



PEDIATRIC HEART TRANSPLANT STUDY

General

Annual Report

November 14, 2010

Patients Listed or Transplanted

January 1, 1993 – December 31, 2009

Prepared by the PHTS Data Collection and Analysis Center at the
University of Alabama at Birmingham

Pediatric Heart Transplant Study

Annual Report

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Introduction

This report is the 17th Annual Report of the Pediatric Heart Transplant Study (PHTS). The research database is owned and directed by the Pediatric Heart Transplant Study Group. PHTS is a not-for-profit organization dedicated to the advancement of the science and treatment of children during listing for and following heart transplantation. The PHTS database is administered by the Data Collection and Analysis Center at the University of Alabama at Birmingham (DCC).

Purpose of PHTS: The purposes of the group are to establish and maintain an international, prospective, event driven database for heart transplantation, to use the database to encourage and stimulate basic and clinical research in the field of pediatric heart transplantation and to promote new therapeutic strategies.

Regulatory Requirements: The DCC undergoes annual review by our certified Institutional Review Board (IRB). The IRB requires that the DCC have a copy of each participating institution's current IRB approval with FWA number on file. We may not enter data from an institution unless this approval is on file. A copy of UAB's approval is available for those institutions that require a copy. Please email Susanna Lenderman at slende@uab.edu with any questions or requests.

Status of Data: Data collection began on January 1, 1993. Currently, PHTS has 40 member institutions, with 4,366 listed and 3,132 transplanted patients in the database as of December 31, 2009. Through November of 2009, there have been 63 presentations at international and national meetings. 29 papers have been published with more in preparation. More information, including a complete list of PHTS presentations and publications, membership list, forms, and a copy of the overall sections from this annual report can be found on the PHTS website at www.uab.edu/ctsresearch/phts.

Data Quality: Maintaining and improving the quality of the database is always a matter of utmost importance to us. We make every effort to capture each event at participating institutions. Currently, we conduct quality assessments to insure that:

1. All listed and transplanted patients have been submitted.
2. All event forms (rejection, infection, etc.) for each patient have been submitted.
3. Incorrect data entry has been corrected.
4. Missing data values have been investigated.

Report Overview: The following sections contain the summary and analyses of the database. Institution-specific analyses are included if your institution meets the following criteria:

1. Current IRB
2. 2010 Dues (Current or Pending)
3. 2009 data submitted before July 1, 2010.
4. At least 20 listed and/or transplanted patients

**Pediatric Heart Transplant Study: Annual Report: Overall
January 1993 - December 2009
Summary of Listed Patients**

Recipient Age at Listing				
Age_at_Listing	Frequency	Percent	Cumulative Frequency	Cumulative Percent
A: prior to birth	47	1.08	47	1.08
B: 0 - 1mo	863	19.77	910	20.84
C: 1 - <6mo	598	13.70	1508	34.54
D: 6mo - <1 yr	340	7.79	1848	42.33
E: 1yr - <6yr	926	21.21	2774	63.54
F: 6yr - <12yr	634	14.52	3408	78.06
G: 12yr - <18yr	958	21.94	4366	100.00

Recipient Race		
Recipient_Ethnicity	Frequency	Percent
American In	31	0.71
Asian	144	3.30
Black	772	17.68
Hispanic	88	2.02
Indian subc	23	0.53
Mid-east/Ar	63	1.44
Other	79	1.81
Pacific Isl	13	0.30
Unknown	3	0.07
Unspecified	13	0.30
White	3137	71.85

Recipient Gender		
Recipient_Gender	Frequency	Percent
A: Male	2450	56.12
B: Female	1915	43.86
Unspecified	1	0.02

**Pediatric Heart Transplant Study: Annual Report: Overall
January 1993 - December 2009
Summary of Listed Patients**

Diagnostic Group		
Diagnostic_Group	Frequency	Percent
A: Hypoplastic LV	592	13.56
B: Congenital	1733	39.69
C: Non - Congenital	2041	46.75

Year Listed				
Listing_Year	Frequency	Percent	Cumulative Frequency	Cumulative Percent
1993	215	4.92	215	4.92
1994	182	4.17	397	9.09
1995	216	4.95	613	14.04
1996	170	3.89	783	17.93
1997	219	5.02	1002	22.95
1998	243	5.57	1245	28.52
1999	218	4.99	1463	33.51
2000	215	4.92	1678	38.43
2001	236	5.41	1914	43.84
2002	260	5.96	2174	49.79
2003	240	5.50	2414	55.29
2004	266	6.09	2680	61.38
2005	214	4.90	2894	66.28
2006	308	7.05	3202	73.34
2007	330	7.56	3532	80.90
2008	431	9.87	3963	90.77
2009	403	9.23	4366	100.00

**Pediatric Heart Transplant Study: Annual Report: Overall
January 1993 - December 2009
Summary of Listed Patients**

Status at Listing		
Status_at_Listing	Frequency	Percent
A: Status 1	905	20.73
B: Status 1A	1992	45.63
C: Status 1B	413	9.46
D: Status 2	1008	23.09
Unspecified	48	1.10

Transplanted ?		
Transplanted	Frequency	Percent
A: Yes	3132	71.74
B: No	1234	28.26

Died Prior to Transplant ?		
Death_Before_Tx	Frequency	Percent
A: Yes	624	14.29
B: No	3742	85.71

Table of Status_at_Listing by Listing_Year											
Status_at_Listing(Status at Listing)	Listing_Year(Year Listed)										
	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
Frequency											
A: Status 1	154	138	158	115	155	178	7	0	0	0	0
B: Status 1A	0	0	0	1	0	2	116	121	132	155	154
C: Status 1B	0	0	0	0	0	0	37	35	37	34	37
D: Status 2	61	44	58	54	64	63	58	59	67	71	49
Unspecified	0	0	0	0	0	0	0	0	0	0	0
Total	215	182	216	170	219	243	218	215	236	260	240

**Pediatric Heart Transplant Study: Annual Report: Overall
January 1993 - December 2009
Summary of Listed Patients**

Table of Status_at_Listing by Listing_Year							
Status_at_Listing(Status at Listing)	Listing_Year(Year Listed)						Total
Frequency	2004	2005	2006	2007	2008	2009	
A: Status 1	0	0	0	0	0	0	905
B: Status 1A	174	141	187	214	301	294	1992
C: Status 1B	36	28	42	43	44	40	413
D: Status 2	56	43	65	56	79	61	1008
Unspecified	0	2	14	17	7	8	48
Total	266	214	308	330	431	403	4366

