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ISHLT International Registry for Heart and Lung Transplantation—Into the Fourth Decade, From Strength to Strength

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This year, the ISHLT International Registry for Heart and Lung Transplantation enters into its fourth decade. With data from more than 160,000 thoracic transplant recipients, the Registry is the largest repository of heart and lung transplant data in the world.

The Registry has had an interesting and somewhat tumultuous history. One of the authors, Jeffrey Hosenpud was directly involved in its earliest times. His first direct involvement was in 1988 when, after performing a transplant in a patient with amyloid light-chain (AL)

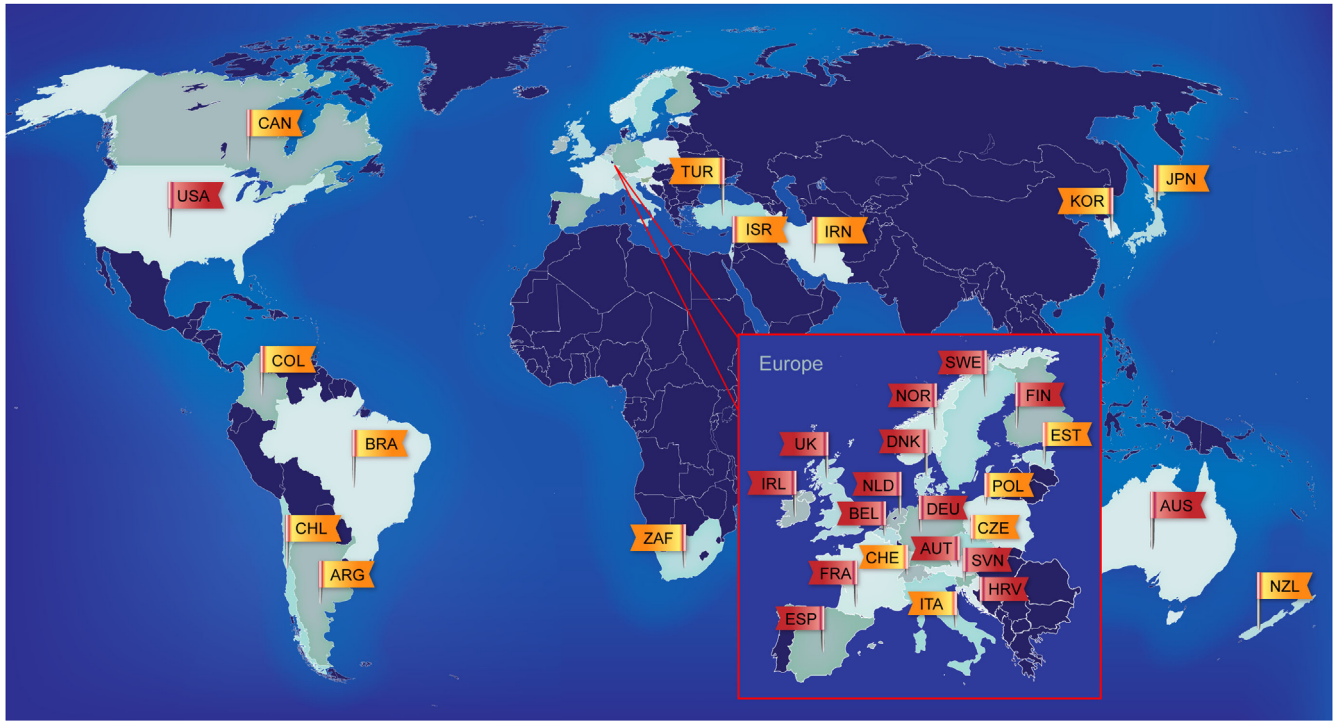

Figure 1 Countries participating in the ISHLT International Registry for Heart and Lung Transplantation. Red flag indicates national or collaborative data submission; yellow flag indicates direct submission of data by individual centers.

