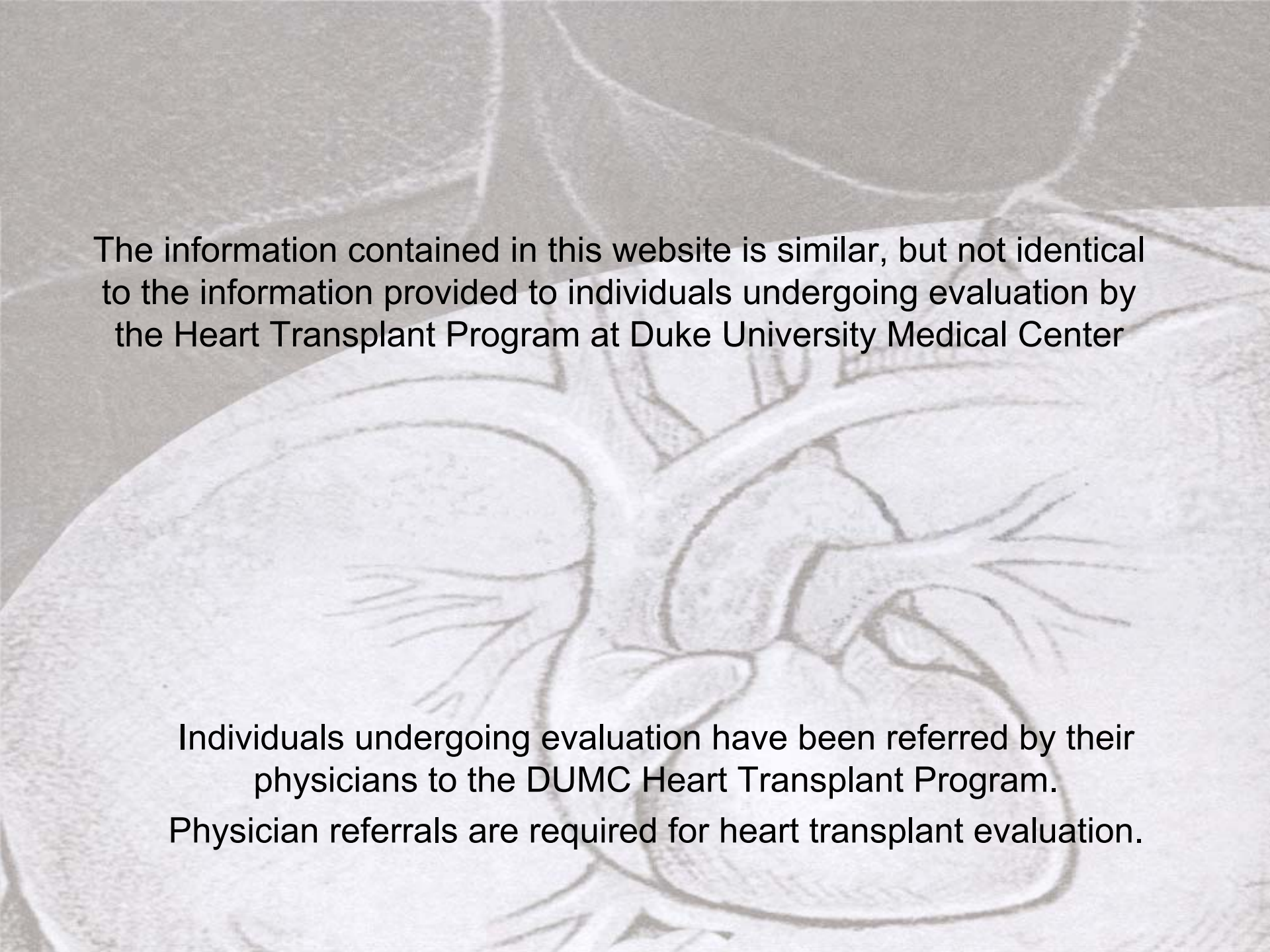


An anatomical illustration of a human heart, showing the four chambers (right and left atria and ventricles) and the major blood vessels (superior and inferior vena cava, aorta, and pulmonary artery). The illustration is rendered in a light, monochromatic style, possibly a medical drawing or a scan of a physical model. The heart is positioned centrally, with the vessels branching out from it. The overall tone is light and clinical.

