# Cardiac Transplantation

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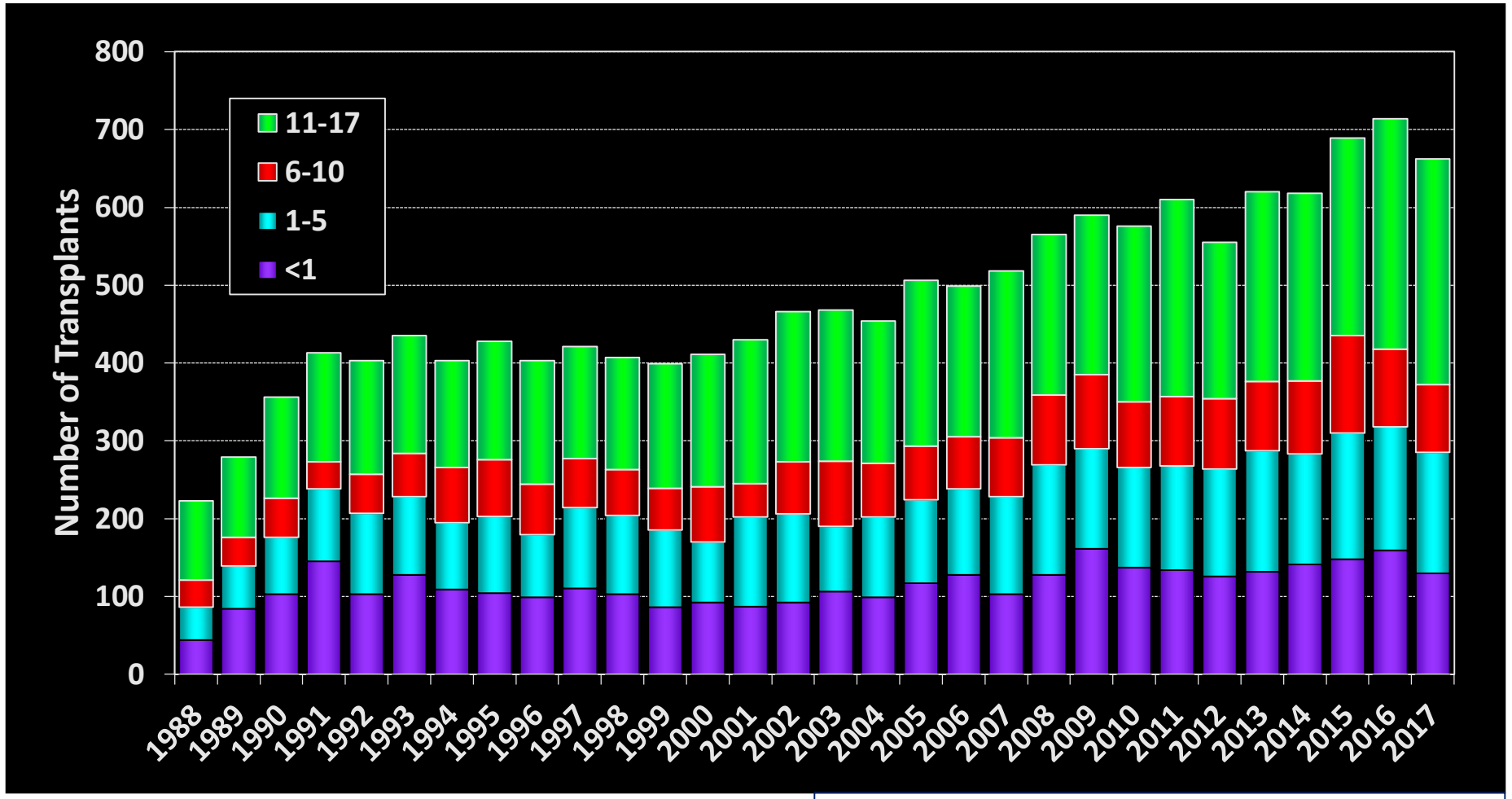
# Pediatric Heart Transplants (Worldwide) Reported to the ISHLT
## Recipient Age (in Years) Distribution by Year of Transplant