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amyloidosis—at the time considered an absolute contraindication to transplantation, he wanted to know if there were other patients who had received transplants for that disease. Hosenpud flew to San Diego to meet with Dr Mike Kaye, the first Registry director, and "queried" the Registry, which was an Excel spreadsheet with about half the patient data entered, and several boxes of index cards that were gone through by hand. Despite the not quite optimal organization of the data, several other patients with AL-chain amyloidosis were identified, and this series was ultimately published.[1]

In the United States, the United Network for Organ Sharing (UNOS) was awarded the government contract for the Organ Procurement and Transplantation Network (OPTN) in 1986 and the Scientific Registry of Transplant Recipients (SRTR) contract in 1987. Kaye was instrumental in developing the data collection instrument for the UNOS Thoracic Registry (basing it primarily on the ISHLT Registry) and coordinated data submission to the Registry through UNOS. As submission of data to UNOS was mandated in the United States, the quality of the ISHLT Registry data also immediately improved. Unfortunately, the relationship between UNOS and the Registry was not all honey and roses: Conflicts arose regarding additional data collection, timely submission of data from UNOS to the Registry, cost, and oversight issues. This friction ultimately led the ISHLT Board to sever relations with UNOS in 1990, and ISHLT began the process of getting United States centers to once again submit data separately.

As the UNOS Scientific Advisory Committee Vice Chair, Hosenpud was the de facto UNOS Thoracic Registry Director starting in 1991. He received an unexpected call from the ISHLT President Dr Billingham expressing regret about the separation of the 2 registries. There was also resistance from United States transplant centers regarding the request to submit similar data to 2 registries. Billingham wondered if the relationship could be repaired and requested a "secret" meeting in Chicago, which included Billingham, ISHLT Board Member John B. O'Connell, UNOS Executive Director Gene Pierce, UNOS Assistant Executive Director Walter Graham, and Hosenpud. They agreed to work behind the scenes to bring the 2 organizations and registries back together, which was ultimately accomplished.

Hosenpud was appointed the ISHLT Registry Director in 1993, and his first official accomplishment was obtaining additional funding from the ISHLT to contract with UNOS for all data collection and a yearly data analysis and slide generation. ISHLT Registry data were electronically integrated and maintained separately from UNOS data as a unique database. The first report and slides analyzed and generated in collaboration with UNOS was the 1994 Registry report.[2] In 1997, Dr Mark Boucek was named the Associate Registry Director, with responsibility for pediatric data, and separate pediatric and adult Registry reports were initiated.

Under the tenure of Marshall Hertz, the Registry Steering Committee was expanded, and generation of separate organ-specific reports was initiated. Over the coming years, collaborative efforts were established between the Registry and 6 other data exchange organizations around the world that now submit data to ISHLT through regular data transfers (Appendix). Additional countries in Europe, Asia, North and South America, and Africa, where centralized data submission is not (yet) possible, participate in the Registry individually, through Web-based data entry. More than 280 centers from 33 countries currently participate in the Registry.

The above retrospective, and conclusion of another decade of work, provides an opportunity to pinpoint the factors that have contributed to the Registry's success. We believe the following have been key in this process:

1. Operation of the Registry by an international professional society that represents multiple stakeholders in thoracic transplantation. The ISHLT has provided not only the logical "home" for the Registry but also the logistical and financial support that has shielded the Registry from financial and other uncertainties of the ever-changing health care environment.
2. Inclusion of both the pediatric and adult populations.
3. Aggressive pursuit of truly international participation (Figure 1).
4. Flexibility of the Registry in allowing different arrangements for data entry while maintaining the necessary quality standards. The Registry has developed mechanisms for efficient data entry from individual centers, for transfer of data from national registries, and for transfer of data from registries of country collectives.[3]
5. Establishing a clear governance and workforce structure through the Registry Steering Committee (Table 1), with defined responsibilities and expectations.
6. Maintaining strong statistical core, directed by Leah Edwards, PhD, which provides year-round support to Registry work.
7. Partnership with the *Journal of Heart and Lung Transplantation*. The Registry reports provide the readers with yearly updates on the developments in the field of thoracic transplantation, and the Registry output is thus widely disseminated.[4–7] The Registry slides, available to ISHLT members, are abundantly used in scientific presentations. The high—and currently increasing—rate of citations of the ISHLT reports and other Registry studies in peer reviewed publications demonstrates the widespread and growing importance of the Registry data to our field. For illustration, the single 2001 Registry report[8] has since received 676 citations, a rate of 56 citations per year. The 2010 Registry report series, consisting of an introduction and 4 organ-specific reports,[9–13] has been cited 608 times, at a running rate of 202 citations per year. Similarly, the Registry data analyses have influenced formulation of recommendations in clinical practice guidelines, further impacting clinical care.[14–21]