**Heart Transplantation  
at  
Duke University Medical Center**



The information contained in this website is similar, but not identical to the information provided to individuals undergoing evaluation by the Heart Transplant Program at Duke University Medical Center

Individuals undergoing evaluation have been referred by their physicians to the DUMC Heart Transplant Program.  
Physician referrals are required for heart transplant evaluation.

# “You may need a heart transplant”

No doubt these words can make you feel anxious and uncertain, but it is important to remember you are not alone.

This will be a stressful time for most individuals and their families.

We expect you to have many questions, and we hope that this information will begin to answer some of them.

At this time, heart transplantation may be something you know very little about.

The purpose of this information is to help provide insight into the evaluation process at Duke University Medical Center, and also provide an idea of what to expect soon after heart transplantation.

# How the heart works

A human heart consists of four chambers: two atria and two ventricles.

The two atria act as collection reservoirs for blood during contraction of the primary pumping chambers, the ventricles.

The right ventricle pumps blood to the lungs in order to exchange waste carbon dioxide for oxygen.

The left ventricle pumps the oxygenated blood throughout the body in order to provide oxygen and nutrients to all of the body's organs.

When the heart is unable to efficiently provide adequate oxygen and nutrients to the body, this condition is referred to as heart failure.

In most cases, heart failure is the result of inadequate function of the left ventricle.

# Heart Failure

A healthy left ventricle is strong and thick, and empties more than 55% of the blood in the chamber with each beat.

The percentage of pumped blood with each beat is called the Ejection Fraction.

Blocked coronary arteries, infectious or inflammatory processes, the stress of pregnancy, birth defects, hereditary conditions, and toxin exposure can all result in a permanently injured heart.

For people with permanent injury, the heart muscle can become enlarged and weakened - a condition known as cardiomyopathy.

To be considered for heart transplantation, the ability of the left ventricle to empty blood with each beat is usually less than 20%.

# Cardiomyopathy

The term, cardiomyopathy means weakness of the heart muscle, and is used to describe heart failure from many causes.

Medical treatments for cardiomyopathy include surgery, pacemakers, and medications, or a combination of these therapies.

Heart transplantation is considered for individuals only after all other available treatments have been tried, and optimized, and the therapies have failed to prevent further deterioration.

The only way to determine if heart transplantation will be a beneficial treatment is to undergo heart transplant evaluation.

# What is heart transplantation

Heart transplantation is an operation during which the diseased heart is removed and replaced with a healthy donor heart.

The donor is a person who has died, and their family has decided to donate the heart to someone else who will benefit from having it.

Organ donation is an act of compassion and kindness during a time of great stress, and it allows good to come from a loved one's unexpected death.

Heart transplantation is not an experimental operation, and since the 1980's has been an effective, medically accepted treatment for cardiomyopathy.

Heart transplantation is not a cure for heart disease, but is a method of treatment for heart failure

# The Purpose of Heart Transplant Evaluation

To assess the extent of an individual's heart disease.

To determine the health of an individual's other body systems (lungs, liver, kidneys, etc.).

To allow the heart transplant team to determine if heart transplantation will be a good therapy for an individual.

To allow a candidate to determine if heart transplantation is the right therapy for them.

To allow the heart transplant candidate and the team members to get to know each other.

# Heart Transplantation Candidates

There are three programs at DUMC that lead to heart transplantation.

The Standard Criteria Program

The Expanded Criteria Program

The Ventricular Assist Device Program

# Standard Criteria Program

Individuals are less than 65 years old.

Candidates have no additional major disease, or health problems.

Candidates have received maximum treatment for heart disease, but continue to decline, and recovery of cardiac function is not anticipated.

Candidates do not currently use tobacco products.

Candidates rarely use alcohol, and, then, in moderation only.

# Expanded Criteria Program

For individuals who do not meet the Standard Program criteria.

Candidates may be more than 65 years old

Candidates may have mild kidney dysfunction

Candidates may have diabetes without other organ damage

Candidates in the Expanded Criteria Program must be willing to accept a donor organ that has good, but somewhat compromised function

# Ventricular Assist Program

Ventricular Assist Devices (VAD's) are mechanical devices that can provide an extended period of support for a failing heart.