**Pediatric Heart Transplant Study
January 1993 - December 2009
Summary of Primary Transplants**

Recipient Age				
Recipient_Age	Frequency	Percent	Cumulative Frequency	Cumulative Percent
B: 0 - 1mo	185	5.86	185	5.86
C: 1 - <6mo	634	20.09	819	25.95
D: 6mo - <1 yr	285	9.03	1104	34.98
E: 1yr - <6yr	731	23.16	1835	58.14
F: 6yr - <12yr	504	15.97	2339	74.11
G: 12yr - <18yr	795	25.19	3134	99.30
H: 18yr - <30yr	18	0.57	3152	99.87
Unspecified	4	0.13	3156	100.00

Recipient Race		
Recipient_Ethnicity	Frequency	Percent
American In	23	0.73
Asian	89	2.82
Asian/Pacif	21	0.67
Black	539	17.08
Hispanic	67	2.12
Indian subc	22	0.70
Mid-east/Ar	54	1.71
Other	55	1.74
Pacific Isl	12	0.38
Unknown	3	0.10
Unspecified	9	0.29
White	2262	71.67

**Pediatric Heart Transplant Study
January 1993 - December 2009
Summary of Primary Transplants**

Recipient Gender		
Recipient_Gender	Frequency	Percent
A: Male	1758	55.70
B: Female	1394	44.17
Unspecified	4	0.13

Donor Age				
Donor_Age	Frequency	Percent	Cumulative Frequency	Cumulative Percent
B: 0 - 1mo	171	5.42	171	5.42
C: 1 - <6mo	426	13.50	597	18.92
D: 6mo - <1 yr	246	7.79	843	26.71
E: 1yr - <6yr	897	28.42	1740	55.13
F: 6yr - <12yr	458	14.51	2198	69.65
G: 12yr - <18yr	445	14.10	2643	83.75
H: 18yr - <30yr	344	10.90	2987	94.65
I: 30yr - 60yr	145	4.59	3132	99.24
Unspecified	24	0.76	3156	100.00

**Pediatric Heart Transplant Study
 January 1993 - December 2009
 Summary of Primary Transplants**

Donor Race		
Donor_Ethnicity	Frequency	Percent
American In	12	0.38
Asian	40	1.27
Black	550	17.43
Hispanic	68	2.15
Indian subc	5	0.16
Mid-east/Ar	7	0.22
Other	88	2.79
Other birac	1	0.03
Pacific Isl	4	0.13
UNKNOWN	2	0.06
Unspecified	224	7.10
White	2155	68.28

Donor Gender		
Donor_Gender	Frequency	Percent
A: Male	1769	56.05
B: Female	1310	41.51
Unspecified	77	2.44

**Pediatric Heart Transplant Study
January 1993 - December 2009
Summary of Primary Transplants**

Year of Transplant				
Year_of_Transplant	Frequency	Percent	Cumulative Frequency	Cumulative Percent
1993	139	4.40	139	4.40
1994	134	4.25	273	8.65
1995	126	3.99	399	12.64
1996	132	4.18	531	16.83
1997	152	4.82	683	21.64
1998	171	5.42	854	27.06
1999	153	4.85	1007	31.91
2000	160	5.07	1167	36.98
2001	160	5.07	1327	42.05
2002	175	5.54	1502	47.59
2003	175	5.54	1677	53.14
2004	184	5.83	1861	58.97
2005	177	5.61	2038	64.58
2006	228	7.22	2266	71.80
2007	261	8.27	2527	80.07
2008	321	10.17	2848	90.24
2009	308	9.76	3156	100.00

Status at Transplant		
Status_at_Transplant	Frequency	Percent
A: Status 1	625	19.80
B: Status 1A	1631	51.68
C: Status 1B	322	10.20
D: Status 2	535	16.95
Unspecified	43	1.36

**Pediatric Heart Transplant Study
January 1993 - December 2009
Summary of Primary Transplants**

Recipient Blood Type		
Recipient_Blood_Type	Frequency	Percent
A	1253	39.70
AB	126	3.99
B	386	12.23
O	1383	43.82
Unspecified	8	0.25

Donor Blood Type		
Donor_Blood_Type	Frequency	Percent
A	972	30.80
AB	46	1.46
B	260	8.24
O	1850	58.62
Unspecified	28	0.89

Ischemic Time (minutes)				
Ischemic_Time	Frequency	Percent	Cumulative Frequency	Cumulative Percent
A: 0 - <=120	289	9.16	289	9.16
B: 121 - 180	577	18.28	866	27.44
C: 181 - 240	1105	35.01	1971	62.45
D: 241 - 300	651	20.63	2622	83.08
E: 301 - 360	259	8.21	2881	91.29
F: 360+	167	5.29	3048	96.58
Unspecified	108	3.42	3156	100.00

**Pediatric Heart Transplant Study
January 1993 - December 2009
Summary of Primary Transplants**

Deaths after Transplant		
Death	Frequency	Percent
A: Yes	707	22.40
B: No	2449	77.60

Recipient_Gender	Donor_Gender	Frequency	Percent
A: Male	A: Male	1004	31.81
A: Male	B: Female	716	22.69
A: Male	Unspecified	38	1.20
B: Female	A: Male	764	24.21
B: Female	B: Female	592	18.76
B: Female	Unspecified	38	1.20
Unspecified	A: Male	1	0.03
Unspecified	B: Female	2	0.06
Unspecified	Unspecified	1	0.03

Recipient_Blood_Type	Donor_Blood_Type	Frequency	Percent
A	A	863	27.34
A	AB	9	0.29
A	B	13	0.41
A	O	356	11.28
A	Unspecified	12	0.38
AB	A	53	1.68
AB	AB	19	0.60
AB	B	30	0.95
AB	O	23	0.73
AB	Unspecified	1	0.03
B	A	8	0.25
B	AB	5	0.16
B	B	188	5.96

**Pediatric Heart Transplant Study
January 1993 - December 2009
Summary of Primary Transplants**

Recipient_Blood_Type	Donor_Blood_Type	Frequency	Percent
B	O	182	5.77
B	Unspecified	3	0.10
O	A	46	1.46
O	AB	13	0.41
O	B	28	0.89
O	O	1285	40.72
O	Unspecified	11	0.35
Unspecified	A	2	0.06
Unspecified	B	1	0.03
Unspecified	O	4	0.13
Unspecified	Unspecified	1	0.03