**NOTE: This figure includes only the heart transplants that are reported to the ISHLT Transplant Registry. As such, this should not be construed as evidence that the number of hearts transplanted worldwide has increased and/or decreased in recent years.**

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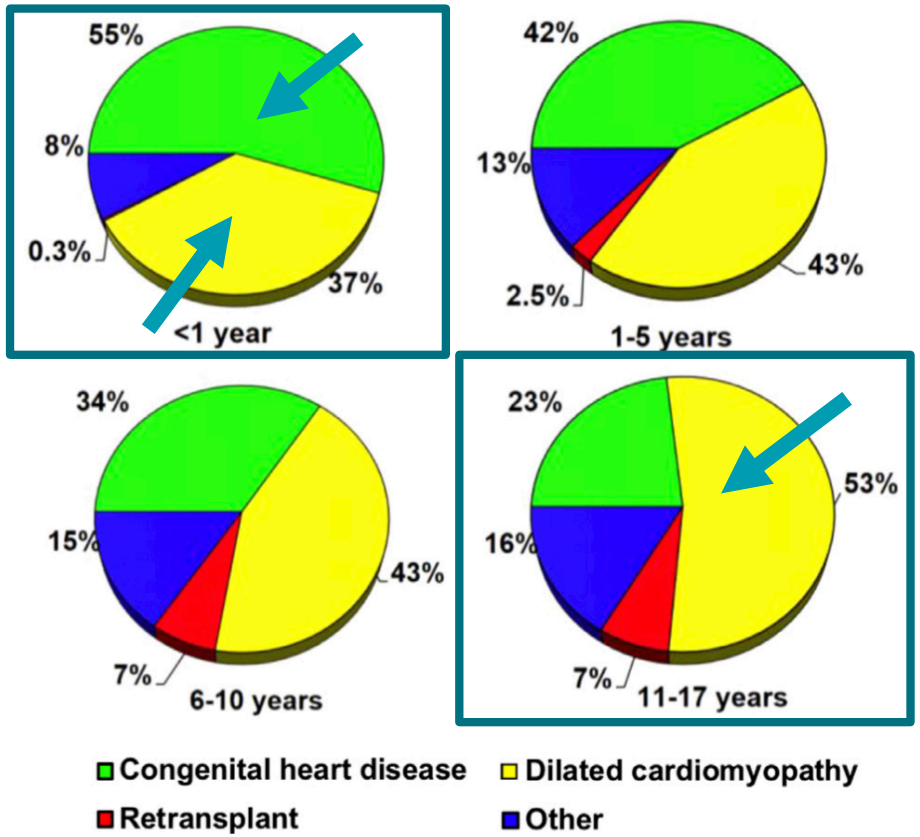
2019

