure of 120/80), indicating the pressure in the arteries when the heart is at rest.

Division of Transplantation (DoT) DoT is the office within DHHS/HRSA whose principal responsibilities include the oversight of management of the Organ Procurement and Transplantation Network (OPTN), the Scientific Registry of Transplant Recipients (SRTR) and the National Marrow Donor Program (NMDP) contracts; public education to increase organ and tissue donation; and technical assistance to organ procurement organizations (OPOs).

Domino transplant A procedure in which an organ is removed from one transplant candidate and immediately transplanted into a second patient, with the first patient receiving a new organ from a deceased donor.

Donate Life America Formerly the Coalition on Donation, Donate Life America is a national not-for-profit alliance of local affiliates and corporate partners that have joined forces to inspire all people to Donate Life through organ, eye and tissue donation. At the core of the organization’s education efforts are the ongoing qualitative and quantitative research of public attitudes about organ and tissue donation and the development and dissemination of effective, motivating public service campaigns. Distributed at the national and community level, these multimedia campaigns effectively communicate two core messages: Transplants give people their life back, and here is how you can help. Founded by the transplant community in 1992, the Coalition publishes brochures, program kits and other materials; provides technical assistance, training, information and referral services; and coordinates the National Campaign for Organ and Tissue Donation. It is comprised of national organizational members and local coalitions across the U.S. that coordinate donation related activities at the local level. Volunteer advertising agencies work with the Coalition and its committees to develop targeted mass media campaigns.

Donation Service Area (DSA) The geographic area designated by CMS that is served by one organ procurement organization (OPO), one or more transplant centers, and one or more donor hospitals. Formerly referred to as Local Service Area or OPO Service Area.

Donor Someone from whom at least one organ or tissue is recovered for the purpose of transplantation. A deceased donor is a patient who has been declared dead using either brain death or cardiac death criteria, from whom at least one transplanted solid organ is recovered for the purpose of organ transplantation. A living donor is one who donates an organ or segment of an organ for the intent of transplantation.

Donor registries Available 24 hours a day, seven days a week, online registries provide authorized professionals access to a confidential database of registered organ donors, allowing easy and quick confirmation of an individual’s consent to organ donation. All registries are voluntary and some are affiliated with the local motor vehicle bureau, while others are independently operated or OPO-based.

End-stage organ disease A disease that leads to the permanent failure of an organ.

Ethnicity For OPTN data purposes, the use of categories such as white, black or African-American, Hispanic, Asian, American Indian/Alaskan Native, Pacific Islander, multiracial.

Expanded criteria donor (ECD) kidney A kidney donated for transplantation from any brain dead donor over the age of 60 years; or from a donor over the age of 50 years with two of the following: a history of hypertension, the most recent serum creatinine greater than or equal to 1.5 mg/dl, or death resulting from a cerebral vascular accident (stroke). This definition applies to the allocation of deceased donor kidneys.

Functional status A way to measure the effects that lung disease may have on a person’s ability to perform routine daily tasks. Functional status is used in the Lung Allocation Score.

Graft survival The length of time an organ functions successfully after being transplanted.

Graft A transplanted organ or tissue.

Glomerular filtration rate (GFR) A measure used to determine kidney function, the GFR indicates the kidney’s ability to filter and remove waste products.

Hepatic Having to do with, or referring to, the liver.

Hepatitis A viral infection or non-specific inflammation of the liver that can lead to liver failure. Hepatitis C is the leading cause of liver failure that leads to transplantation.

High blood pressure See hypertension.

Histocompatibility The examination of human leukocyte antigens (HLA) in a patient, often referred to as “tissue typing” or “genetic matching.” Tissue typing is routinely performed for all donors and recipients in kidney and pancreas transplantation to help match the donor with the most suitable recipients to help decrease the likelihood of rejecting the transplanted organ. See Human Leukocyte Antigen System (HLA System).

Human immunodeficiency virus (HIV) A virus which destroys cells in the immune system, which makes it difficult for the body to fight off infections; toxins, or poisons; and diseases. HIV causes AIDS, a late stage of the virus characterized by serious infections, malignancies, and neurologic dysfunctions.
Hypertension High blood pressure. Occurs when the force of the blood pushing against the walls of the blood vessels is higher than normal because the blood vessels have either become less elastic or have gotten smaller. Hypertension causes the heart to pump harder to move blood through the body. It can cause kidney failure and heart disease if not treated.