Status_at_Listing	Status_at_Transplant	Frequency	Percent
A: Status 1	A: Status 1	558	17.68
A: Status 1	B: Status 1A	8	0.25
A: Status 1	C: Status 1B	6	0.19
A: Status 1	D: Status 2	33	1.05
A: Status 1	Unspecified	1	0.03
B: Status 1A	A: Status 1	1	0.03
B: Status 1A	B: Status 1A	1342	42.52
B: Status 1A	C: Status 1B	38	1.20
B: Status 1A	D: Status 2	10	0.32
B: Status 1A	Unspecified	16	0.51
C: Status 1B	B: Status 1A	98	3.11
C: Status 1B	C: Status 1B	203	6.43
C: Status 1B	D: Status 2	10	0.32
C: Status 1B	Unspecified	4	0.13
D: Status 2	A: Status 1	66	2.09
D: Status 2	B: Status 1A	167	5.29

**Pediatric Heart Transplant Study
January 1993 - December 2009
Summary of Primary Transplants**

Status_at_Listing	Status_at_Transplant	Frequency	Percent
D: Status 2	C: Status 1B	74	2.34
D: Status 2	D: Status 2	482	15.27
D: Status 2	Unspecified	5	0.16
Unspecified	B: Status 1A	16	0.51
Unspecified	C: Status 1B	1	0.03
Unspecified	Unspecified	17	0.54

Table of Status_at_Transplant by Txpl_Year											
Status_at_Transplant(Status at Transplant)	Txpl_Year(Year Transplanted)										
	Frequency	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002
A: Status 1	102	96	99	90	103	128	7	0	0	0	0
B: Status 1A	0	0	0	0	0	1	89	98	93	116	127
C: Status 1B	0	0	0	0	0	0	31	27	31	26	23
D: Status 2	37	38	27	41	48	42	25	35	36	33	24
Unspecified	0	0	0	1	1	0	1	0	0	0	1
Total	139	134	126	132	152	171	153	160	160	175	175

Table of Status_at_Transplant by Txpl_Year							
Status_at_Transplant(Status at Transplant)	Txpl_Year(Year Transplanted)						Total
	Frequency	2004	2005	2006	2007	2008	
A: Status 1	0	0	0	0	0	0	625
B: Status 1A	135	127	155	193	243	254	1631
C: Status 1B	26	20	36	31	41	30	322
D: Status 2	23	24	31	26	26	19	535
Unspecified	0	6	6	11	11	5	43
Total	184	177	228	261	321	308	3156

**Pediatric Heart Transplant Study
January 1993 - December 2009
Summary of Primary Transplants**

Cause of Death		
Primary_Cause_Death	Frequency	Percent
Accidental	1	0.14
Anoxic Insult	3	0.42
Arrhythmic	5	0.71
Aspiration Pneumonia	1	0.14
CAD Infarction	75	10.61
Cardiac Failure	2	0.28
Cerebrovascular accident	12	1.70
Chronic Rejection	1	0.14
Early Graft Failure	55	7.78
Fatal Arrhythmia	10	1.41
Hemorrhage	5	0.71
Infection	88	12.45
Lymphoma	17	2.40
Multi-System Failure	14	1.98
Myocardial Infarction	1	0.14
Necrotizing Enterocolitis	1	0.14
Neurologic	13	1.84
Non-Specific Graft Failure	17	2.40
Obliterative Bronchiolitis	2	0.28
Other (Specify)	92	13.01
Poor Donor Preservation	3	0.42
Post-operative Hemorrhage	6	0.85
Pulmonary Embolism	2	0.28
Pulmonary Hypertension/R.V. Failure	17	2.40
Pulmonary hemorrhage	4	0.57
Rejection Hyperacute	2	0.28
Rejection, Acute	126	17.82
Renal Failure	3	0.42

**Pediatric Heart Transplant Study
January 1993 - December 2009
Summary of Primary Transplants**

Cause of Death		
Primary_Cause_Death	Frequency	Percent
Respiratory Failure	30	4.24
Sudden Cardiac Death	76	10.75
Technical: Intra/Peri Operative	1	0.14
Thrombus - SVC/IVC	1	0.14
Unknown	21	2.97

**Pediatric Heart Transplant Study
January 1993 - December 2009**

Summary of Listed Patients: Information for overall IRB application: Annual Report

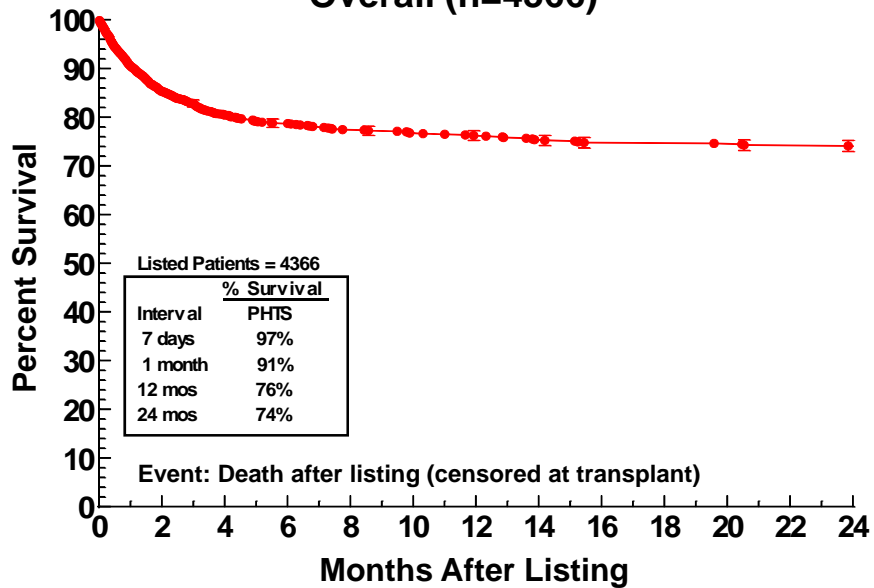
Table of Recipient_Ethnicity by Recipient_Gender				
Recipient_Ethnicity(Recipient Race)	Recipient_Gender(Recipient Gender)			Total
Frequency	A: Male	B: Female	Unspecified	
American In	18	13	0	31
Asian	73	71	0	144
Black	417	354	1	772
Hispanic	49	39	0	88
Indian subc	8	15	0	23
Mid-east/Ar	40	23	0	63
Other	45	34	0	79
Pacific Isl	3	10	0	13
Unknown	2	1	0	3
Unspecified	5	8	0	13
White	1790	1347	0	3137
Total	2450	1915	1	4366

