

SUPPLEMENTAL MATERIAL

Demographics

Record ID

Center

- Ann & Robert H. Lurie Children's Hospital of Chicago
- Arkansas Children's Hospital
- Children's Hospital of Philadelphia
- Children's Hospital of Pittsburgh of UPMC
- Cincinnati Children's Hospital Medical Center
- Columbia University - Morgan Stanley Children's Hospital of New York Presbyterian
- Freeman Hospital, Newcastle upon Tyne
- Le Bonheur Children's Hospital
- Lucile Packard Children's Hospital at Stanford
- Monroe Carell Jr. Children's Hospital at Vanderbilt
- Primary Children's Hospital
- St. Louis Children's Hospital
- Texas Children's Hospital
- University of Alberta
- University of Minnesota Masonic Children's Hospital
- Other

Transplant center

Patient Date of Birth

Gender

- Male
- Female

Blood type

- O
- A
- B
- AB

Race

- Caucasian
- African American
- Asian
- Hispanic
- Other

Congenital heart disease?

- Yes
- No

Details of congenital heart defect

Listing

Indication for transplantation?

Date of initial transplant listing

Listed for multi-organ transplant?

- Yes
 No

In addition to the heart, what other organs was the patient listed for?

- Liver
 Lung
 Kidney
 Other

What other organ was the patient listed for?

Weight at listing

(kg)

Height at listing

(cm)

Initial Listing Status

- 1A
 1B
 2

Initial Listing Status

Location at the time of listing

- In ICU
 Hospitalized, not in ICU
 Outpatient

Support at the time of listing (Check all that apply)

- Ventilator
 ECMO
 Inotropes
 VAD
 Inhaled nitric oxide
 Other
 None of the above

Other support details

VAD type

Biventricular support?

- Yes
 No

Functional status at the time of listing?

- Performs most age-appropriate activities independently
 Performs age-appropriate activities with some assistance
 Required assistance for all activities
 n/a patient < 1 year of age

Events preceding transplant listing

Prior cardiac surgery?

- Yes
 No

Number of prior cardiac surgeries

Most recent preceding cardiac surgery date

Prior malignancy

- Yes
 No

Malignancy type

Date of malignancy diagnosis

Catheterization performed pre-transplant?

- Yes
 No

Date of most recent catheterization preceding listing

Hemodynamics: PVR

_____ (wU)

Hemodynamics: Cardiac Index

_____ (mL/kg/m²)

Hemodynamics: Wedge pressure (mean)

_____ (mmHg)

Other events or other patient comorbidities preceding transplantation

Transplant

Waitlist outcome

- Underwent transplant
- Died or delisted due to clinical deterioration
- Delisted due to clinical improvement
- Other

Date of waitlist death

Delisting date

Other outcome

Date of transplant

Multi-organ transplant?

- Yes
- No

In addition to the heart, what other organs were transplanted? (Check all that apply)

- Liver
- Lung
- Kidney
- Other

What other organ was transplanted?

Weight at transplant

(kg)

Height at transplant

(cm)

Donor weight

(kg)

Donor height

(cm)

Support at the time of transplantation (Check all that apply)

- Ventilator
- ECMO
- Inotropes
- VAD
- Inhaled nitric oxide
- Other
- None of the above

Donor ischemic time

(min)

Required ECMO post-transplant

- Yes
- No

Required dialysis post-transplant?

- Yes
- No

Survived to hospital discharge?

- Yes
- No

Date of initial hospital discharge (post-transplant)

Induction immunosuppression used (check all that apply)

- Steroids
- Thymoglobulin
- Basiliximab
- IVIG
- Other

Other induction immunosuppression detail

Maintenance immunosuppression at the time of discharge (check all that apply)

- Steroids
- Tacrolimus
- Mycophenolate
- Azathioprine
- Cyclosporine
- Sirolimus
- Everolimus
- Other

Other maintenance immunosuppression detail

Did you alter your standard immunosuppression strategy due to the presence of Down syndrome?

- Yes
- No

How was immunosuppression altered for this patient compared to your standard practice?

Treated infection prior to hospital discharge

- Yes
- No

Details of infection prior to hospital discharge

Follow-up

Date of last known follow-up

Last known patient status

- Alive
- Deceased
- Retransplanted

Retransplant date

Indication for retransplantation

Cause of death

Has the patient been transitioned to an adult practice?