Immune response The body’s natural defense against foreign objects or organisms, such as bacteria, viruses or transplanted organs or tissue.

Immune system The organs, tissues, cells and cell products in your body that work to find and neutralize foreign substances including bacteria, viruses and transplanted organs.

Immunosuppression Prevention or inhibition of the immune system to respond to foreign substances in the body. Medications often used to prevent a recipient’s immune system from rejecting a transplanted organ or tissue include prednisone, methylprednisolone, azathioprine, mycophenolate mofetil, cyclosporine, tacrolimus, and sirolimus, among others.

Immunosuppressive Relating to the weakening or reducing of your immune system’s responses to foreign material; immunosuppressive drugs reduce your immune system’s ability to reject a transplanted organ.

Induction therapy Medications given for a short finite period in the perioperative period for the purpose of preventing acute rejection. Though the drugs may be continued after discharge for the first 30 days after transplant, it will not be used long-term for immunosuppressive maintenance.

Infection A condition that occurs when a foreign substance, such as bacteria, enters your body, causing your immune system to fight the intruder. All transplant recipients can get infections more easily because their immune systems are suppressed. It is more difficult for them to recover from infection (such as urinary tract infections, colds and the flu).

Inflammation The swelling, heat and redness produced when the body is injured or infected.

International normalized ratio (INR) A measure of a patient’s coagulation (clotting) system. INR is used in the MELD and PELD calculations.

Kidneys A pair of organs that remove wastes from the body through the production of urine. All of the blood in the body passes through the kidneys about 20 times every hour. Kidneys can be donated from living and deceased donors and transplanted into patients with kidney failure.

Leukocyte A white blood cell.

Liver The largest organ in the body, made up of a spongy mass of wedge-shaped lobes. The liver secretes bile, which aids in digestion, helps process proteins, carbohydrates, and fats, and stores substances like vitamins. It also removes wastes from the blood. A living donor can give part of their liver, after which the liver will regenerate itself in both the donor and recipient.

Match The compatibility between the donor and the recipient. The more appropriate the match, the greater the chance of a successful transplant.

Medicaid A partnership between the Federal government and the individual states to share the cost of providing medical coverage for recipients of welfare programs and allowing states to provide the same coverage to low-income workers not eligible for welfare. Programs vary greatly from state to state.

Medicare The program of the Federal government that provides hospital and medical insurance, through social security taxes, to people age 65 and over, those who have permanent kidney failure and certain people with disabilities.

Multiple listing Being on the waiting list for the same organ at more than one transplant center.

National Organ Transplant Act (N Ota) The National Organ Transplant Act (1984 Public Law 98-507), approved October 19, 1984 and amended in 1988 and 1990, outlawed the sale of human organs and provided for the establishment of the Task Force on Organ Transplantation; authorized the Secretary of HHS to make grants for the planning, establishment, and initial operation of qualified OPOs; and established the formation of the Organ Procurement and Transplantation Network (OPTN) and Scientific Registry of Transplant Recipients (SRTR).

New York Heart Association Functional Classification (NYHA) An assessment of a patient’s heart failure based on the severity of symptoms. Range is Class I-IV.

Noncompliance 1) Failure of patients to follow the instructions of the medical team, 2) Failure of OPTN members to adhere to the policies and bylaws of the OPTN.

Organ A part of the body made up of tissues and cells that enable it to perform a particular function. Transplantable organs are the heart, liver, lungs, kidneys, pancreas and intestines.

Organ donation To give an organ or a part of an organ to be transplanted into another person. Organ donation can occur with a deceased donor, who can give kidneys, pancreas, liver, lungs, heart, intestinal organs, and with a live donor, who can give a kidney, or a portion of the liver, lung, or intestine.

Organ preservation Methods used to preserve organs while they are out of the body, between procurement from a donor and transplantation into a recipient.

Organ procurement The removal or retrieval of organs from a donor for transplantation.