PHTS Annual Report: 1993-2009

Overall

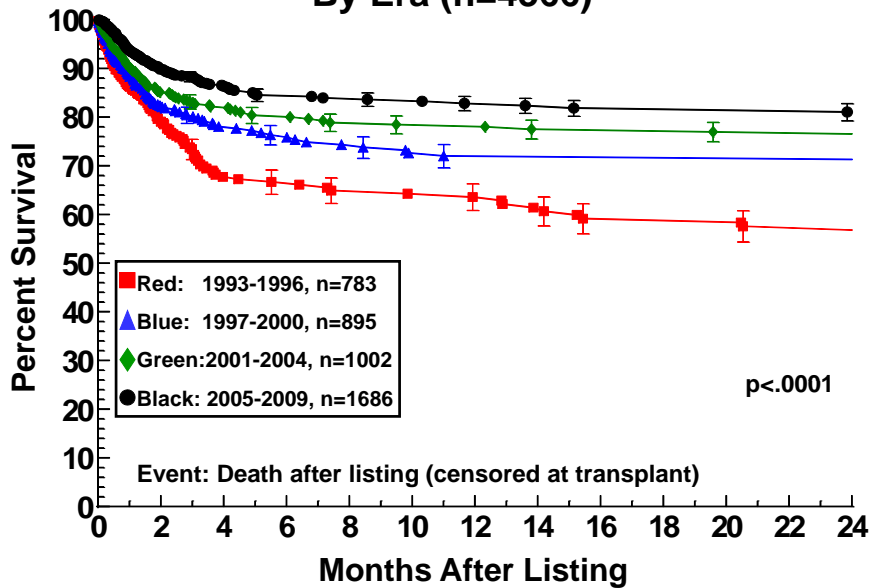
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Overall (n=4366)



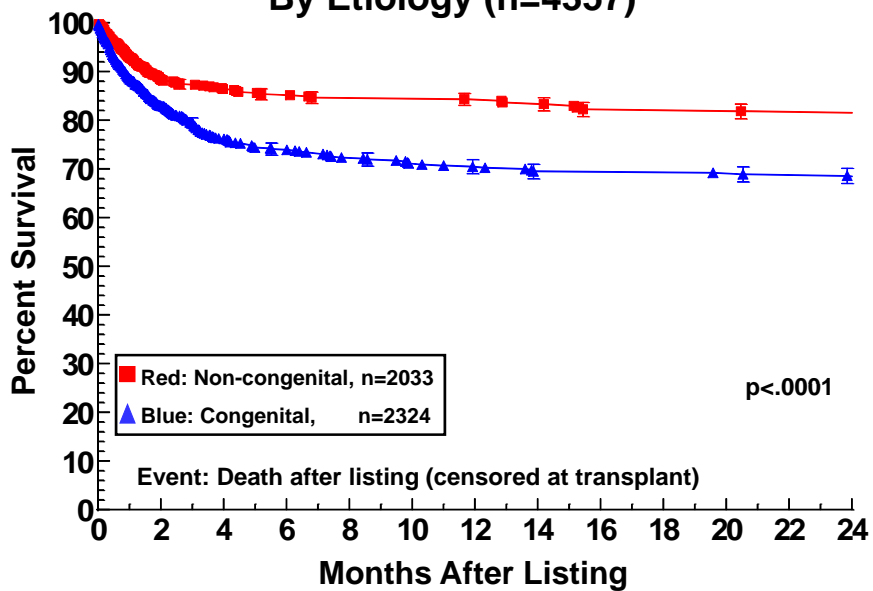
PHTS Annual Report: 1993-2009

By Era (n=4366)



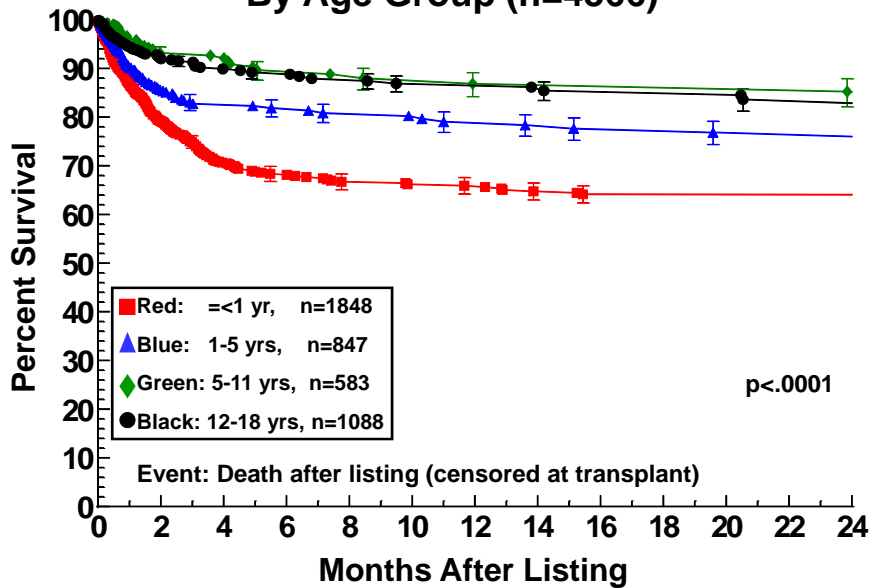
PHTS Annual Report: 1993-2009

By Etiology (n=4357)