After 3 decades, the Registry remains very relevant to our everyday practice, and this has been further boosted by recent developments in our field. The expanding use of mechanical circulatory assist in advanced heart failure,

clinical application of ex vivo organ perfusion, increasing acceptance of donation after circulatory death (DCD) in lung transplantation, successful implementation of ABO-incompatible transplantation, and other emerging clinical approaches are changing the questions we ask of the Registry. Further, the rapid global growth of heart and lung transplantation represents additional opportunities for expanding the Registry and starting new collaborations. Now under the direction of Josef Stehlik, the Registry continues to evolve, and innovative approaches to answer the needs of the thoracic transplant community are being pursued. Examples of recent and planned Registry work include:

- Presentation of results from a DCD Mini-registry at the 2013 ISHLT Annual Scientific Sessions in Montreal.[22] The "mini-registry" approach allows investigators from a group of centers with a special interest in a particular clinical question to design a focused database where supplementary data pertinent to the topic of interest are collected on existing transplants in the Registry, so that detailed follow-up information is already available for these patients in the main Registry. Centers from Canada, Europe, Australia, and the United States are currently participating in the DCD Mini-registry.
- We continue to promote the Transplant Registry Early Career Awards, which provide an opportunity for junior investigators to obtain access to Registry data while receiving financial support to conduct the analyses. This is also a natural way for junior members to network with members of the Registry steering committee and other ISHLT content experts and so become involved in the Society's core activities. This mechanism has funded 12 junior investigators since 2007 (Table 2), and 2 presented their work at the annual sessions this year.[23,24] We would like to encourage junior investigators, especially those from non-North American programs, to explore the data elements posted on the Registry Web site and consider submitting an application for a 2014 Award (http://www.ishlt.org/awards/awardTxRegistry.asp, dead line in January 2014).
- Thoracic transplantation is gradually gaining ground in regions that have not traditionally been among the core geographic areas in our field. The ISHLT is greatly interested in the active participation of transplant professionals from these countries in our Society. The Registry provides a platform for international collaborations and for learning from each other's experiences. Last year we welcomed new centers from Brazil, Estonia, Poland, Turkey, and Iran to the family of more than 280 centers from 33 countries worldwide that participate in the Registry. Continued efforts will be directed at further expansion of the Registry's member base.

Figure 2 New ISHLT Registry logo.

- This year we introduce a new feature to our annual Reports. In addition to providing the core information regarding demographics, immunosuppression, and outcomes, a focus theme will explore a defined topic in more detail every year. The 2013 report explores age as an important donor and recipient variable and its effect on the transplant process and outcomes. In addition to information presented in the printed version of the reports published in this issue of the *Journal*, an online Registry data set, complete with a brand new Registry logo (Figure 2), also offers a number of expanded focus theme analyses.[25]

We hope we are starting off another successful decade for the Registry. We sincerely thank ISHLT members, staff at participating hospitals, and staff at data exchange organizations for their active support (Appendix 1). Without this enthusiastic support the ISHLT International Registry for Heart and Lung Transplantation would have long departed.

Table 1 Steering Committee and Staff of the ISHLT International Registry for Heart and Lung Transplantation

Steering Committee	Position
Josef Stehlik, MD	Medical Director
Jason Christie, MD	Associate Director, Lung Transplantation
Roger Yusen, MD[a]	Associate Director, Lung Transplantation
Christian Benden, MD	Associate Director, Pediatric Lung Transplantation
Lars Lund, MD[a]	Associate Director, Heart Transplantation
Anne Dipchand, MD	Associate Director, Pediatric Heart Transplantation
Richard Kirk, MD	Associate Director, Pediatric Heart Transplantation
Axel Rahmel, MD	Associate Director, OEO and Transplant Center Relations
FabienneDobbels, PhD	Associate Director, Outcomes Analysis
Leah Edwards, PhD	Associate Director, Data Analysis
Amanda Rowe	ISHLT Executive Director
Staff	
Kathryn Philibin, RN	ISHLT Registry Administrator
Frank Gilg	Director, TII Informatix
Jaime Williamson	Data Analyst
Anna Kucheryavaya, MS	Assistant Biostatistician
Susan Groff	ISHLT Support Coordinator
Jo Smith	ISHLT Support Coordinator

ISHLT, International Society for Heart and Lung Transplantation; OEO, organ exchange organization.
[a]Newly appointed members of the Steering Committee.