Organ Procurement and Transplantation Network (OPTN) In 1967, Congress passed the National Organ Transplant Act that mandated the establishment of the OPTN and Scientific Registry of Transplant Recipients. The purpose of the OPTN is to improve the effectiveness of the nation’s organ procurement, donation and transplantation system by increasing the availability of and access to donor organs for patients with end-stage organ failure. The Act stipulated that the Network be a non-profit, private sector entity comprised of all U.S. transplant centers, organ procurement organizations and histocompatibility laboratories. These members along with professional and voluntary healthcare organizations and the representatives of the general public are governed by a Board of Directors which reports to the Division of Transplantation, HHS, and ultimately HHS. UNOS holds the OPTN contract.

Organ Procurement Organization (OPO) An organization designated by the Centers for Medicare and Medicaid Services (CMS) and responsible for the procurement of organs for transplantation and the promotion of organ donation. OPOs serve as the vital link between the donor and recipient and are responsible for the identification of donors, and the retrieval, preservation and transportation of organs for transplantation. They are also involved in data follow-up regarding deceased organ donors. As a resource to the community OPOs engage in public education on the critical need for organ donation. See also Donation Service Area (DSA).

Pancreas Irregularly shaped gland that lies behind the stomach and secretes pancreatic enzymes into the small intestines to aid in
the digestion of proteins, carbohydrates and fats. Islet cells within the pancreas secrete glucagon, which regulates blood sugar levels and insulin, which lowers blood sugar levels. If the pancreas fails, the individual becomes diabetic, and may need to take insulin. The pancreas can be donated and transplanted.

**Panel reactive antibody (PRA)** The percent PRA value is a measure of a patient’s level of sensitization to HLA antigens. It is the percentage of cells from a panel of blood donors against which a potential recipient’s serum reacts. The PRA reflects the percentage of the general population that a potential recipient makes antibodies (is sensitized) against. For example, a patient with a PRA of 80 percent will be incompatible with 80 percent of potential donors. Kidney patients with a high PRA are given priority on the waiting list. The higher the PRA, the more sensitized a patient is to the general donor pool, and thus the more difficult it is to find a suitable donor. A patient may become sensitized as a result of pregnancy, a blood transfusion, or a previous transplant.

**PCO2** A blood gas test is performed to measure the amount of CO2 in the blood. When the lung’s ability to exchange oxygen and CO2 becomes impaired, the PCO2 level may become increased. The candidate’s current PCO2 and change in PCO2 are both considered in the lung allocation score calculation to reflect worsening PCO2 values. PCO2 is used in the Lung Allocation Score.

**Peritoneal dialysis** A treatment technique for kidney failure that uses the patient’s own body tissues inside of the (abdominal cavity to act as a filter. The intestines lie in the abdominal cavity, the space between the abdominal wall and the spine. A plastic tube called a “dialysis catheter” is placed through the abdominal wall into the abdominal cavity. A special fluid is then flushed into the abdominal cavity and washes around the intestines. The lining (peritoneum) of the abdominal cavity and of intra-abdominal organs act as a filter between this fluid and the blood stream. By using different types of solutions, waste products and excess water can be removed from the body through this process.

**Plasmapheresis** A process in which plasma is removed from the body and the remaining components, mostly red blood cells, are returned to the donor. The process may be used in transplantation to remove pre-formed antibodies.

**Procurement** The surgical procedure of removing an organ from a donor. Also referred to as recovery.

**Pulmonary** Having to do with, or referring to, the lungs.

**Race** See ethnicity.

**Recipient** A person who receives a transplant.

**Recovery (organ)** The surgical procedure of removing an organ from a donor.

**Rejection** A phenomenon that occurs when a recipient’s immune system attacks a transplanted organ, tissue, or cell. Immunosuppressive drugs help prevent or treat rejection.

**Renal** Having to do with, or referring to, the kidneys.

**Required request** Hospitals must tell the families of suitable donors that their loved one’s organs and tissues can be used for transplant. This law is expected to increase the number of donated organs and tissues for transplantation by giving more people the opportunity to donate.

**Retransplantation** Due to rejection or failure of a transplanted organ, some patients receive another transplant.

**Retrieval** The surgical procedure of organ recovery. Also referred to as procurement.

**Risk pools** State-created, nonprofit associations that do not require tax dollars for operational purposes. The risk pools are a temporary stopping place for individuals who are denied health insurance for medical reasons. Risk pools often help individuals who, because of their physical condition, are unable to purchase health insurance at any price.