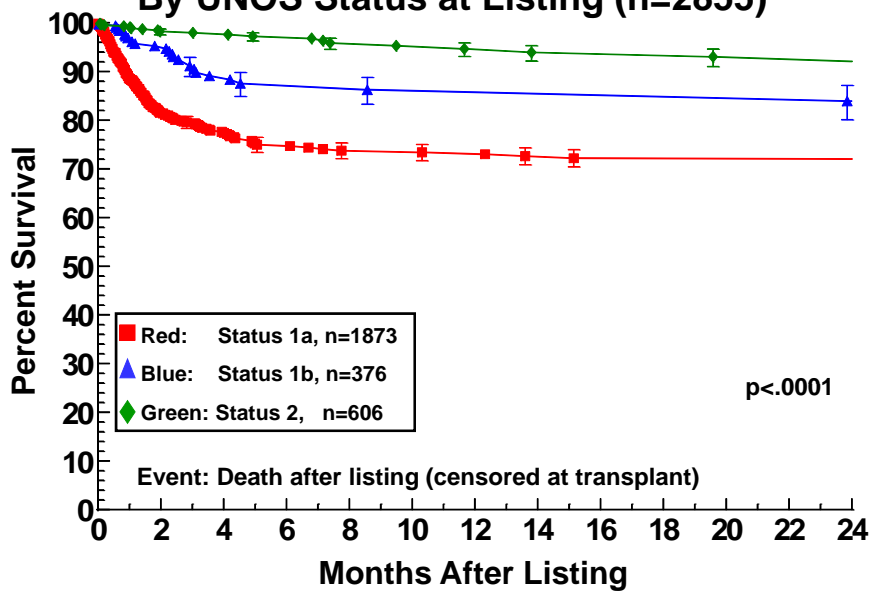
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By Age Group (n=4366)

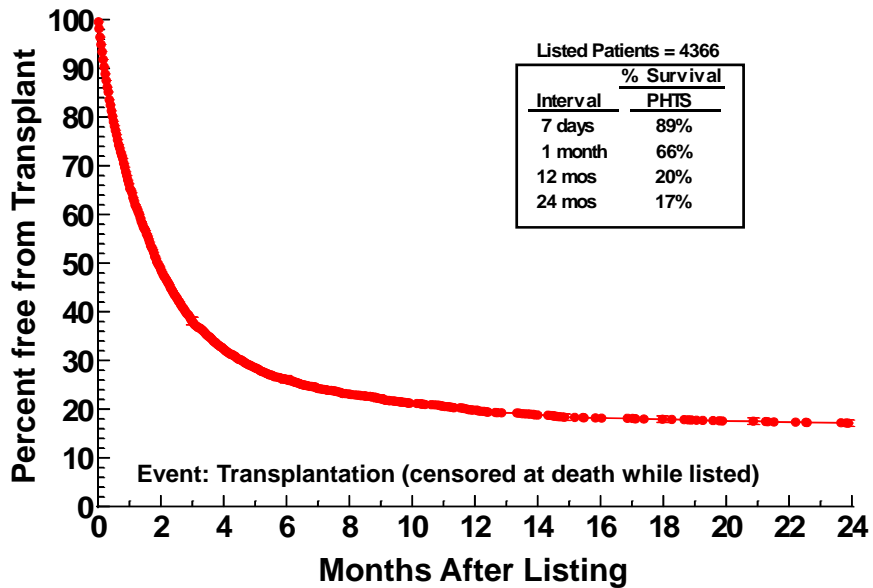


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By UNOS Status at Listing (n=2855)

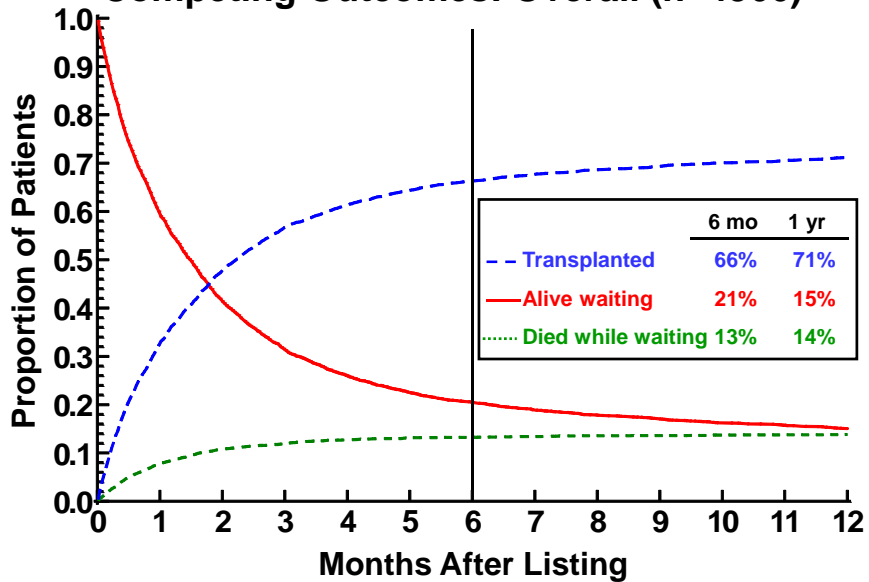


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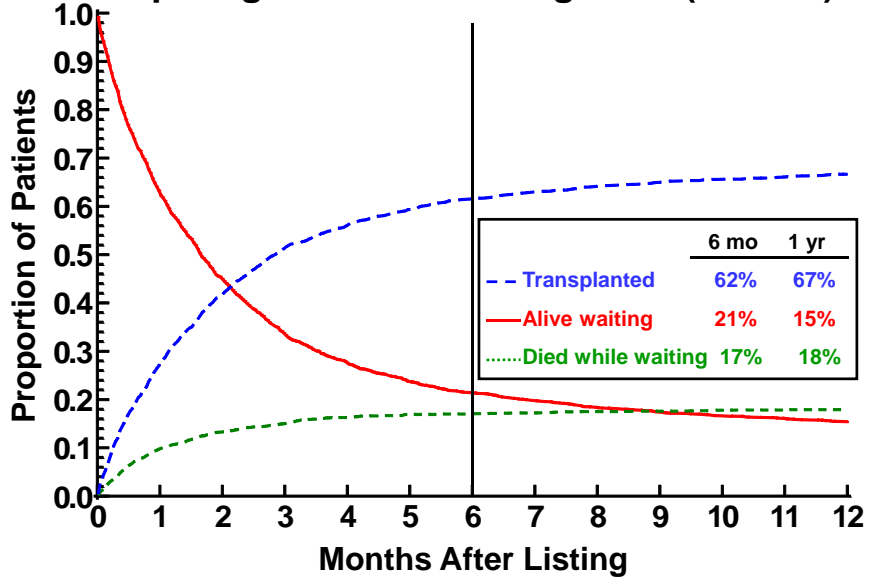
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Competing Outcomes: Overall (n=4366)