Table 2 Transplant Registry Early Career Award Recipients

2007	Institution	Research
Beth D. Kaufman, MD	The Children's Hospital of Philadelphia, Philadelphia, PA	Influence of Nutritional Status on Outcomes in Pediatric Heart Transplantation
2008		
Cynthia Gries, MD, MSc	University of Washington, Seattle, WA	Development of a Predictive Model for Long Term Survival in Lung Transplantation
Scott Halpern, MD, PhD	University of Pennsylvania, Philadelphia, PA	Decision Analysis of Single versus Double Lung Transplant for Patients with COPD
Josef Stehlik, MD, MPH	University of Utah School of Medicine, Salt Lake City, UT	Interactions Among Donor and Recipient Characteristics and Their Impact on Post-Transplant Survival
2010		
Jennifer Conway, MD, FRCPC	Hospital for Sick Children, Toronto, Canada	Survival Outcomes and Long Term Morbidities in Children Undergoing Retransplantation
Kiran K. Khush, MD, MAS	Stanford University School of Medicine, Stanford, CA	Does Sex Matter? Investigating the Impact of Donor and Recipient Sex on Outcomes After Heart Transplantation
2011		
Jose Nativi, MD	University of Utah, Salt Lake City, UT	Post Transplant Outcomes of Patients Requiring Biventricular Mechanical Bridge to Transplant
2012		
Erin M. Lowery, MD	Loyola University Medical Center, Maywood, IL	Risk Factors for the Development of PTLD in Patients with Cystic Fibrosis Following Lung Transplantation
Omar Wever-Pinzon, MD	University of Utah, Salt Lake City, UT	Impact of Recipient Age on Differential Causes of Heart Transplant Mortality
2013		
Chesney Castleberry, MD	Cincinnati Children's Hospital, Cincinnati, OH	mTOR Inhibitors in Pediatric Heart Transplantation: Do the potential benefits outweigh the risks?
Aaron Healy, MD	University of Utah, Salt Lake City, UT	Predictors of Post-Transplant Outcomes in Patients Bridged to Transplantation with Continuous-Flow LVADs
Eugene DePasquale, MD	UCLA, Los Angeles, CA	Influence of Chronic Kidney Disease Stage on Patient Selection for Heart and Heart-Kidney Transplantation

COPD, chronic obstructive pulmonary disease; LVAD, left ventricular assist device; mTOR, mammalian target of rapamycin; PTLD, post-transplant lymphoproliferative disorder.

Disclosure statement

The authors thank Dr Michael Kaye, the first Registry director, for his important contributions.

All relevant disclosures for the authors are on file with the ISHLT and can be made available for review by contacting the Executive Director of the ISHLT.

Appendix List of Thoracic Transplant Centers Reporting Data To the International Society for Heart and Lung Transplantation Transplant Registry for transplants performed between January 1, 2011 and June 30, 2012

Country (ISO code)	Center
Argentina (ARG)	Fundacion Favaloro
	Hospital Italiano
Australia[a] (AUS)	St. Vincent's Hospital
	The Royal Children's Hospital
	The Prince Charles Hospital
	The Alfred Hospital
	Royal Perth Hospital
Austria[b] (AUT)	Allgemeines Krankenhaus Wien
	Universitätsklinik Innsbruck
	Landeskrankenhaus Graz

