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The Journal of Heart and Lung Transplantation

http://www.jhltonline.org

ANNUAL ISHLT REGISTRY REPORTS

The International Society for Heart and Lung Transplantation Registries in the Era of Big Data With Global Reach

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This issue of the *Journal of Heart and Lung Transplantation* (*JHLT*) brings the 32nd annual publication of the reports of the International Heart and Lung Transplant (ISHLT) Registry (Registry). The focus theme for the 4 reports this year is early graft failure and centers on the most severe forms of graft dysfunction that resulted in death or need for retransplantation within 30 days of transplant. In addition to the information provided in the manuscripts,[1–4] more detailed analyses are available in the online Registry slide sets (http://ishlt.org/registries/slides.asp?slides=heartLungRegistry). We hope these data will contribute to the ongoing discussion regarding the risk factors, diagnosis, and treatment of graft failure taking place early after transplant.

The ISHLT members have long viewed the Registry as one of the integral activities supporting the mission of the Society, and the Registry has therefore benefited from dependable support from the Society and its members. The respectable duration of the Registry operation has been complemented by its continued growth—both in the number of heart and lung transplant procedures reported and in the number of countries and centers participating in this endeavor (Appendix).

As the transplant registry has matured, this experience and expertise has been valuable as strategic decisions into diversification of ISHLT Registries are being considered

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1053-2498/$ - see front matter Published by Elsevier Inc.
http://dx.doi.org/10.1016/j.healun.2015.08.001

and implemented. Three additional areas that have already been embraced are mechanical circulatory support through the ISHLT Mechanically Assisted Circulatory Support (IMACS) Registry, novel donor strategies through the international Donation after Circulatory Death (DCD) Registry, and most recently, pediatric advanced heart disease through the International Pediatric Heart Failure Registry (iPHFR). Indeed, an attentive execution will be needed so that the ongoing expansion of the Registries can be successful and sustainable.

With this goal in mind, the ISHLT Board of Directors has restructured the Registries and Databases Committee. Its membership will now be constituted by steering committee chairs of the individual registries and by individuals intimately involved in the operation of the registries. The Registries and Databases Committee will be responsible for the oversight of all ISHLT-funded registries, implementation of the applicable policies, procedures and standards, oversight of ISHLT registry grants, and review of new registry requests.

Another part of the updated oversight process has been completion of a formal selection and appointment of the registry chairs, similar to the process in place for the Thoracic Transplant Registry Director. The individuals appointed through this process are Dr James Kirklin (University of Alabama, Birmingham, AL), as the chair of the IMACS Registry, and Dr Dirk Van Raemdonck (University Hospital Gasthuisberg, Leuven, Belgium), who will continue the work of Dr Marcelo Cypel as the chair of the DCD Registry.

The iPHFR, as the most recently approved ISHLT registry, will aim to enroll a large cohort of pediatric patients with heart failure and establish the natural history and the efficacy of treatments not limited to transplant or mechanical circulatory support in this population. The preparatory and implementation work for the iPHFR was done through the ISHLT Pediatric Council under the leadership of Dr Richard Kirk (Freeman Hospital, Newcastle Upon Tyne, United Kingdom) and Dr Anne Dipchand (University of Toronto, Toronto, ON, Canada). Dr Dipchand has been appointed as the inaugural chair of the iPHFR. Steering committee members for the different ISHLT Registries have and will be sought through the individual ISHLT Councils, and members interested in registry work are encouraged to apply for these positions.

Updated criteria have also been developed to evaluate requests to start new registries. The application process for approval of new registries will assess the main scientific questions of the proposed registry, competing projects, the relationship to the existing ISHLT registries, anticipated number of participating institutions and cost. This process should establish the feasibility and the value of the proposed new activity to the membership of the Society. Several councils have already expressed their interest in exploring additional clinical areas of importance to the ISHLT through registry work, including pulmonary hypertension disease states and new technologies in organ preservation.