- Yes
- No

Last known functional status

- Performs most age-appropriate activities independently
- Performs age-appropriate activities with some assistance
- Required assistance for all activities
- n/a patient < 1 year of age

Rejection Events

Has the patient had any episodes of treated rejection?

- Yes
- No

How many episodes of treated rejection has the patient had?

- 1
- 2
- 3
- 4 or more

Date of rejection episode #1

Hemodynamic compromise with rejection episode #1?

- Yes
- No

Type of rejection event #1

- Cellular
- Antibody mediated
- Mixed
- No biopsy performed / empiric therapy

Date of rejection episode #2

Hemodynamic compromise with rejection episode #2?

- Yes
 No

Type of rejection event #2

- Cellular
 Antibody mediated
 Mixed
 No biopsy performed / empiric therapy

Date of rejection episode #3

Hemodynamic compromise with rejection episode #3?

- Yes
 No

Type of rejection event #3

- Cellular
 Antibody mediated
 Mixed
 No biopsy performed / empiric therapy

Date of rejection episode #4

Hemodynamic compromise with rejection episode #4?

- Yes
 No

Type of rejection event #4

- Cellular
 Antibody mediated
 Mixed
 No biopsy performed / empiric therapy

Post-transplant malignancy

Has the patient had malignancy post-transplant?

- Yes
 No

Date of post-transplant malignancy diagnosis

Type of post-transplant malignancy?

Post-transplant infection

Hospitalized for infection in the first year post-transplant?

- Yes
 No

Number of hospitalizations for infection in the first year post-transplant?

- 1
 2
 3
 4 or more

Date of infection #1

Type of infection: Episode #1

Date of infection #2

Type of infection: Episode #2

Date of infection #3

Type of infection: Episode #3

Date of infection #4

Type of infection: Episode #4

Figure S1. Number of patients with down syndrome listed for transplant by year.
Dashed line demonstrates the linear trend over time.

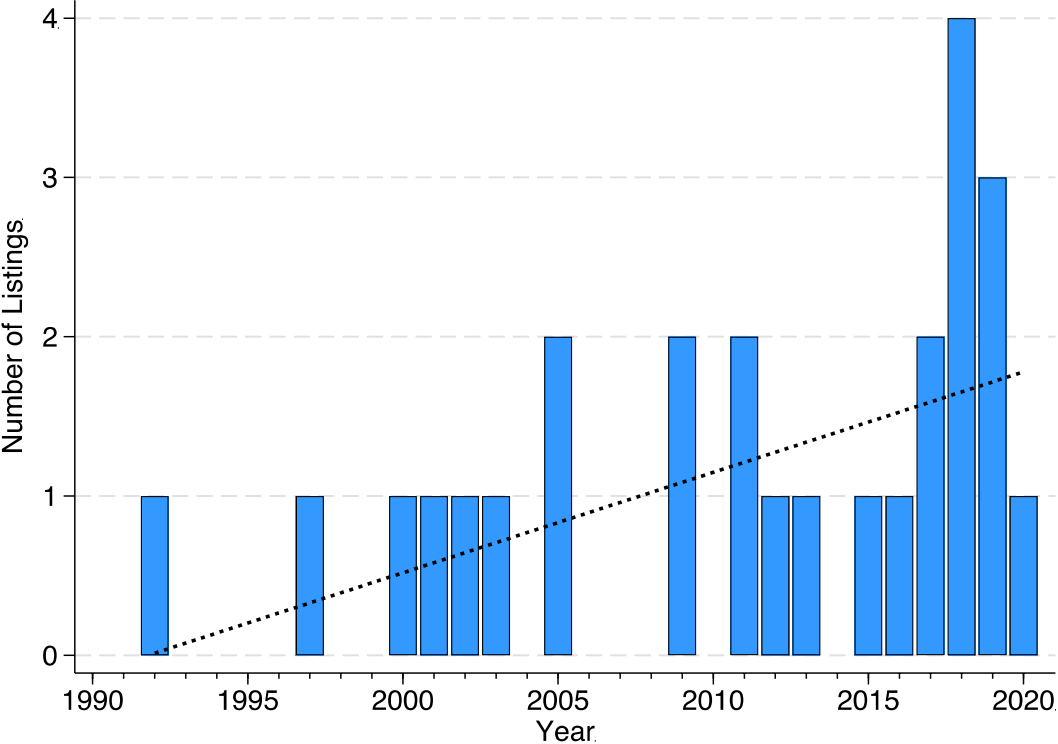


Figure S2. Age distribution of listed patients and associated indications for listing.

