

Additional Resources



Original Artwork by
Aaron, Age 7



Glossary

Acute Cellular Rejection

Rejection of a new heart by a person's white blood cells.

Advance Directive

A legal document allowing older teens and adults to state their wishes about end-of-life care ahead of time.

Ambulatory Blood Pressure Monitoring

Monitoring a person's blood pressure at set intervals while they do everyday activities as part of their normal routine.

Anesthetist

A doctor who specializes in giving sleep medicine before an operation.

Antibodies

Proteins in the body that fight infection.

Antibody-Mediated Rejection

Rejection of a new heart because antibodies see it as a "foreign" object in the body.

Biopsy

A test to take tiny samples of tissue and examine them under a microscope.

Bone Mineral Density Test

A test, usually involving a type of x-ray, to check the strength of a person's bones.

B-type Natriuretic Peptide (BNP)

A type of hormone that reaches high levels in cases of heart failure.

Cardiac Allograft Vasculopathy

A gradual, long-term rejection of a transplanted heart causing its blood vessels to narrow.

Cardiac Catheterization

A test using a thin tube to check the pressure in a person's heart and blood vessels.

Cardiologist

A doctor who specializes in the heart.

Cardiomyopathy

Having weak heart muscles.

Catheter

A thin hollow tube.

Chemotherapy

Literally, treatment with chemicals; usually refers to medications to treat cancer.

Cognitive Difficulties

Difficulties understanding, learning, remembering or sharing information.

Compatible Blood Groups

Blood groups enabling a transplant or blood transfusion from one person to another; the blood groups do not need to be exactly the same.

Congenital Heart Disease

Heart disease a person has from when they are born.

Coronary Angiography

A test using dye and an x-ray machine to look at the size and shape of the coronary arteries at different times after transplant.

Creatinine

A waste product removed by the kidneys before it is released from the body in urine; high creatinine levels in the blood can be a sign the kidneys are not working properly.

Cytomegalovirus

A virus that is a member of the herpes virus family and can cause fever, joint pains, pneumonia, severe stomach upset and reduced white blood cells after transplant.

Developmental Assessment

A test to see how well a child is developing. For example, how well they can walk, speak, hear, engage with other people and understand what is happening around them.

Developmental Play

Activities such as drawing or games aiming to develop social or cognitive skills.

Dexterity

Having good control over the muscles of the hands and fingers (also known as fine motor skills.)

Echocardiogram (echo)

A test using sound waves to check the size and shape of the heart and see how well it pumps blood.

Electrocardiogram (ECG or EKG)

A test measuring the strength and frequency of a person's heart beat.

Endomyocardial Biopsy (EMB)

A type of heart biopsy.

Epstein-Barr Virus

A virus that is a member of the herpes virus family and usually carries no or very mild symptoms; in transplant patients, it can increase the chance of developing post-transplant lymphoproliferative disorder (PTLD.)

Glomerular Filtration Rate (GFR) Test

A test to see how well a person's kidneys filter waste.

Health Care Proxy

A document allowing a patient to appoint someone to make healthcare decisions for them if they can no longer decide for themselves, for example, if they become too ill.

Hepatologist

A doctor who specializes in the liver.

Hypertension

High blood pressure.

Immunosuppressant

Medication suppressing, or weakening, the immune system so it will not reject a new heart.

Incision

A cut or an opening made during surgery.

Inpatient

A person staying in a hospital overnight for tests or treatment.

Interdisciplinary team

A team including people with different disciplines or professions, for example, social workers, dietitians, doctors, nurses and psychologists.

Magnetic Resonance Imaging (MRI)

A type of x-ray showing detailed pictures of the inside structures of the body, such as the chambers of the heart and blood vessels.

Nephrologist

A doctor who specializes in the kidneys.

Neurologist

A doctor who specializes in the nervous system, which is made up of the brain, spinal cord and nerves around the body.

Neuropsychologist

A person trained to work with children and teens to understand how the brain works and how an illness can affect their behavior.

Non-specific Allograft Failure

Poor functioning of a transplanted heart without any clear reason.

Oncology Team

A team specializing in cancer treatment.

Outpatient

A person who has tests or treatment in hospital but goes home later the same day.

Palliative Care

Also known as end-of-life care or hospice care; helps patients and families maintain a good quality of life and as normal a routine as possible in times of very serious illness.

Pediatrics

A branch of medicine involving the care of babies, children and adolescents.

Pediatrician

A doctor specializing in offering care to babies, children and adolescents.

Post-transplant Lymphoproliferative Disorder (PTLD)

A disease after transplant causing a person's lymph glands to become larger after a viral infection. Over time, there is a risk the enlarged lymph glands could turn into a cancerous tumor.

Pulmonary Function Test

A test to see how the lungs are working.

Pulmonologist

A doctor who specializes in the lungs.

Respirologist

See Pulmonologist.

Rating of Perceived Exertion (RPE)

A scale to measure how hard the heart works to pump blood around the body during exercise.

Transition

In medical terms, the gradual, planned movement of teenagers and young adults to an adult-centered healthcare system.