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Appendix *(Continued)*

Country (ISO code)	Center
Belgium [b] (BEL)	Hôpital Erasme Bruxelles
	Universitair Ziekenhuis Antwerpen
	Onze Lieve Vrouw Ziekenhuis Aalst
	Universitair Ziekenhuis Gent
	Centre Hospitalier Universitaire Liège
	Cliniques Universitaires, Université Catholique de Louvain
	UZ Gasthuisberg Leuven
Brazil (BRA)	Heart Institute—Universidade de São Paulo
	Hospital de Messejana
	Real Hospital Português de Beneficiência em Pernambuco
	Instituto de Cardiologia do Distrito Federal
Canada (CAN)	Royal Victoria Hospital
	The Toronto General Hospital
	Quebec Heart Institute—Laval Hospital
	Ottawa Heart Institute
	University of Alberta Hospitals/Walter C. Mackenzie Health Sciences
	The Hospital For Sick Children
Chile (CHL)	Instituto Nacional del Torax
Colombia (COL)	Clinica Cardiovascular
	Fundacion Valle Del Lili
	Fundacion Cardioinfantil—Instituto de Cardiologia
	Fundacion Cardiovascular de Colombia
	Fundacion Clinica Shaio
Croatia[2] (HRV)	University Clinical Hospital Zagreb
	University Hospital Dubrava
The Czech Republic (CZE)	University Hospital Motol
Denmark[3] (DNK)	Skejby University Hospital
	Rigshospitalet, National University Hospital
Estonia (EST)	Tartu University Hospital
Finland[c] (FIN)	Helsinki University Central Hospital
	Children's Hospital, University of Helsinki
France[d] (FRA)	Marseille Sainte Marguerite (APM) (A)—Chirurgie Thoracique
	Marseille Timone adultes (APM) (A)—Chirurgie Cardiaque
	Marseille Timone enfants (APM) (A+P)—Chirurgie Cardio-Vasculaire
	Caen (A)—Chirurgie Cardiaque
	Dijon (A)—Chirurgie Cardiaque
	Toulouse (A)—Chirurgie Thoracique
	Toulouse (A)—Chirurgie Cardio-Vasculaire
	Bordeaux (A+P)—Unite de Transplantation Cardiaque
	Bordeaux (A+P)—Chirurgie Thoracique
	Montpellier (A)—Unite de Transpl. Cardio-thoracique
	Rennes (A)—Centre Cardio-Pneumologique
	Tours (A+P)—Chirurgie Cardiaque
	Grenoble (A)—Chirurgie Cardiaque
	Grenoble (A)—Pneumologie
	Nantes (A+P)—Chirurgie Cardio-Vasculaire
	Nancy (A+P)—Chirurgie Cardio-Pulmonaire
	Lille (A+P)—Chirurgie Cardio-Vasculaire
	Clermont-Ferrand (A)—Chirurgie Cardiaque
	Strasbourg (A)—Chirurgie Thoracique
	Strasbourg (A)—Chirurgie Cardio-Pulmonaire
	Lyon (A+P)—Pole de Transplantation Pulmonaire
	Lyon I (HCL) (A+P)—Pole de Transplantation Cardiaque
	Lyon II (HCL) (A)—Pole De Transplantation Cardiaque
	Paris Pitié-Salpêtrière (AP-HP) (A+P)—Chirurgie Cardio-Vasculaire
	Paris Necker Enfants Malades (AP-HP) (A+P)—Cardiologie Pediatrique
	Clichy Beaujon (AP-HP) (A)—Pneumologie B et Transplantation Pulmonaire
	Paris Bichat (AP-HP) (A)—Chirurgie Cardio-Vasculaire