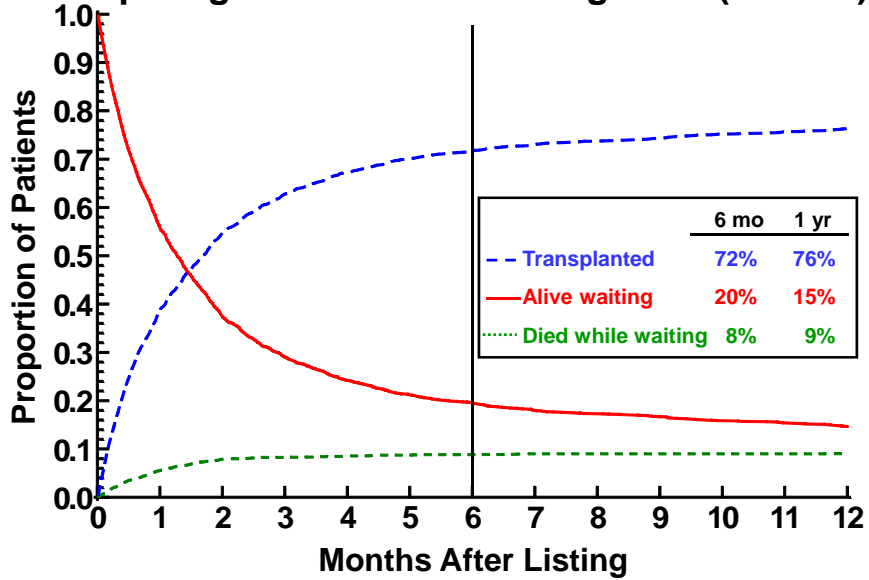
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Competing Outcomes: Congenital (n=2324)



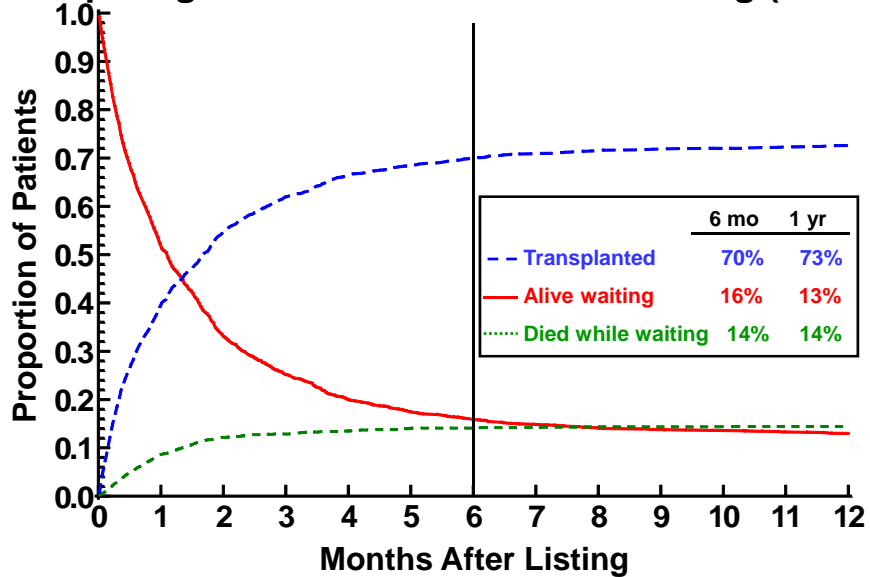
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Competing Outcomes: Noncongenital (n=2033)



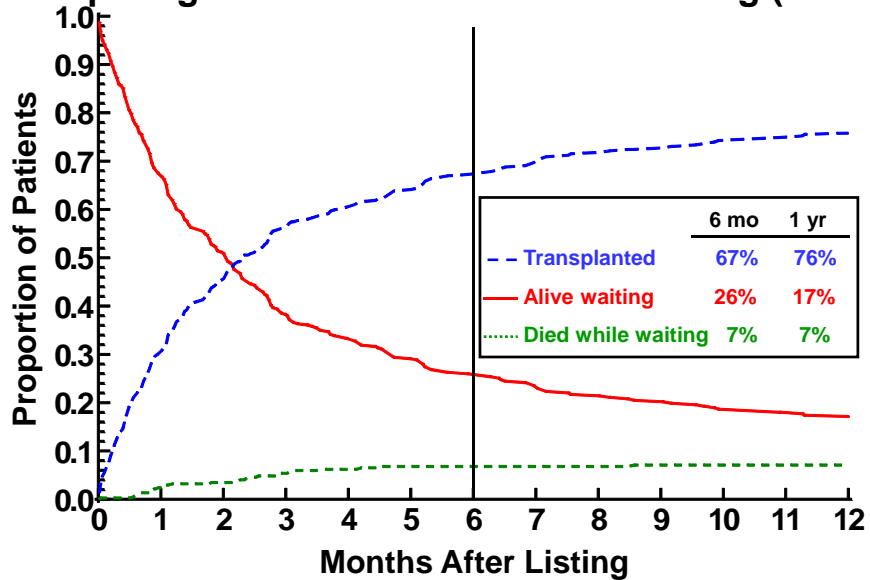
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Competing Outcomes: Status 1a at Listing (n=1873)



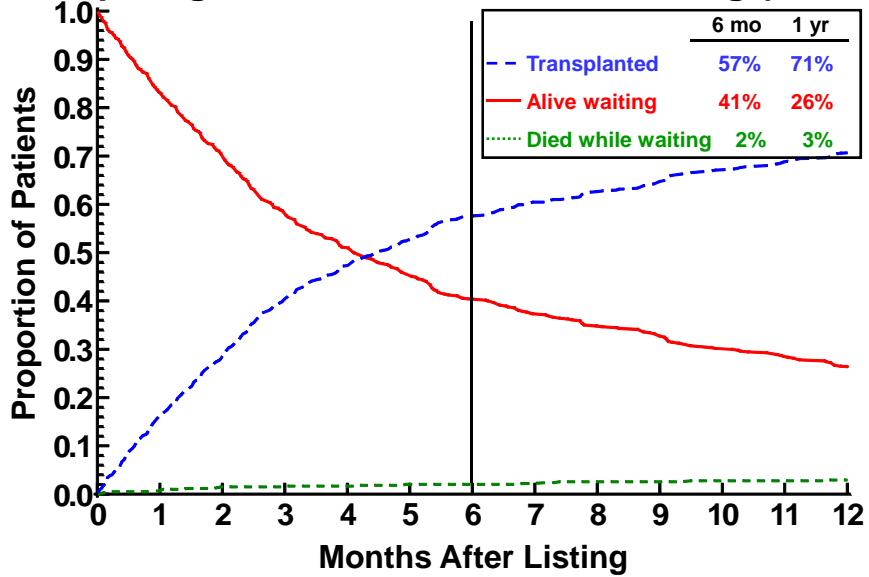
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Competing Outcomes: Status 1b at Listing (n=376)