The support provided by VAD's is beyond the short term capabilities of traditional devices such as intra-aortic balloon pumps (IABP's).

As with many other heart surgeries, the sternum is cut to allow placement of the device, then closed.

Support times can range from months to several years depending on the type of device used

Depending on the type of device used, it is possible to return home after recovering from surgery, and while awaiting transplantation

Candidates for this therapy will be referred to a specialist coordinator.

# Physiologic Evaluation



## Left Heart Catheterization

Provides information about the arteries supplying blood to the heart

## Right Heart Catheterization

Provides information about overall heart and lung function

## Level I Exercise Test

Provides information about the heart's response to exercise, and need for transplantation

## Ventilation/Perfusion Scan (V/Q Scan)

Provides information about the blood supply to the lungs

## Pulmonary Function Testing

Provides information about the ability to move air in and out of the lungs

# Physiologic Evaluation

## Echocardiogram

Provides information about heart valves, and heart function

## Gallbladder Ultrasound

Provides information about the gallbladder, liver, and abdominal aorta

## Carotid Ultrasound

Provides information about blood flow to the head and brain

## 24-hour Holter Monitor

Provides a 24 hour record of the heart's electrical activity

## Serologies (Blood Tests)

Provides information about functioning of kidneys, liver, and immune systems

All listed tests may not be performed, and others may be added if determined to be necessary by the transplant team members

# The Transplant Team

## **Transplant Cardiologist**

**A physician who specializes in evaluating and treating people with end stage heart failure. This physician is involved in both pre and post transplant medical care.**

## **Transplant Surgeon**

**A physician who specializes in, and performs the transplant or ventricular assist device surgery. This physician directs peri-operative care after heart transplant or ventricular assist device surgery.**

## **Transplant Coordinator**

**A specialist advanced practice nurse who serves as the primary point of contact with the remainder of the transplant team for patients in the heart transplant program.**

## **Ventricular Assist Device Coordinator**

**A specialist advanced practice nurse who serves as the primary point of contact with the remainder of the team for patients in the ventricular assist device program.**

# The Transplant Team

## **Transplant Psychologist**

**A mental health professional who specializes in assessing personal issues that can affect transplant recipients, and their support system.**

## **Transplant Social Worker**

**A specialist who helps potential recipients and their support system determine their ability to cope with the impact of transplantation, and can assist in identifying strategies for making any necessary adjustments.**

## **Transplant Financial Coordinator**

**A transplant financial specialist who will assist in determining current available personal resources, and can help identify ways of accessing any needed additional resources.**

# Personal Responsibility and Heart Transplantation

**A new heart will mean new responsibilities. It is important to think not only of the continuation of life, but also the immediate and long term impact that transplantation can have on the individual receiving a heart transplant, and their families.**

**Things to consider include:**

**Commitment to a healthy lifestyle after transplantation**

**Taking multiple medications daily for the remainder of your life**

**Daily monitoring of your health status and providing the records at each post-transplant follow-up appointment**

**The role of family and friends who will provide significant support while waiting, and during the first post-transplant year**

**Financial considerations related to the cost of medications, and care for both routine, and potentially, extraordinary health issues**

# While Waiting for Transplantation

Once accepted into the DUMC program, the potential recipient's name is entered into a national waiting list

Not all enrollees in the DUMC program will be fortunate enough to receive a heart transplant. Traditionally there are more individuals who can benefit from transplantation than donor organs available.

Enrollees must be able to be contacted at any time of the day or night once their name is on the national waiting list

Enrollees must be able to arrive at DUMC three and a half hours from the time that a donor organ becomes available

# Waiting Time

Fifty thousand individuals may benefit from heart transplant yearly

Between two and three thousand heart transplants are performed in the United States yearly

Approximately 60 cardiac transplants are performed yearly at DUMC

Individuals with blood type O typically wait longer

Individuals between 5'2" and 5'9" tall typically have a shorter waiting time

Individuals should expect to wait an average of six months from the time of listing

# Recipient Notification

With the initial offer of a potential donor organ, the potential recipient is called by the transplant coordinator and instructed to come to DUMC. Again, the potential recipient must be able to arrive at DUMC in 3.5 hours

During this period, the transplant surgeon continues to evaluate the suitability of the offered donor organ

If the organ is deemed suitable, preparations for surgery continue

If the offered organ is deemed not suitable, surgical preparation is halted. The potential recipient for whom the organ was offered is notified.