The ISHLT Registries have reached beyond the traditional territories and are providing insights into the heterogeneity of the demographics of patients, diseases, treatments, and the associated outcomes in different regions. In this way, the ISHLT Registries serve as a conduit for global advocacy and for balancing the scientific playing field. Registry research awards are a good example: This investment in young scientists who are provided with access to the data fosters meaningful networking opportunities with regional, transcontinental, and intercontinental mentorship. This year's

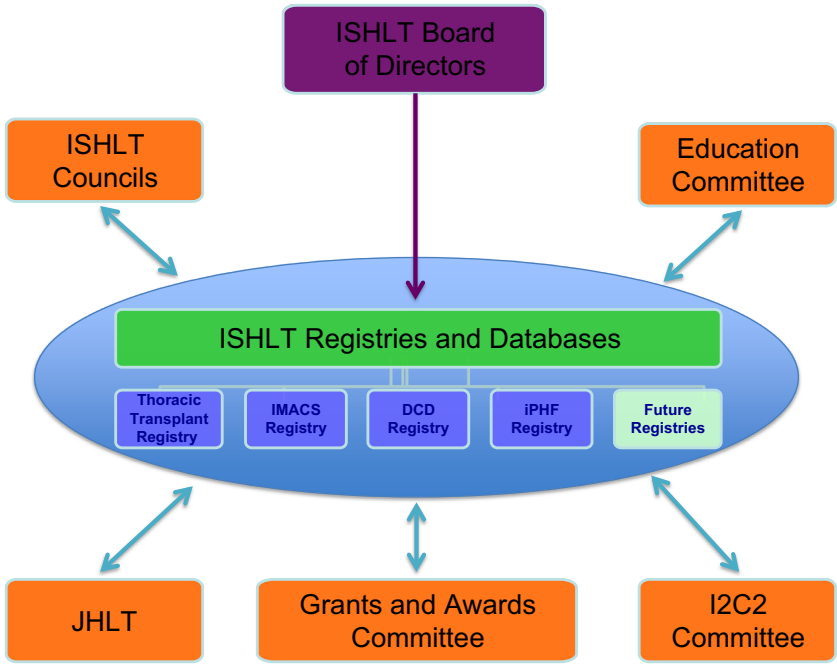


Figure Registries and databases committee structure and interactions within the International Society for Heart and Lung Transplantation (ISHLT). DCD, Donation after Circulatory Death; I2C2, International & Inter-Society Coordination Committee; IMACS, ISHLT Mechanically Assisted Circulatory Support; iPHF, International Pediatric Heart Failure; JHLT, *Journal of Heart and Lung Transplantation*.

Transplant Registry Early Career Award applications were submitted by young investigators from 10 countries, and the awardees included recipients and mentors from Brazil, Canada, Germany, South Korea, and the United States (http://ishlt.org/awards/currentRecipients.asp).

The Registries benefit from a synergistic relationship with the *JHLT*. The journal has enhanced its standing by the important publications of the Registries, and in turn the *JHLT*'s rising impact completes the circle of enhancing the prestige of the Registries' scientific output.

The data-driven aspects of the Registries provide important "business intelligence" to ISHLT committees and councils, which increases their ability to network more effectively and to embrace activities occurring in countries beyond those with a traditionally strong membership base in the ISHLT. To this end, the International & Inter-Society Coordination Committee (I2C2) has embarked on initiating and enhancing synergistic collaborations among individuals, professional societies, and governmental agencies globally, activities that advance the mission of the Society. An example of this effort is the creation of the ISHLT Latin American Working Group, which held its first meeting this April in Nice. The charge of this group is to add to the current benefits that ISHLT membership brings to the professionals from Latin America by creating a platform for communication at a regional level. One of the approaches discussed has already been implemented with the creation of the Latin American Discussion Forum on ISHLT Connect—the online ISHLT community (http://community.ishlt.org/home)—which is positioned to become a user-friendly communication tool for the group in the near future.

The above illustrates how the activities of the ISHLT Registries integrate with multiple facets of our Society (Figure). Indeed, the success could not be achieved without the support of the individual centers and data exchange collectives, and we express strong gratitude to all those who support Registry work through data submission. This allows the Registry to make contributions to the field of advanced heart and lung disease and thoracic transplantation that have global relevance as well as a global reach.