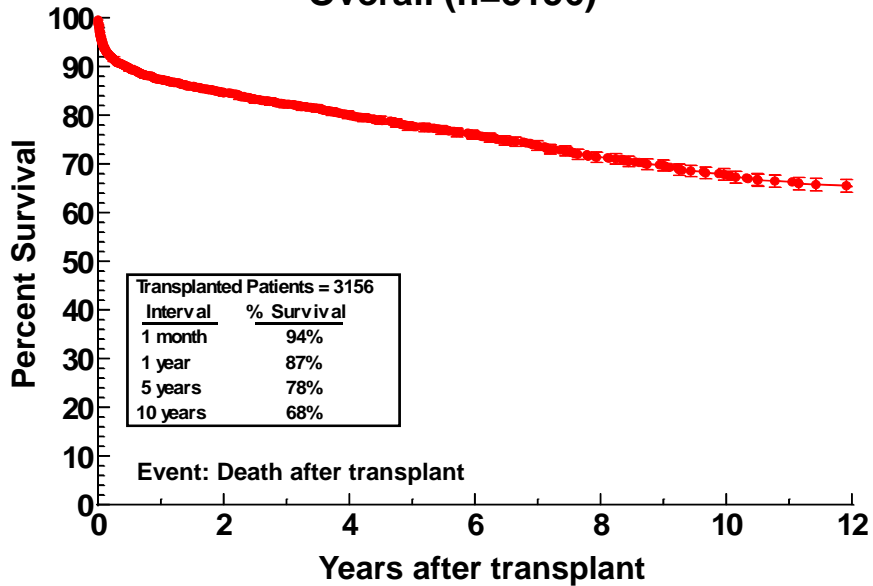
PHTS Annual Report: 2000-2009

Competing Outcomes: Status 2 at Listing (n=606)



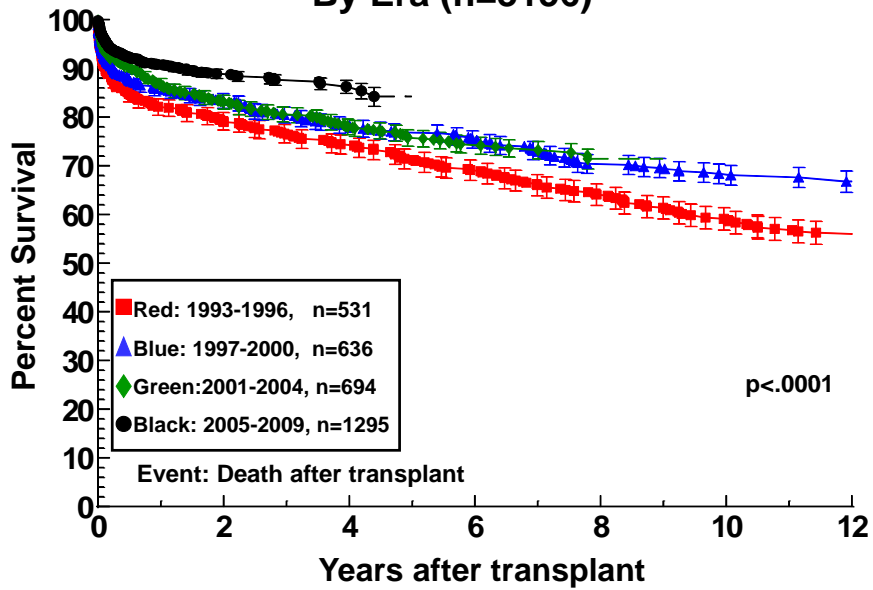
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Overall (n=3156)



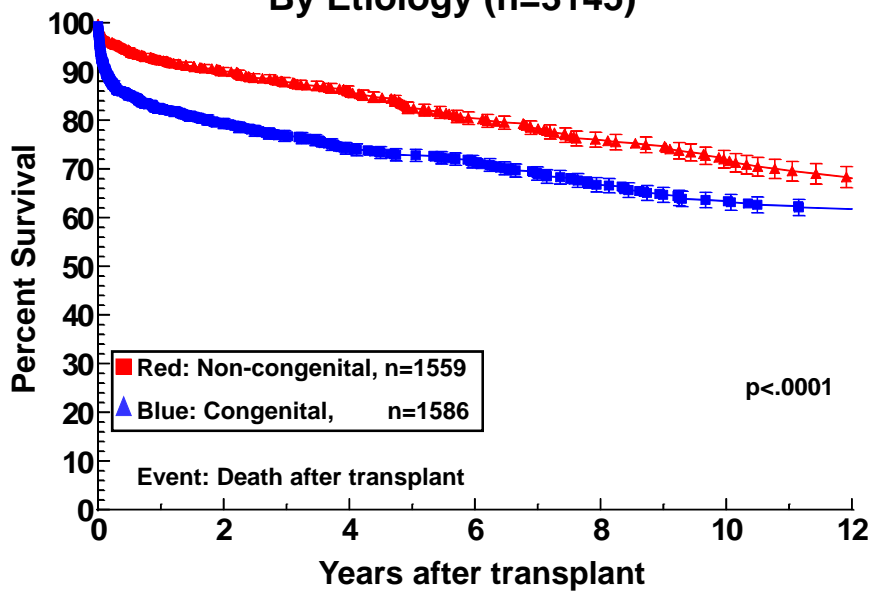
PHTS Annual Report: 1993-2009

By Era (n=3156)