# The Transplant Operation

The surgery typically takes four to six hours not including preoperative preparation time or postoperative transport to and initial assessment in the recovery area

Surgical staff will occasionally discuss progress of the surgery with your family members in the waiting room

Your family will be instructed to wait in the surgical waiting area, and will be given a notification device so they can take personal breaks without fear of missing surgical updates

After arrival of the donor organ in the operating room, the recipient's diseased heart will be removed and the new donor heart will be sewn in place

# Initial Recovery Phase

At arrival in the recovery area, recipients remain sedated, on a ventilator, and vital signs are closely monitored while multiple intravenous medications are adjusted.

The intensive care unit staff will discuss the purpose of the medications and support devices with family members, and update families about the recipient's progress.

During the first twenty four hours many of the supportive medications and monitoring equipment may be discontinued when their use is no longer needed.

During the first twenty four hours, discontinuation of ventilatory support is typical, and the recipient may get out of bed to a chair.

# Possible complications

Any of the complications listed below may have serious long term health consequences. There are therapies which will often reverse, or prevent the serious complications, but not all therapies will succeed. Everyone is encouraged to discuss them with members of the Heart Transplant Team

**Bleeding** – Some post-operative bleeding is to be expected. If the amount of bleeding is more than expected, treatment may consist of medications, additional use of blood products, or a return to surgery.

**Stroke** – May be the result of pre-existing medical conditions, or the result of surgical complications. The long term impact of stroke can range from no, or minimal, to severe cognitive and/or physical impairment

# Possible complications

Respiratory dysfunction – Individuals with known severe pre-existing respiratory disease are unlikely to benefit from heart transplantation alone and may be referred for heart-lung transplantation. However, heart transplant patients can experience prolonged respiratory dysfunction and may require more than twenty four hours of ventilator support. Rarely, an individual will remain on a ventilator for more than seven days, and may require a tracheostomy.

Kidney dysfunction – The stress of surgery and bypass can impair kidney function. Impaired function is typically temporary, but prolonged dysfunction can occur and may require temporary or permanent dialysis, or kidney transplant at a later time.

Arrhythmia – may occur for many reasons, and may result from stresses of explantation and implantation of the donor heart. The tendency to develop arrhythmias are generally resolve within 48 hours, but in rare instances may require additional medical therapies.

# Possible complications

Infection – all patients receive post transplant antibiotic prophylaxis, but infection, mild to serious, remains a possibility. Routine postoperative monitoring allows for early detection, and additional treatment when necessary.

Coronary artery disease – for reasons not yet well understood, and unlike typical arterial blockages by fatty deposits, narrowing of the coronary arteries may occur after transplant.

Graft rejection – despite the efforts taken to ensure compatibility of organs between donor and recipients, the recipient's immune system may attack the donor heart in spite of anti-rejection medications and may eventually result in mild to serious heart dysfunction

# Possible complications

Graft dysfunction – refers to the inability of the donor organ to effectively pump blood to the recipients body. Dysfunction may occur as a result of electrical conduction problems, rejection, or may have other causes, If appropriate the recipient will be immediately re-listed for a second a transplantation surgery

Death – may occur despite the sustained efforts of the many members of the transplant program. The risk of death during the perioperative period is less than 10%

# Length of Hospitalization

The length of stay is frequently influenced by the level and longevity of a recipient's incapacity prior to the time of transplant, however:

Recipients typically transfer from the Intensive Care to the Step-down Unit approximately forty-eight hours after surgery

Discharge from the hospital usually occurs seven to ten days after the transplant operation.

At discharge, transplant recipients are followed as outpatients in the cardiac transplant clinic every week for the first month and progressively less frequently until, by three years post transplant, recipients may be seen yearly.

# Survival Statistics at DUMC

90% of recipients are living at 1 year

83% of recipients are living at 3 years

75% of recipients are living at 5 years

46% of recipients transplanted 10 years ago are living

42% of recipients transplanted more than 10 years ago are living

# Heart transplant statistics

An anatomical illustration of a human heart, showing the four chambers (right and left atria and ventricles) and the major blood vessels (superior and inferior vena cava, aorta, and pulmonary artery and vein). The heart is shown in a slightly elevated, anterior view, with the major vessels branching out from the base. The illustration is rendered in a light, sketch-like style with fine lines and shading to indicate the texture and structure of the heart muscle and vessels.