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Appendix *(Continued)*

Country (ISO code)	Center
	Paris Georges Pompidou (AP-HP) (A)—Transplantation Cardiaque
	Paris Georges Pompidou (AP-HP) (A+P)—Transplantation Pulmonaire et Cardio-Pulmonaire
	Rouen (A+P)—Chirurgie Thoracique Et Cardio-Vasculaire
	Limoges (A)—Chirurgie Cardiaque
	Suresnes Foch (A)—Chirurgie Thoracique
	Le Plessis-Robinson Marie-Lannelongue (A+P)—Chirurgie Cardiaque
	Le Plessis-Robinson Marie-Lannelongue (A+P)—Chirurgie Thoracique Cardio-Vasculaire
	Créteil Henri Mondor (AP-HP) (A)—Chirurgie Cardio-Vasculaire
Germany[b] (DEU)	Universität des Saarlandes Homburg/Saar
	Herzzentrum Dresden GmbH
	Deutsches Herzzentrum Berlin
	Universitätsklinik Köln
	Universität Leipzig—Herzzentrum
	Kerckhoff Klinik, Bad Nauheim
	Klinikum der Universität Regensburg
	Herzzentrum Nordrhein-Westfalen Bad Oeynhausen
	Universitätsklinikum Essen
	Johannes Gutenberg Universität Mainz
	Heinrich-Heine-Universität Düsseldorf
	Universitätsklinikum Münster
	Ruprecht-Karls-Universität Heidelberg
	Medizinische Hochschule Hannover
	Universitätsklinikum Göttingen
	Universitätsklinikum Aachen
	Klinikum der Justus-Liebig-Universität Giessen
	Universitätsklinikum Schleswig-Holstein Kiel
	Friedrich Schiller Universität Jena
	Friedrich Alexander Universität Erlangen
	Universitätsklinikum Würzburg
	Ludwig Maximilians Universität München
	Universitätsklinikum Hamburg
	Klinikum der Albert-Ludwigs-Universität Freiburg im Breisgau
Iran (IRN)	Cardiac Surgery and Transplantation Research Center
Ireland[e] (IRL)	Mater Hospital
Israel (ISR)	Rabin Medical Center (Belinson Campus)
	Sheba Medical Center
Italy (ITA)	Policlinico S. Orsola—Universitadegli Studi
Japan (JPN)	Tohoku University Hospital
	Osaka University Hospital
	Kyoto University Hospital
	Saitama Medical School Hospital
Netherlands[b] (NLD)	Universitair Medisch Centrum Utrecht
	Erasmus Medisch Centrum Rotterdam
	Universitair Medisch Centrum Groningen
New Zealand (NZL)	Auckland City Hospital
Norway[c] (NOR)	Rikshospitalet—National Hospital of Norway
Poland (POL)	Regional Pulmonary Hospital
The Republic of Korea (KOR)	Gangnam Severance Hospital
Slovenia[b] (SVN)	University Medical Center Ljubljana
South Africa (ZAF)	Milpark Hospital
Spain (ESP)	Complejo Hospitalario Universitario Juan Canalejo[f,g]
	Hospital Universitario Marques de Valdecilla[f,h]
	Hospital de Bellvitge. Barcelona[h]
	Hospital Virgen Del Rocio, Sevilla[h]
	Hospital Santa Creu I Sant Pau, Barcelona[h]
	Hospital Universitario 12 de Octubre[f,h]
	Hospital Universitario Reina Sofia[f,h]
	Hospital Gregorio Marañón, Madrid[h]

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Appendix *(Continued)*

Country (ISO code)	Center
	Hospital Universitario Puerta de Hierro[f]
	Hospital Universitari I Politècnic La Fe, Valencia[f,h]
	Hospital Clinic I Provincial, Barcelona[h]
	Hospital Universitario Vall D'Hebron[f,h]
	Hospital Central de Asturias[g]
	Hospital La Paz. Madrid. Niños[h]
	Hospital Virgen de La Arrixaca, Murcia[h]
	Hospital Miguel Servet, Zaragoza[h]
	Hospital Clínico, Valladolid[h]
Sweden[c] (SWE)	Sahlgrenska University Hospital
	University Hospital of Lund
Switzerland (CHE)	University Hospital Zurich
	Centre Hospitalier Universitaire Vaudois
Turkey (TUR)	Heart Center, Ankara University
	Hospital of Akdeniz University
United Kingdom[e] (UK)	Great Ormand Street Hospital for Children
	University of Glasgow/Glasgow Royal Infirmary
	The Freeman Hospital
	Harefield Hospital
	Wythenshawe Hospital
	Queen Elizabeth Hospital
	Papworth Hospital
United States[i] (USA)	University of Alabama Hospital, Birmingham, Alabama
	Baptist Medical Center, Little Rock, Arkansas
	Arkansas Children's Hospital, Little Rock, Arkansas
	Mayo Clinic Hospital, Phoenix, Arizona
	Phoenix Children's Hospital, Phoenix, Arizona
	St. Joseph's Hospital and Medical Center, Phoenix, Arizona
	University Medical Center, University of Arizona, Tucson, Arizona
	Children's Hospital Los Angeles, Los Angeles, California
	Cedars-Sinai Medical Center, Los Angeles, California
	Loma Linda University Medical Center, Loma Linda, California
	Lucile Salter Packard Children's Hospital, Palo Alto, California
	California Pacific Medical Center, San Francisco, California
	University of California San Diego Medical Center, San Diego, California
	University of California San Francisco Medical Center, San Francisco, California
	Sutter Memorial Hospital, Sacramento, California
	Sharp Memorial Hospital, San Diego, California
	Stanford University Medical Center, Stanford, California
	University of California Los Angeles Medical Center, Los Angeles, California
	Keck Hospital of University of Southern California, Los Angeles, California
	Children's Hospital Colorado, Aurora, Colorado
	University of Colorado Hospital/Health Sciences Center, Aurora, Colorado
	Hartford Hospital, Hartford, Connecticut
	Yale New Haven Hospital, New Haven, Connecticut
	Washington Hospital Center, Washington, District of Columbia
	Alfred I duPont Hospital for Children, Wilmington, Delaware
	All Children's Hospital, St. Petersburg, Florida
	Florida Hospital Medical Center, Orlando, Florida
	Memorial Regional/Joe DiMaggio Children's Hospital, Hollywood, Florida
	Jackson Memorial Hospital, Miami, Florida
	Mayo Clinic Florida, Jacksonville, Florida
	Tampa General Hospital, Tampa, Florida
	Shands Hospital at University of FL, Gainesville, Florida
	Children's Healthcare of Atlanta, Atlanta, GA
	Emory University Hospital, Atlanta, GA
	Piedmont Hospital, Atlanta, GA
	St. Joseph's Hospital of Atlanta, Atlanta, GA