JHLT. 2019 Oct; 38(10): 1015-1066

# What do these patients look like going into transplant? Indications




*JHLT Pediatric Heart Registry Report, 2018*

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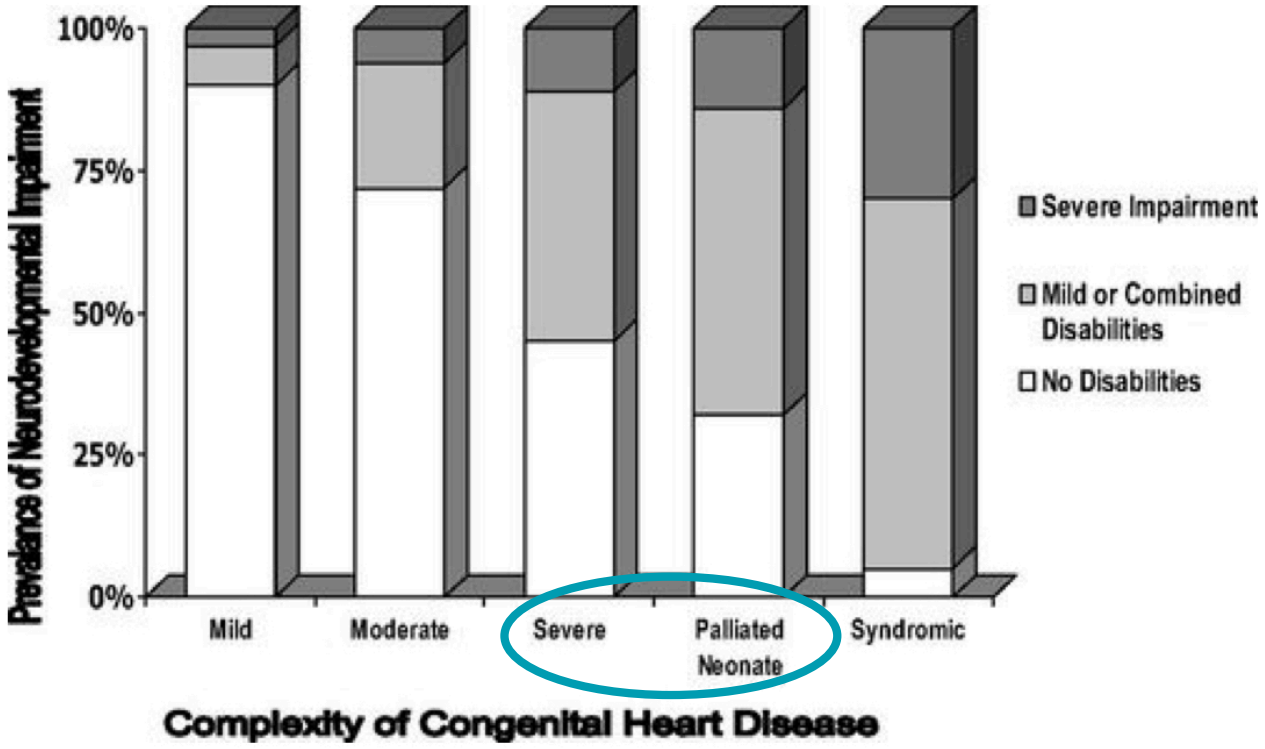
# What do these patients look like going into transplant? Neurologic co-morbidities




*Marino, et al, AHA Scientific Statement, 2012*

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# What do these patients look like going into transplant? Quality of Life

- Quality of life is defined as *"an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."* (World Health Organization)

- Pediatric Quality of Life Inventory (PedsQL)
  - Physical functioning
  - Emotional functioning
  - Psychosocial functioning
  - Social functioning
  - School functioning

- Health Related Quality of Life Inventory (HRQoL)