Approximately 4,000 heart transplants are performed worldwide each year.

Over 2,000 heart transplants are performed yearly in the United States

Established in 1986, the DUMC program has performed over 500 heart transplants to date.

The heart transplant program at DUMC is responsible for more than 50 transplants per year

# After Discharge Home

As noted earlier, heart transplantation is not a cure for heart disease, but is, instead, a method of managing heart disease. Some of the ongoing therapies necessitated by transplantation may result in new health issues that require management.

Heart transplant recipients do best if they are active participants in their post transplant health.

Active participation consists of taking medications daily, regular health care follow up, maintaining a healthy diet, exercising regularly, avoiding tobacco and alcohol products, and cardiac follow up with the heart transplant team.

# Biopsies

Biopsies are the only reliable means of monitoring the balance between the activity of the immune system and immune suppressing medications required for continued function of a transplanted heart

Early after transplant, biopsy centered assessment of cardiac function is done weekly, but the interval between biopsies lengthens over time, and are typically done at four month intervals after the first year from the date of transplantation.

# ISHLT Biopsy grading

Biopsy scores range from grade 0, to grade 4.

Grade 0 = No rejection

Grade 1A = focal area of white blood cells without death of tissue

Grade 1B = diffuse but sparse areas of white blood cells without death of tissue

Grade 2 = single area of aggressive white blood cells and/or a small area of white blood cell damage

Grade 3A = multiple aggressive white blood cells and/or white blood cell damage

Grade 3B = active inflammatory process with tissue death

Grade 4 = active, aggressive white blood cell infiltrates with swelling, bleeding, inflammation of blood and/or lymph vessels, and tissue death

# Treatment of rejection

Biopsy grades of 0, 1A, 1B, and 2 generally do not require treatment, although an individual may be asked to return sooner than the typical follow up schedule.

A biopsy grade of 3A typically requires treatment in an outpatient setting.

Biopsy grades 3B, and 4 require inpatient medical treatment.

An additional biopsy is generally done two weeks after treatment.

# Team Members

## Heart Transplant Surgeons:

James Jagers MD

Shu Lin MD

Andrew Lodge MD

Carmelo Milano MD

Sinan Simsir MD

## Heart Transplant Cardiologists:

G Michael Felker MD

Adrian Hernandez MD

Joseph Rogers MD

Paul Rosenberg MD

## Heart Transplant Coordinators:

Lisa Marks RN BSN

Brad Persing RN MSN

Beth Soule RN MSN

Jonathan Warren RN BSN

## Ventricular Assist Device Coordinator:

Laura Blue RN MSN NP

## Clinical Specialist, Advanced Heart Failure

Dianne Leloudis RN, MSN

# Team Members

Transplant Social Worker:  
Ellen Stone MSW LCSW

Heart Transplant Psychologists:  
Krista Barbour PhD  
Lara LaCaille PhD

Transplant Financial  
Coordinators:  
Julia Boatwright-Holden  
Janet Tate

Heart Transplant Office  
Secretaries:  
Denise Mosley  
Jane Wilkerson

Transplant Programs  
Administration  
Syvil Burke

Heart Center Support Program:  
Leatrice Martin

# Heart Transplant Program Contacts

Mailing Address: Box 3235

Duke University Medical Center (DUMC)  
Durham, NC 27710

Telephone: 1-800-238-1489 or 1-919-684-2651

8:30AM – 4:30PM Monday – Friday

Fax #: 1-919-681-8860

Evenings, nights and weekends

for urgent issues from individuals in the heart transplant program:

919-684-8111 and ask for the Heart Transplant Coordinator on-call pager # 0097.

Heart Center Support Program: 1-919-681-5031

# In Conclusion

The heart transplant team at Duke is committed to achieving the best outcomes possible for individuals in for whom we care

We ask that individuals undergoing evaluation discuss issues of concern both with the team and members of their support system

We also suggest that you consider discussing an Advance Directive with your support team. Advance Directives are legal documents that provide a set of directions for guiding an individual's health care when they are unable to make decisions for themselves. The office of Patient and Visitor Relations (919-681-2020) can provide Advance Directive forms that comply with North Carolina laws

The team understands that considering heart transplantation can be a difficult and confusing time. We hope that the information we have provided is helpful .