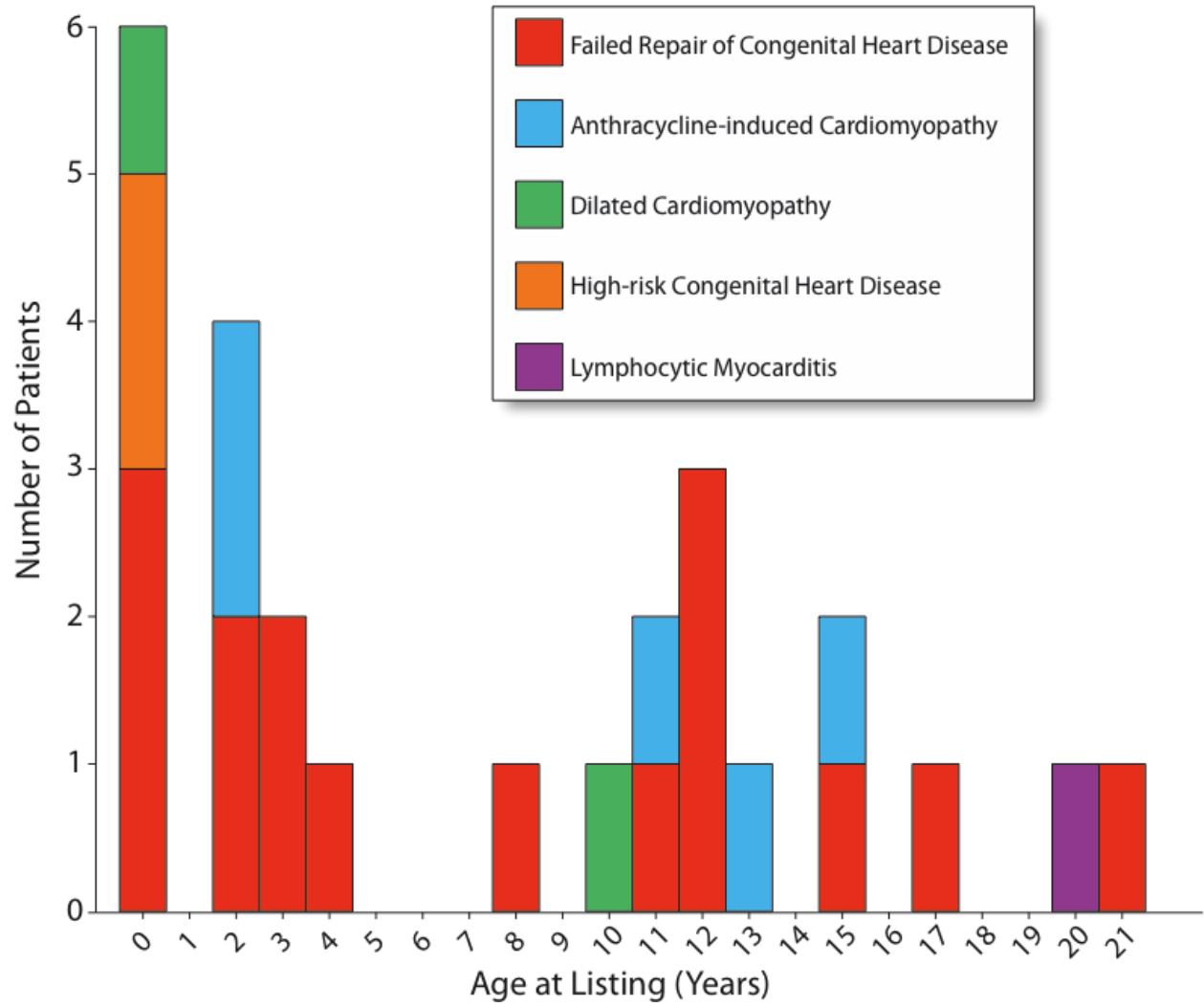


Figure S3. Distribution of indexed pulmonary vascular resistance for patients who underwent a pre-transplant catheterization.