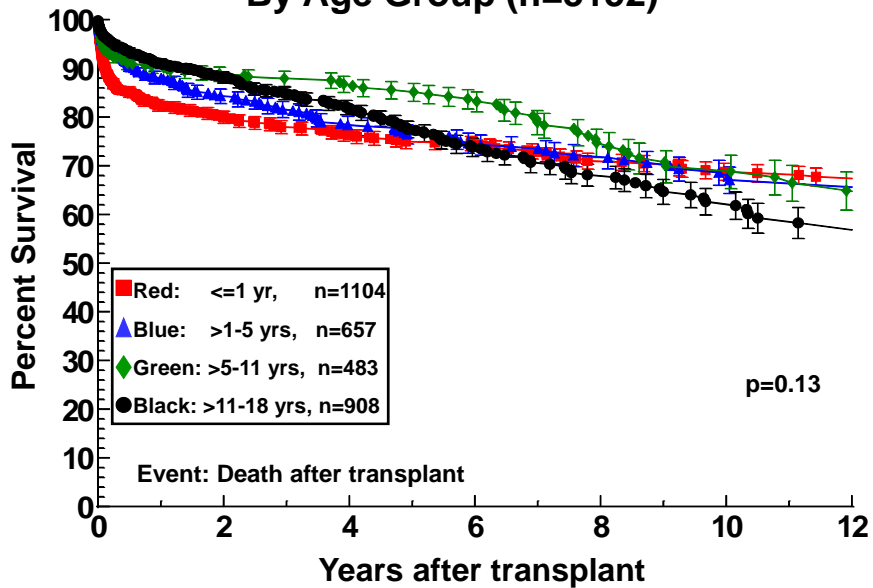
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By Etiology (n=3145)



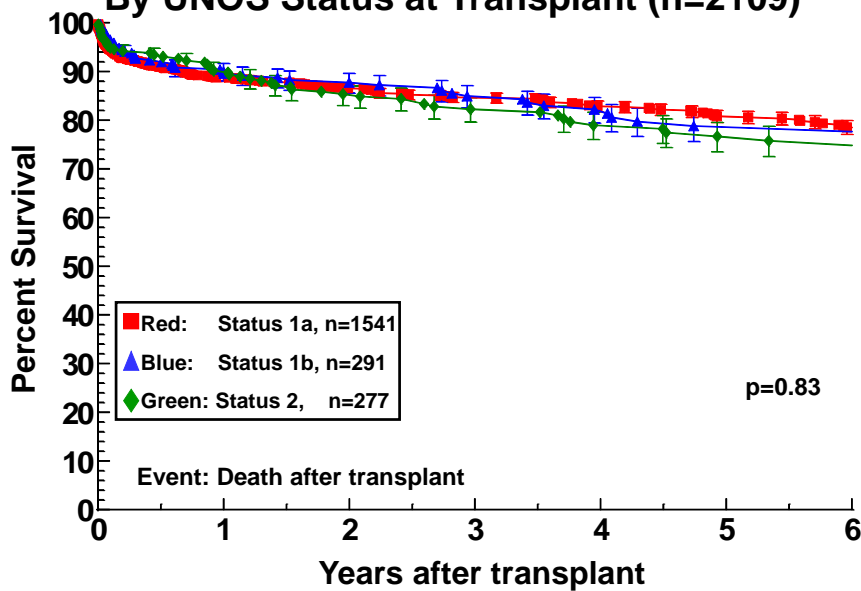
PHTS Annual Report: 1993-2009

By Age Group (n=3152)



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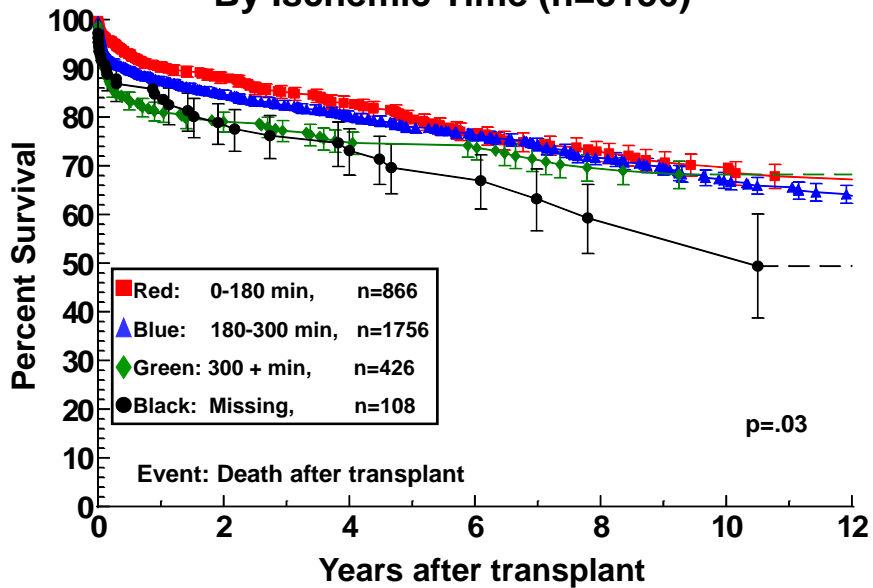
By UNOS Status at Transplant (n=2109)



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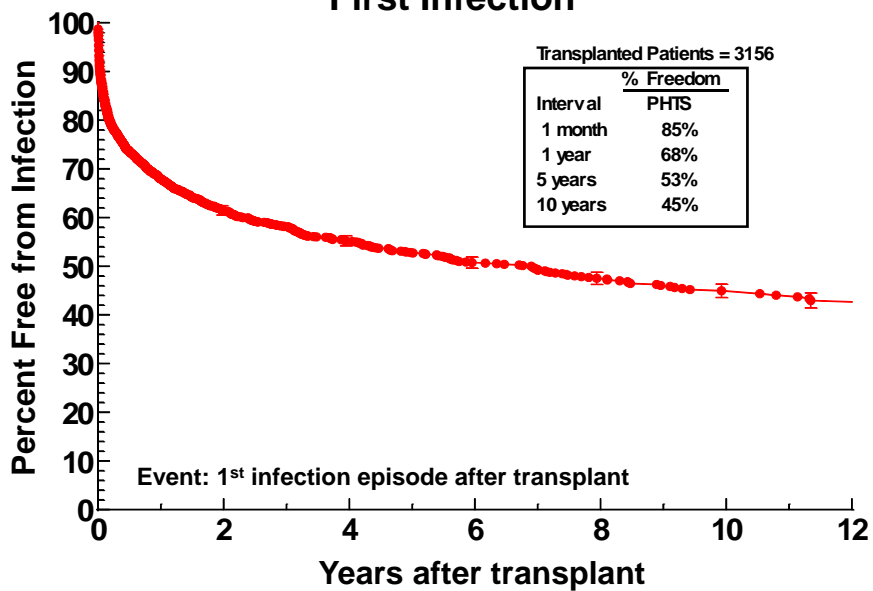
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By Ischemic Time (n=3156)



PHTS Annual Report: 1993-2009

First Infection



PHTS Annual Report: 1993-2009

First Rejection