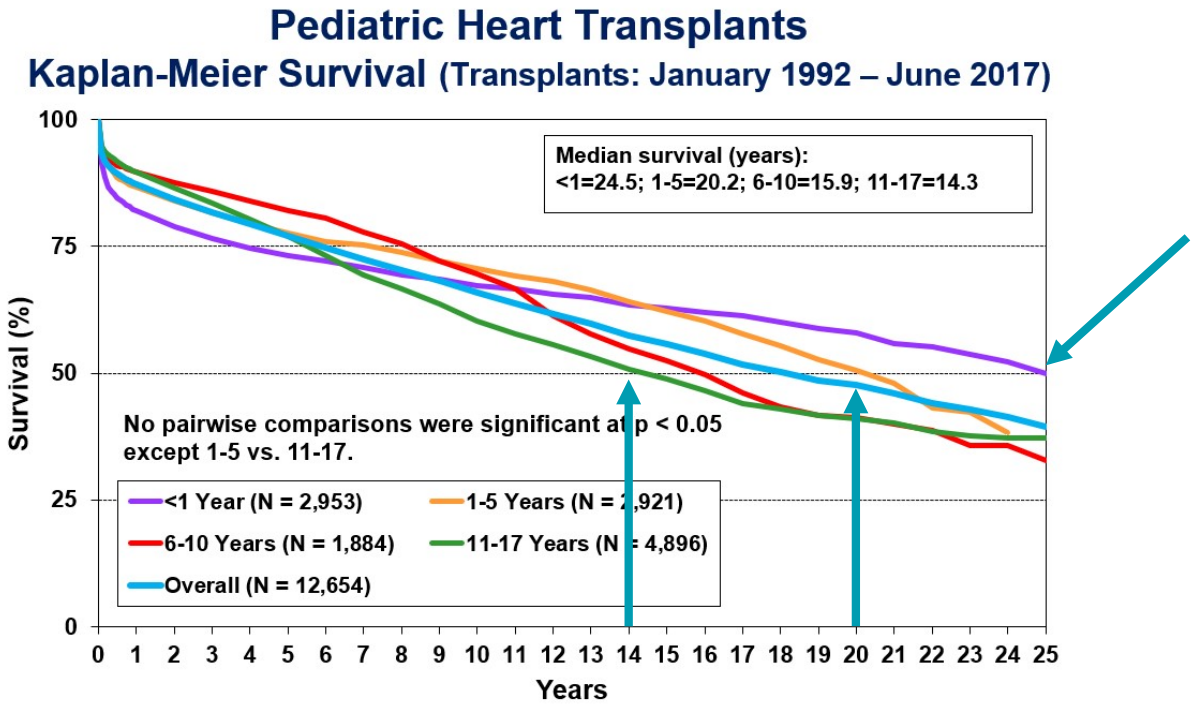
# What do these patients look like going into transplant? Physical health of CHD patients

- Congenital heart disease patients:
  - **Infants**: Often very sick, on life support, and waiting for transplant as the risk of (standard) cardiac surgery is too high.
  - **Young children**: Often had a previous surgery as an infant or young child but is now in need. These individuals are often sick and fragile and require hospitalization while waiting for transplant.
  - **Older children and adolescents**: Often had previous surgeries which now have failed. These individuals often do not require hospitalization while waiting for transplant but tend to stay at home and be not well enough to attend school.

# What do these patients look like going into transplant? Physical health of cardiomyopathy patients

- Pediatric cardiomyopathy patients who are considered for cardiac transplantation generally are too fragile to attend school.
- Often these individuals are hospitalized for months on intravenous medications supporting their heart function.
- Some develop severe dysfunction of the heart requiring mechanical support devices (Ventricular Assist Devices or VADs) or total artificial heart devices (Syncardia™)
  - Risk of strokes and other sequalae from thromboembolic events