Disclosure statement

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 ISHLT Transplant Registry for transplants performed between January 1, 2013 and June 30, 2014

Country (ISO Code)	Center
Argentina[a] (ARG)	Fundacion Favaloro
	Centro de Trasplante Cardiaco Del Sanatorio Allende
	Hospital Italiano de Buenos Aires
	Hospital de Alta Complejidad Pte Juan Domingo Peron
	Harefield S.A.—Hospital Italiano De Mendoza
	Hospital El Cruce
	Sanatorio Parque
	Instituto de Cardiologia de Corrientes Juana F. Cabral
	Hospital de Pediatria Juan P. Garrahan
	Hospital Aleman
	Centro de Trasplante Cardiaco Hospital Privado Cordoba
	Clinica de Nefrologia Urologia Y Enfermedades Cardiovasculares
	Hospital Privado Del Sur
	Sanatorio de La Trinidad Mitre
	Hospital Cordoba
	Instituto Cardiovascular de Buenos Aires
	Centro de Trasplante Cardiaco Hospital Italiano Cordoba
	Centro Privado de Cardiologia Srl
	Hospital General de Agudos Dr Cosme Argerich
	Centro de Programa de Trasplante Cardiaco Clinica Velez Sarsfield
	Hospital Español de Mendoza
	Hospital Universitario Austral
	Programa de Trasplante Pulmonar Hospital Privado Cordoba
	Centro de Trasplante Pulmonar Hospital Italiano Cordoba
Australia[b] (AUS)	St. Vincent
	Royal Children
	The Prince Charles Hospital
	The Alfred Hospital
	Royal Perth Hospital

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Appendix (*Continued*)

Country (ISO Code)	Center
Austria[c] (AUT)	Allgemeines Krankenhaus Wien
	Universitätsklinik Innsbruck
	Landeskrankenhaus Graz
Belgium[c] (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)	Hospital de Messejana
	Real Hospital Portugues de Beneficiencia Em Pernambuco
	Instituto de Medicina Integral
	Hospital de Clinicas de Porto Alegre
	Procardiaco Hospital
Canada (CAN)	Royal Victoria Hospital
	The Toronto General Hospital
	Hospital Sainte-Justine
	Hospital Notre-Dame
	Quebec Heart Institute—Laval Hospital
	University of Alberta Hospitals/Walter C. Mackenzie Health Sciences
	St. Paul's Hospital
	Vancouver General Hospital
	The Hospital For Sick Children
Chile (CHL)	Instituto Nacional del Torax
Colombia (COL)	Clinica Cardiovascular
	Fundacion Cardioinfantil—Instituto de Cardiologia
	Fundacion Cardiovascular de Colombia
	Fundacion Clinica Shaio
Croatia[c] (HRV)	University Clinical Hospital Zagreb
	University Hospital Dubrava
Czech Republic (CZE)	University Hospital Motol
Denmark[d] (DNK)	Skejby University Hospital
	Rigshospitalet, National University Hospital
Estonia (EST)	Tartu University Hospital
Finland[d] (FIN)	Helsinki University Central Hospital
	Children's Hospital, University of Helsinki
France[e] (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 Transplantation 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

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Appendix (*Continued*)

Country (ISO Code)	Center
	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
	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[c] (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
	Johann Wolfgang Goethe Universität Frankfurt/Main
	Friedrich Schiller Universität Jena
	Friedrich Alexander Universität Erlangen
	Universitätsklinikum Würzburg
	Ludwig Maximilians Universität München
	Universitätsklinikum Hamburg
	Klinikum der Albert-Ludwigs-Universität Freiburg im Breisgau
India (IND)	Apollo Hospital
Iran (IRN)	Cardiac Surgery and Transplantation Research Center
	Masih Daneshvari Hospital
Israel (ISR)	Rabin Medical Center (Belinson Campus)
	Sheba Medical Center
	Hadassah University Hospital
Italy (ITA)	Policlinico S. Orsola—Universita degli Studi
Japan (JPN)	Tohoku University Hospital
Netherlands[c] (NLD)	Universitair Medisch Centrum Utrecht
	Erasmus Medisch Centrum Rotterdam
	Universitair Medisch Centrum Groningen
New Zealand (NZL)	Auckland City Hospital
Norway[d] (NOR)	Rikshospitalet—National Hospital of Norway
Republic of Korea (KOR)	Seoul National University Hospital
	Severance Hospital
Russia (RUS)	Federal V. Shumakov Research Centre of Transplantology & Artificial Organs
Saudi Arabia (SAU)	King Faisal Specialist Hospital and Research Center
Slovenia[c] (SVN)	University Medical Center Ljubljana
South Africa (ZAF)	Milpark Hospital

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Appendix (*Continued*)