Ultrasound

A test using sound waves to create images of organs or tissue inside the body.

Ventricular Assist Device (VAD)

A small machine that pumps blood around the body for a short time while a person is recovering from heart surgery.

Ventilator

A machine to help a person breathe.

Visual Processing

A person's ability to see and understand information, whether in words or pictures.



Helpful Websites and Resources

NOTE: All website information and links were up-to-date at the time of printing.

Transplant-Related Organizations and Websites

American Heart Association

Offers easy-to-read medical information and pictures on congenital heart defects and children.

www.americanheart.org/children

Canadian Transplant Association (CTA)

A registered charity that includes transplant recipients and others who are committed to identifying and removing barriers to organ donation. The CTA encourages and motivates transplant recipients to maintain a healthy lifestyle by supporting athletic and other awareness events.

www.organ-donation-works.org

Children's Organ Transplant Association

An organization that works to make life-saving organ transplants accessible to all. COTA works with individuals of all ages to arrange the necessary funding for transplant expenses. Call 1-800-366-2682.

www.cota.org

David Foster Foundation

Dedicated to providing financial support to Canadian families with children in need of life-saving organ transplants.

In addition to helping families with their non-medical expenses, the Foundation strives to increase organ donor awareness in Canada and the United States.

www.davidfosterfoundation.org

National Foundation for Transplants

National, non-profit organization that offers a program of healthcare and financial support services and patient advocacy for transplant candidates, recipients and their families. Call 1-800-489-3863.

www.transplants.org

Trillium Gift of Life Network

Created to help save and enhance lives by maximizing organ and tissue donations for transplantation.

www.giftoflife.on.ca

Trio

A non-profit organization committed to providing support, awareness, education and advocacy to those involved with organ transplants. Call 1-800-TRIO-386.

www.trioweb.org

United Network for Organ Sharing (UNOS)

A non-profit membership organization that manages the National Organ Procurement and Transplant Network (OPTN) and US Scientific Registry under contracts with the US Department of Health and Human Services. Call 1-800-TXINFO-1.

www.unos.org

World Transplant Games Federation

The organizing body of the World Transplant Games with the purpose to “visibly demonstrate the benefits of successful organ transplantation, work to increase public awareness of its success and thereby increase organ donation rates, as well as promote the full rehabilitation and wellbeing of our participants.”

www.wtgf.org

Adjustment and Coping Websites

Band Aids and Blackboards

Designed for children with medical challenges of all types, this site is highly interactive, with information for kids, teens and adults.
www.lehman.cuny.edu/faculty/jfleitas/bandaides/index.html

Experience Journal

Provides stories and videos of families and clinicians facing pediatric heart disease along with a hospital preparation manual titled *Helping Your Child with a Medical Experience, A Practical Parent Guide*.
www.experiencejournal.com

Mind Your Mind

Award-winning site for youth by youth, offering information, resources and tools to help manage stress, crisis and mental health.
www.mindyourmind.ca

Kids Stress

Learn strategies to recognize, address and help reduce stress in your child.
www.bloorview.ca/resourcecentre/familyresources/managingkidsstress.php

Parental Stress

Effective strategies on how to combat stress.
www.bloorview.ca/resourcecentre/familyresources/managingstress.php

Sibling Support

Support to individuals who have siblings with special needs.
www.siblingsupport.org/sibshops/index_html

Transition

MyHealthPassport

<http://www.sickkids.on.ca/myhealthpassport/>

Food Safety

Canadian Food Inspection Agency food recalls and allergy alerts

<http://www.inspection.gc.ca/about-the-cfia/newsroom/food-recalls-and-allergy-alerts/complete-listing/eng/1351519587174/1351519588221>

- Sign up for updates about food recalls at <http://www.inspection.gc.ca/about-the-cfia/newsroom/food-recalls-and-allergy-alerts/eng/1299076382077/1299076493846> by choosing from the option(s) in the box titled “Get the latest news about food recalls” at the top right of the page.

Canadian Partnership for Consumer Food Safety Education

<http://www.canfightbac.org/cpcfse/en/>

Food Safety for Transplant Recipients (FDA/USDA/CDC)

<http://www.foodsafety.gov/~fsg/f08trans.html>

- This is a long document (20 pages). It can be downloaded as a PDF or read online.

Canadian Food Inspection Agency – Additional useful Food Safety Tips

<http://www.inspection.gc.ca/english/fssa/concen/tipcone.shtml>

USDA and Partnership for Food Safety Education

<http://www.fightbac.org/>

- Hover your mouse over “Downloads” on the bar across the screen and then click “Brochures and Fliers.”