# What do these patients look AFTER transplant? Overall survival and half-life

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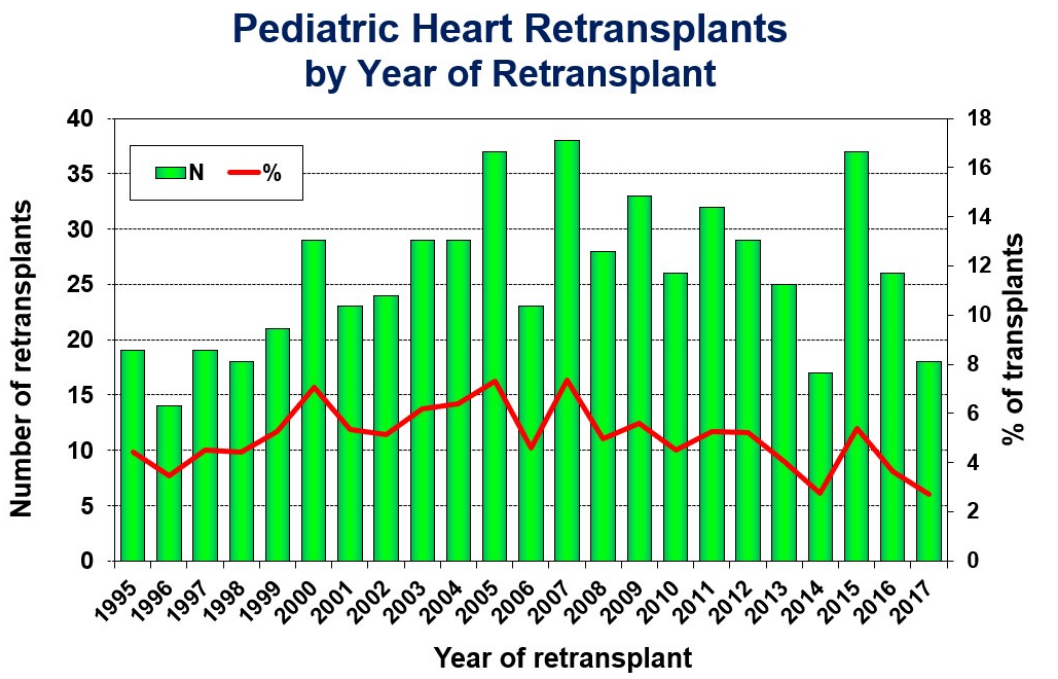
# What do these patients look AFTER transplant? Re-transplantation

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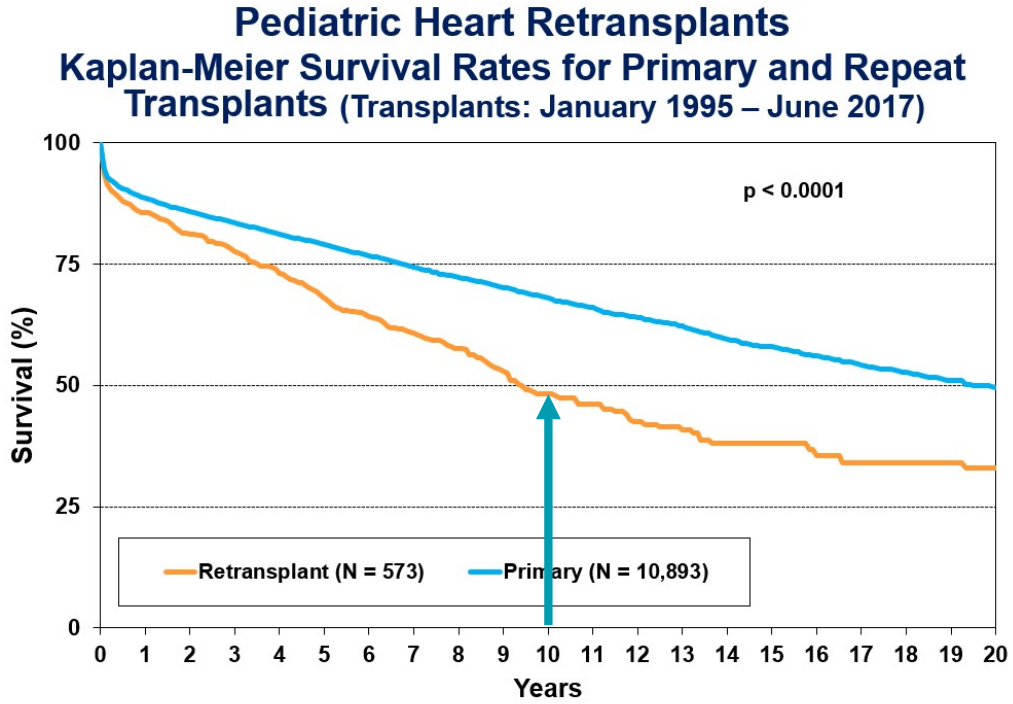
Only patients who were less than 18 years old at retransplant are included.