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Appendix *(Continued)*

Country (ISO code)	Center
	University of Iowa Hospital and Clinics, Iowa City, IA
	Advocate Christ Medical Center, Oak Lawn, Illinois
	Ann and Robert H. Lurie Children's Hospital, Chicago, Illinois
	Loyola University Medical Center, Maywood, Illinois
	Northwestern Memorial Hospital, Chicago, Illinois
	Rush University Medical Center, Chicago, Illinois
	University of Chicago Medical Center, Chicago, Illinois
	Indiana University Health, Indianapolis, Indiana
	Lutheran Hospital of Ft Wayne, Ft Wayne, Indiana
	St. Vincent Hospital and Health Care Center, Indianapolis, Indiana
	Jewish Hospital, Louisville, Kentucky
	Kosair Children's Hospital, Louisville, Kentucky
	University of Kentucky Medical Center, Lexington, Kentucky
	Ochsner Foundation Hospital, New Orleans, Louisiana
	Tulane Medical Center, New Orleans, Louisiana
	Boston Children's Hospital, Boston, Massachusetts
	Massachusetts General Hospital, Boston, Massachusetts
	Tufts Medical Center, Boston, Massachusetts
	Brigham and Women's Hospital, Boston, Massachusetts
	Johns Hopkins Hospital, Baltimore, Maryland
	University of Maryland Medical System, Baltimore, Maryland
	Children's Hospital of Michigan, Detroit, Michigan
	Henry Ford Hospital, Detroit, Michigan
	SpeCenterum Health, Grand Rapids, Michigan
	University of Michigan Medical Center, Ann Arbor, Michigan
	Abbott Northwestern Hospital, Minneapolis, Minnesota
	St. Mary's Hospital (Mayo Clinic), Rochester, Minnesota
	University of Minnesota Medical Center, Minneapolis, Minnesota
	Barnes-Jewish Hospital, St. Louis, Missouri
	Cardinal Glennon Children's Hospital, St. Louis, Missouri
	St. Louis Children's Hospital, St. Louis, Missouri
	St. Luke's Hospital of Kansas City, Kansas City, Missouri
	University of MS Medical Center, Jackson, Mississippi
	North Carolina Baptist Hospital, Winston-Salem, North Carolina
	Carolinas Medical Center, Charlotte, North Carolina
	Duke University Hospital, Durham, North Carolina
	University of North Carolina Hospitals, Chapel Hill, North Carolina
	The Nebraska Medical Center, Omaha, Nebraska
	Newark Beth Israel Medical Center, Newark, New Jersey
	Robert Wood Johnson University Hospital, New Brunswick, New Jersey
	New York-Presbyterian/Columbia, New York, New York
	Strong Memorial Hospital, Rochester, New York
	Montefiore Medical Center, Bronx, New York
	Mount Sinai Medical Center, New York, New York
	Westchester Medical Center, Valhalla, New York
	Cleveland Clinic Foundation, Cleveland, Ohio
	Nationwide Children's Hospital, Columbus, Ohio
	Children's Hospital Medical Center, Cincinnati, Ohio
	Ohio State University Medical Center, Columbus, Ohio
	University Hospital of Cleveland, Cleveland, Ohio
	Integris Baptist Medical Center, Oklahoma City, Oklahoma
	Providence Portland Medical Center, Portland, Oregon
	Oregon Health and Science University, Portland, Oregon
	Allegheny General Hospital, Pittsburgh, Pennsylvania
	Children's Hospital of Pittsburgh of University of Pittsburgh Medical Center, Pittsburgh, Pennsylvania
	Children's Hospital of Philadelphia, Philadelphia, Pennsylvania
	Penn State Milton S Hershey Medical Center, Hershey, Pennsylvania