Country (ISO Code)	Center
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]
	Hospital Universitario Puerta de Hierro[f]
	Hospital Universitario La Fe[f, h]
	Hospital Clinic I Provincial, Barcelona[h]
	Hospital Universitario Vall D'Hebron[f,h]
	Hospital Central de Asturias[g]
	Hospital La Paz Infantil[f,h]
	Hospital Virgen de La Arrixaca, Murcia[h]
	Hospital Miguel Servet, Zaragoza[h]
	Hospital Clínico, Valladolid[h]
Sweden[d] (SWE)	Sahlgrenska University Hospital
	University Hospital of Lund
Switzerland (CHE)	University Hospital Zurich
Taiwan (TWN)	Cheng-Hsin General Hospital
Turkey (TUR)	Istanbul Florence Nightingale Hospital
	Heart Center, Ankara University
United Kingdom[i] (GBR)	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[j] (USA)	University of Alabama Hospital, Birmingham, AL
	Baptist Medical Center, Little Rock, AR
	Arkansas Children's Hospital, Little Rock, AR
	Phoenix Children's Hospital, Phoenix, AZ
	Mayo Clinic Hospital, Phoenix, AZ
	St Joseph's Hospital and Medical Center, Phoenix, AZ
	University Medical Center, University of AZ, Tucson, AZ
	Children's Hospital Los Angeles, Los Angeles, CA
	Cedars-Sinai Medical Center, Los Angeles, CA
	Loma Linda University Medical Center, Loma Linda, CA
	Lucile Salter Packard Children's Hospital, Palo Alto, CA
	California Pacific Medical Center, San Francisco, CA
	UCSD Medical Center, San Diego, CA
	University of CA San Francisco Medical Center, San Francisco, CA
	Sutter Memorial Hospital, Sacramento, CA
	Sharp Memorial Hospital, San Diego, CA
	Stanford University Medical Center, Stanford, CA
	UCLA Medical Center, Los Angeles, CA
	Keck Hospital of USC, Los Angeles, CA
	Children's Hospital Colorado, Aurora, CO
	University of Colorado Hospital/HSC, Aurora, CO
	Hartford Hospital, Hartford, CT
	Yale New Haven Hospital, New Haven, CT
	Children's National Medical Center, Washington, DC
	Washington Hospital Center, Washington, DC
	Alfred I duPont Hospital for Children, Wilmington, DE
	All Children's Hospital, St. Petersburg, FL
	Florida Hospital Medical Center, Orlando, FL
	Memorial Regional/ Joe DiMaggio Children's Hospital, Hollywood, FL

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Appendix (*Continued*)

Country (ISO Code)	Center
	Jackson Memorial Hospital, Miami, FL
	Mayo Clinic Florida, Jacksonville, FL
	Tampa General Hospital, Tampa, FL
	UF Health Shands Hospital, Gainesville, FL
	Children's Healthcare of Atlanta, Atlanta, GA
	Emory University Hospital, Atlanta, GA
	Piedmont Hospital, Atlanta, GA
	University of Iowa Hospital and Clinics, Iowa City, IA
	Advocate Christ Medical Center, Oak Lawn, IL
	Ann and Robert H. Lurie Children's Hospital, Chicago, IL
	Loyola University Medical Center, Maywood, IL
	Northwestern Memorial Hospital, Chicago, IL
	Rush University Medical Center, Chicago, IL
	University of Chicago Medical Center, Chicago, IL
	Indiana University Health, Indianapolis, IN
	Lutheran Hospital of Ft Wayne, Ft Wayne, IN
	St. Vincent Hospital and Health Care Center, Indianapolis, IN
	Jewish Hospital, Louisville, KY
	University of Kentucky Medical Center, Lexington, KY
	Ochsner Foundation Hospital, New Orleans, LA
	Boston Children's Hospital, Boston, MA
	Massachusetts General Hospital, Boston, MA
	Tufts Medical Center, Boston, MA
	Brigham and Women's Hospital, Boston, MA
	Johns Hopkins Hospital, Baltimore, MD
	University of Maryland Medical System, Baltimore, MD
	Henry Ford Hospital, Detroit, MI
	Spectrum Health, Grand Rapids, MI
	University of Michigan Medical Center, Ann Arbor, MI
	University of MN Amplatz Children's Hospital, Minneapolis, MN
	Abbott Northwestern Hospital, Minneapolis, MN
	St. Mary's Hospital (Mayo Clinic), Rochester, MN
	University of Minnesota Medical Center, Minneapolis, MN
	Barnes-Jewish Hospital, St. Louis, MO
	Cardinal Glennon Children's Hospital, St. Louis, MO
	St. Louis Children's Hospital, St Louis, MO
	St. Luke's Hospital of Kansas City, Kansas City, MO
	University of MS Medical Center, Jackson, MS
	Wake Forest Baptist Medical Center, Winston Salem, NC
	Carolinas Medical Center, Charlotte, NC
	Duke University Hospital, Durham, NC
	UNC Hospitals, Chapel Hill, NC
	Children's Hospital and Medical Center, Omaha, NE
	The Nebraska Medical Center, Omaha, NE
	Newark Beth Israel Medical Center, Newark, NJ
	Robert Wood Johnson University Hospital, New Brunswick, NJ
	New York-Presbyterian/Columbia, New York, NY
	Strong Memorial Hospital, Rochester, NY
	Montefiore Medical Center, Bronx, NY
	Mount Sinai Medical Center, New York, NY
	Westchester Medical Center, Valhalla, NY
	Cleveland Clinic Foundation, Cleveland, OH
	Nationwide Children's Hospital, Columbus, OH
	Children's Hospital Medical Center, Cincinnati, OH
	Ohio State University Medical Center, Columbus, OH
	Integris Baptist Medical Center, Oklahoma City, OK
	Oregon Health and Science University, Portland, OR
	Allegheny General Hospital, Pittsburgh, PA
	Children's Hospital of Pittsburgh of UPMC, Pittsburgh, PA