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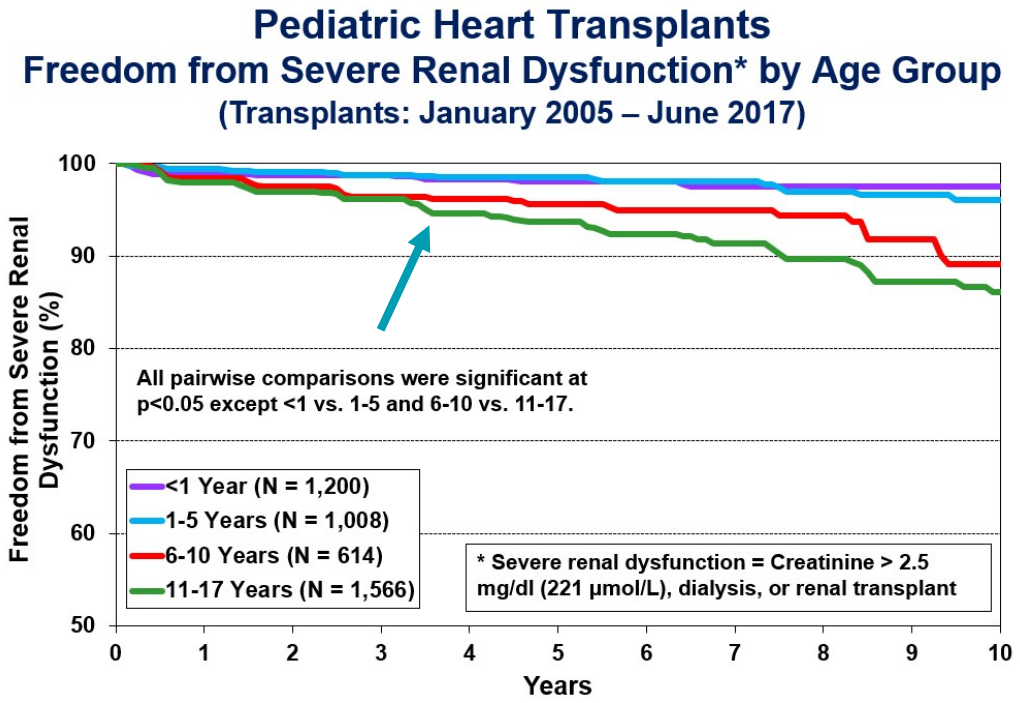
# What do these patients look AFTER transplant? Kidney disease

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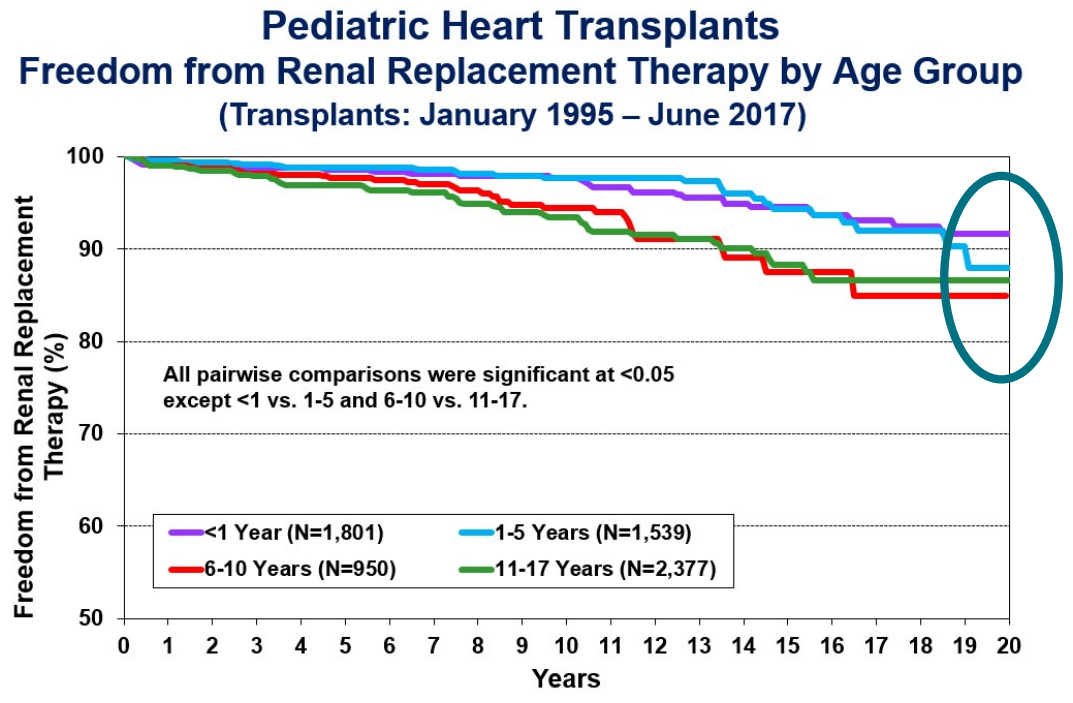