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Appendix *(Continued)*

Country (ISO code)	Center
	Hahnemann University Hospital, Philadelphia, Pennsylvania
	University of Pittsburgh Medical Center, Pittsburgh, Pennsylvania
	Thomas Jefferson University Hospital, Philadelphia, Pennsylvania
	Temple University Hospital, Philadelphia, Pennsylvania
	The Hospital of the University of PA, Philadelphia, Pennsylvania
	Cardiovascular Center of Puerto Rico, San Juan, Puerto Rico
	Medical University of South Carolina, Charleston, South Carolina
	Baptist Memorial Hospital, Memphis, Tennessee
	St. Thomas Hospital, Nashville, Tennessee
	Vanderbilt University Medical Center, Nashville, Tennessee
	University Hospital, San Antonio, Texas
	Children's Medical Center of Dallas, Dallas, Texas
	Seton Medical Center, Austin, Texas
	Medical City Dallas Hospital, Dallas, Texas
	St Luke's Episcopal Hospital, Houston, Texas
	Methodist Specialty and Transplant Hospital, San Antonio, Texas
	University of Texas Medical Branch, Galveston, Texas
	The Methodist Hospital, Houston, Texas
	University Hospital—St. Paul, Dallas, Texas
	Scott and White Memorial Hospital, Temple, Texas
	Texas Children's Hospital, Houston, Texas
	Baylor University Medical Center, Dallas, Texas
	Intermountain Medical Center, Murray, Utah
	University of Utah Health Sciences Center, Salt Lake City, Utah
	Primary Children's Medical Center, Salt Lake City, Utah
	Inova Fairfax Hospital, Falls Church, Virginia
	MCV Hospitals, Richmond, Virginia
	McGuire Virginia Medical Center, Richmond, Virginia
	Sentara Norfolk General Hospital, Norfolk, Virginia
	University of Virginia HSC, Charlottesville, Virginia
	Seattle Children's Hospital, Seattle, Washington
	Sacred Heart Medical Center, Spokane, Washington
	University of Washington Medical Center, Seattle, Washington
	Children's Hospital of Wisconsin, Milwaukee, Wisconsin
	Froedtert Memorial Lutheran Hospital, Milwaukee, Wisconsin
	Aurora St. Luke's Medical Center, Milwaukee, Wisconsin
	University of Wisconsin Hospital and Clinics, Madison, Wisconsin

A, adult; P, pediatric; ISO, International Organization for Standardization.
[a]Data provided via Australia and New Zealand Cardiothoracic Transplant Registry (ANZCOTR).
[b]Data provided via Eurotransplant (ET).
[c]Data provided via Scandiatransplant.
[d]Data provided via L'Agence de la Biomédicine.
[e]Data provided via United Kingdom Transplant Support Service Authority (UKTSSA).
[f]Lung data provided via Organización Nacional de Trasplantes (ONT).
[g]Heart data provided directly to ISHLT Registry.
[h]Heart data provided via Registro Español de Trasplante Cardíaco.
[i]Data provided via United Network for Organ Sharing (UNOS).

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