**Scientific Registry of Transplant Recipients (SRTR)** As called for by the National Organ Transplant Act (NOTA), the purpose of the SRTR is to provide ongoing evaluation of clinical data about donors, transplant candidates, and recipients, as well as patient and graft survival rates. With oversight and funding from the DoT, the SRTR is currently administered by the Chronic Disease Research Group (CDRG) of the Minneapolis Medical Research Foundation (MMRF).

**Sensitization** Transplant candidates are “sensitized” if their immune system makes antibodies against a general donor pool. Sensitization usually occurs as a consequence of pregnancy, blood transfusions, or previous transplantation. The degree of sensitization is measured by panel reactive antibody (PRA). Highly sensitized patients are less likely to match with available donors and more likely to reject an organ than unsensitized patients.

**Status** An indication of the degree of medical urgency for patients awaiting heart or liver transplants. Examples: status 1A, status 1B, or status 2.

**Steroids** Naturally occurring hormones in the body that help control important body functions. Synthetic or man-made steroids can be used to suppress the immune system.

**Survival rates** Survival rates indicate the percentage of patients that are alive and the grafts (organs) that are still functioning after a certain amount of time. Survival rates are used in developing OPTN policy.

**Systolic blood pressure** The top number in the blood pressure (the 120 in a blood pressure of 120/80) measures the maximum pressure exerted on the vessel wall when the heart contracts.

**Tissue** An organization of a great many similar cells that perform a special function. Examples of tissues that can be transplanted are blood, bone, bone marrow, corneas, heart valves, ligaments, saphenous veins, and tendons.

**Tissue typing** A blood test that helps evaluate how closely the tissues of the donor match those of the recipient.

**Uniform Determination of Death Act (UDDA)** The 1987 Uniform Determination of Death Act is a model statute defining “brain death.” Versions of this Act have been adopted in 39 states and the District of Columbia. The act states that an individual who has sustained either (a) irreversible cessation of circulatory or respiratory functions or (b) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.

**United Network for Organ Sharing (UNOS)** The private, nonprofit membership organization that coordinates the nation’s transplant system through its OPTN contract. As OPTN contractor, UNOS is responsible for meeting all contract requirements. As contractor since the first OPTN contract award in 1986, UNOS has established and continually strives to improve tools, systems and quality processes that support OPTN contract objectives and requirements. These include:
• Managing the national organ transplant waiting list
• Collecting, managing and reporting of sensitive clinical data in a secure, fail-safe environment
• Facilitating an open, inclusive forum for development and continuous refinement of evidence-based policies and standards
• Member and policy performance assessment to ensure equitable, safe treatment of candidates and recipients
• Increasing donation and making the most of every organ that is donated through professional education, research, patient services and resources and public and professional education
• Continuously improving the care, quality of life and outcomes of organ transplant candidates and recipients

Varices (esophageal) Enlarged and swollen veins at the bottom of the esophagus, near the stomach. A common condition caused by increased venous pressure in the liver. These veins can ulcerate and bleed.

Vascular Referring to blood vessels and circulation.

Ventilator A machine that “breathes” for a patient when the patient is not able to breathe properly.

Virus A group of tiny organisms capable of growing and copying themselves while living within cells of the body.

Warm ischemic time (WIT) If the donor is a DCD donor, the warm ischemic time is the time from:

1. the time of Agonal Phase onset (from the time of cardiac arrest when the systolic pressure meets the following conditions for greater than five (5) minutes) to the time when core cooling is initiated. Agonal Phase onset:
   a. Newborn up to 28 days, with a systolic blood pressure less than 60 mmHg, or
   b. 29 days up to 12 months, with a systolic blood pressure less than 70 mmHg, or
   c. 1 year up to 10 years, with a systolic blood pressure less than 70 mmHg, plus 2 times the age of the patient in years, not to exceed 79 mmHg, or
   d. 11 years or older, with a systolic blood pressure less than 80 mmHg, or when the oxygen saturation is less than 80% at any age,

• The calculated time using the serial data to be collected beginning with the agonal phase and ending with the initiation of core cooling.

Xenograft An organ or tissue procured from a different species for transplantation into a human.

Glossary adapted from transplantliving.org, a UNOS website.