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# What do these patients look AFTER transplant? Cancer

## Pediatric Heart Transplants
## Post-Transplant Malignancy
## Cumulative Morbidity Rates in Survivors
### (Transplants: January 1995 – June 2017)

| Malignancy/Type | | 1-Year Survivors | 5-Year Survivors | 10-Year Survivors |
|---|---|---|---|---|
| No Malignancy | | 6,471 (98.2%) | 3,786 (95.4%) | 1,662 (90%) |
| Malignancy (all types combined) | | 116 (1.8%) | 183 (4.6%) | 185 (10%) |
| *Malignancy Type** | *Lymphoma* | 107 | 174 | 169 |
| | *Other* | 9 | 12 | 19 |
| | *Skin* | 0 | 1 | 2 |
| | *Type not reported* | 0 | 0 | 1 |

*Recipients may have experienced more than one type of malignancy so sum of individual malignancy types may be greater than total number with malignancy.

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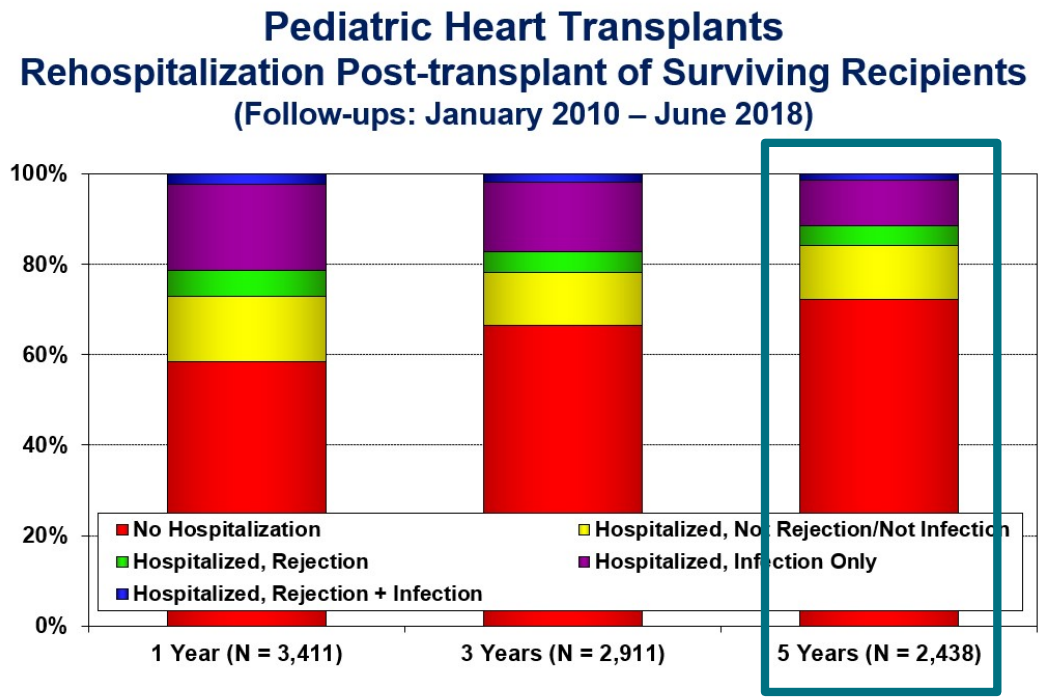
# What do these patients look AFTER transplant? Hospitalization and functional status