Appendix 1: Contributors and Affiliations

| | |
|--|--|
| <p>Allain-Rooney, Tina Research Nurse and Transplant Nurse Coordinator Hospital for Sick Children University of Toronto Toronto, Canada</p> | <p>Bannister, Louise Registered Dietitian Hospital for Sick Children University of Toronto Toronto, Canada</p> |
| <p>Barnes, Alessia Assistant Professor of Pediatrics Medical Director of Cardiac Transplantation University of Texas Southwestern Children's Medical Center of Dallas Dallas, Texas</p> | <p>Bastardi, Heather Pediatric Nurse Practitioner, Heart Transplant Coordinator Boston Children's Hospital Boston, Massachusetts</p> |
| <p>Burge, Mary Heart Transplant Nurse Coordinator Lucile Packard Children's Hospital Stanford University Palo Alto, California</p> | <p>Burnette, Ali Heart Transplant Coordinator Medical University of South Carolina South Carolina</p> |
| <p>Cassils, Leigh Registered Nurse, Cardiovascular OR Hospital for Sick Children University of Toronto Toronto, Canada</p> | <p>Conway, Jennifer Heart Failure/Transplant Cardiologist Hospital for Sick Children University of Toronto Toronto, Canada</p> |
| <p>Das, Bibhuti Associate Professor, Division of Cardiology Children's Medical Center University of Texas Southwestern Medical Center Dallas, Texas</p> | <p>Dodd, Bernadette Clinical Nurse Specialist Pediatric Heart Transplant Stollery Children's Hospital Edmonton, Alberta</p> |
| <p>Dodd, Debra Medical Director, Pediatric Heart Transplant Program Vanderbilt Children's Hospital Nashville, Tennessee</p> | <p>Drabble, Alison Heart Transplant Nurse Coordinator Hospital for Sick Children University of Toronto Toronto, Canada</p> |
| <p>Dupuis, Joanne Post-Transplant Coordinator Children's Hospital of Michigan Detroit Medical Center Detroit, Michigan</p> | <p>Fester, Keith Clinical Pharmacy Manager – Pediatric Transplants Morgan Stanley Children's Hospital of New York-Presbyterian Columbia University Medical Center New York, New York</p> |

Additional Resources

| | |
|--|--|
| <p>Friedland-Little, Joshua Pediatric Cardiology Fellow University of Michigan Congenital Heart Center Ann Arbor, Michigan</p> | <p>Giblin, Tara Transplant Nurse Practitioner and Donor Coordinator Morgan Stanley Children’s Hospital of New York-Presbyterian Columbia University Medical Center New York, New York</p> |
| <p>Gold, Anna Clinical Psychologist Hospital for Sick Children University of Toronto Toronto, Canada</p> | <p>Hollander, Seth Clinical Assistant Professor, Pediatrics (Cardiology) Associate Section Chief, Pediatric Heart Failure & Transplantation Lucile Packard Children’s Hospital Stanford University Medical Center Palo Alto, California</p> |
| <p>Lee, Donna Pediatric Heart/Lung Transplant Coordinator/ Nurse Practitioner Lucile Packard Children’s Hospital Stanford University Medical Center Palo Alto, California</p> | <p>Lin, Aileen Heart Failure Nurse Practitioner Lucile Packard Children’s Hospital at Stanford Palo Alto, California</p> |
| <p>Maleszewski, Joseph J. Cardiovascular Pathologist College of Medicine, Mayo Clinic Rochester, Minnesota</p> | <p>Markham, Michael Heart Transplant Nurse Coordinator Nationwide Children’s Hospital Columbus, Ohio</p> |
| <p>Martin, Kathy Nurse Practitioner Hospital for Sick Children University of Toronto Toronto, Canada</p> | <p>Massey, Terri Heart Transplant Coordinator & CV Clinician Kosair Children’s Hospital Louisville, Kentucky</p> |
| <p>McDonald, Nancy Pediatric Nurse Practitioner – Heart Transplant Lucile Packard Children’s Hospital at Stanford Palo Alto, California</p> | <p>Missler, Heather Heart Transplant Nurse Coordinator Nationwide Children’s Hospital Columbus, Ohio</p> |
| <p>Nalli, Nadya Staff Pharmacist Hospital for Sick Children University of Toronto Toronto, Canada</p> | <p>Parent, Janet Registered Nurse, Transplant and Cardiology Hospital for Sick Children University of Toronto Toronto, Canada</p> |

Additional Resources

| | |
|--|---|
| <p>Robie, Sharon Heart Transplant Nurse Coordinator Loma Linda Medical Center Loma Linda, California</p> | <p>Rodriguez, Rose Senior Nurse Practitioner Morgan Stanley Children's Hospital of New York-Presbyterian Columbia University Medical Center New York, New York</p> |
| <p>Rosenthal, David Associated Professor of Pediatrics Director, PACT Program Lucile Packard Children's Hospital Stanford University Palo Alto, California</p> | <p>Schumacher, Kurt Clinical Assistant Professor University of Michigan Congenital Heart Center Ann Arbor, Michigan</p> |
| <p>Stendahl, Gail Heart Transplant Nurse Practitioner Children's Hospital of Wisconsin Milwaukee, Wisconsin</p> | <p>Trainor, Kelly Advanced Practice Nurse/Certified Pediatric Nurse Practitioner Heart Transplant/Heart Failure Ann & Robert Lurie Children's Hospital of Chicago Chicago, Illinois</p> |