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Appendix (*Continued*)

Country (ISO Code)	Center
	Children's Hospital of Philadelphia, Philadelphia, PA
	Penn State Milton S Hershey Medical Center, Hershey, PA
	Hahnemann University Hospital, Philadelphia, PA
	University of Pittsburgh Medical Center, Pittsburgh, PA
	Thomas Jefferson University Hospital, Philadelphia, PA
	Temple University Hospital, Philadelphia, PA
	The Hospital of the University of PA, Philadelphia, PA
	Cardiovascular Center of PR, San Juan, PR
	Medical University of SC, Charleston, SC
	Baptist Memorial Hospital, Memphis, TN
	Vanderbilt University Medical Center, Nashville, TN
	University Hospital, San Antonio, TX
	Children's Medical Center of Dallas, Dallas, TX
	Seton Medical Center, Austin, TX
	Medical City Dallas Hospital, Dallas, TX
	Memorial Hermann Hospital, Houston, TX
	CHI St Luke's Health Baylor College, Houston, TX
	Methodist Specialty and Transplant Hospital, San Antonio, TX
	University of Texas Medical Branch, Galveston, TX
	The Methodist Hospital, Houston, TX
	University Hospital—St. Paul, Dallas, TX
	Scott and White Memorial Hospital, Temple, TX
	Texas Children's Hospital, Houston, TX
	Baylor University Medical Center, Dallas, TX
	Intermountain Medical Center, Murray, UT
	University of Utah Medical Center, Salt Lake City, UT
	Primary Children's Medical Center, Salt Lake City, UT
	Inova Fairfax Hospital, Falls Church, VA
	MCV Hospitals, Richmond, VA
	McGuire VA Medical Center, Richmond, VA
	Sentara Norfolk General Hospital, Norfolk, VA
	University of Virginia HSC, Charlottesville, VA
	Seattle Children's Hospital, Seattle, WA
	Sacred Heart Medical Center, Spokane, WA
	University of Washington Medical Center, Seattle, WA
	Children's Hospital of Wisconsin, Milwaukee, WI
	Froedtert Memorial Lutheran Hospital, Milwaukee, WI
	Aurora St. Luke's Medical Center, Milwaukee, WI
	University of Wisconsin Hospital and Clinics, Madison, WI

[a]Data provided via the Instituto Nacional Central Único Coordinador de Ablación e Implante (INCUCAI).
[b]Data provided via Australia and New Zealand Cardiothoracic Transplant Registry (ANZCOTR).
[c]Data provided via Eurotransplant (ET).
[d]Data provided via Scandiatransplant.
[e]Data provided via L'Agence de la Biomédicine.
[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 Kingdom Transplant Support Service Authority (UKTSSA).
[j]Data provided via United Network for Organ Sharing (UNOS).

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