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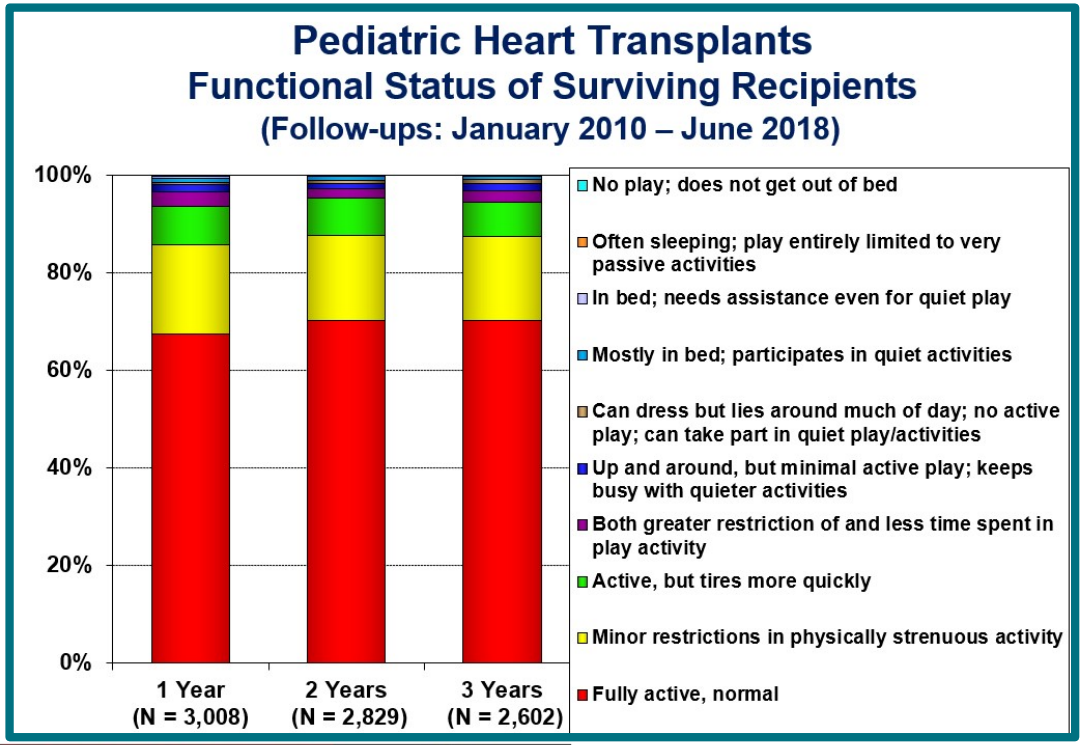


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# What do these patients look like AFTER transplant? Ability to exercise

- Reduced exercise capacity (compared to healthy children)
  - Higher resting heart rate and lower peak heart rate
  - Lower peak oxygen consumption
  - Lower peak power
  - Lower peak work
  - Lower exercise duration
- Deconditioning before and after transplant can be contributing factors.
- Pediatric Cardiac Rehabilitation?
  - Adult studies show significant increases in exercise capacity after rehab and increased muscle strength after resistance training.

# Cardiac Transplantation: Final thoughts

- Significant consequences for adulthood
  - Developmental
  - Social
  - Medical/Physical
- Barriers currently exist hindering ”success” as an adult:
  - Impact of developmental delay and cognitive function
  - Lack of pediatric resources to improve physical health
  - Problems of transitioning from a pediatric hospital based program to an adult hospital based program