# Additional Resources

## American Heart Association

(Information on heart healthy diet, support and ventricular assist devices.)

7272 Greenville Avenue, Dallas, TX 75231

800-242-8721

[www.americanheart.org](http://www.americanheart.org)

## American Organ Transplant Association

(Helps patients obtain and sustain transplantation.)

1603 Oak Place Court, Pearland, Texas 77581

800-373-1646

[www.a-o-t-a.org](http://www.a-o-t-a.org)

# Additional Resources

## Angel Flight

(Free air transportation for financially eligible patients)

800-446-1231

310-390-2958

[www.angel-flight.org](http://www.angel-flight.org)

## Carolina Donor Services

(Information on organ donation.)

3622 Lyckan Parkway, Suite 6002, Durham, North Carolina 27707

919-489-8404

[www.carolinaservices.org](http://www.carolinaservices.org)

## Children's Organ Transplant Association

(Fundraising assistance for transplant patients.)

800-366-2682

2501 COTA Dr., Bloomington, IN 47403

[www.cota.org](http://www.cota.org)

# Additional Resources

Children's Transplant Association

PO Box 53699, Dallas, TX, 75253

214-287-8484

(Private, nonprofit organization that assists with fundraising.)

Duke Outpatient Pharmacy

Duke South/Clinics First Floor

919-684-2908

Durham Veteran's Affairs Medical Center

919-286-0411

Food And Drug Administration

(Ventricular Assist Devices.)

[www.fda.gov/hearthealth/treatments/medicaldevices/vad.html](http://www.fda.gov/hearthealth/treatments/medicaldevices/vad.html)

# Additional Resources

## Friends Health Connection

(Connects patients with same disease for support.)

800-483-7436

[www.48friend.com](http://www.48friend.com)

## Heart Center Online

(Up to date information available by web-site.)

[www.heartcenteronline.com](http://www.heartcenteronline.com)

## Life In Limbo

(Support for patients and caregivers.)

[www.life-in-limbo-com](http://www.life-in-limbo-com)

# Additional Resources

Marcelino Pan y Vino Inc.

(Provides financial, social and emotional support to Latino children needing transplants.)

Fr. Jose Eugenio Hoyos

St. Anthony's Catholic Church

3305 Glen Carlyn Road, Falls Church, VA 22041

703-820-7111

Medic Alert

(Offers membership and medic alert bracelets.)

2323 Colorado Avenue, Turlock, CA 95382

800-432-5378

[www.medicalert.org](http://www.medicalert.org)

Medicare Hotline

800-672-3071

# Additional Resources

## Medscape

(Comprehensive web-site for medical research and abstracts.)

[www.medscape.com](http://www.medscape.com)

## National Foundation for Transplants

(Fundraising assistance for transplant patients.)

800- 489-3863

901- 684-1697

1102 Brookfield Road, Suite 200, Memphis, TN 38119

[www.transplants.org](http://www.transplants.org)

## National Transplant Assistance Fund

800-642-8399

3475 West Chester Pike, Suite 230, Newtown Square, PA 19073

[www.transplantfund.org](http://www.transplantfund.org)

# Additional Resources

NC Division of Veteran's Affairs

919-733-3851

NC Division of Vocational Rehabilitation

919-733-3364

Organ Donation in Support of Life

[www.lifebanc.org](http://www.lifebanc.org)

Partnership for Caring

(Information on advance directives.)

1620 Eye St. NW, Suite 202, Washington, DC 20006

800-989-9455

[www.partnershipforcaring.org](http://www.partnershipforcaring.org)

PharmaCare

(Transplant mail order medication program.)

800-238-7828

[www.pharmacare.com](http://www.pharmacare.com)

# Additional Resources

## Ronald McDonald House

(Housing for pediatric transplant patients and their families.)

506 Alexander Avenue, Durham, NC 27705

919-286-9305

[www.ronaldhousedurham.org](http://www.ronaldhousedurham.org)

## Social Security Administration

(Applications for retirement, survivorship, disability, SSI and Medicare benefits.)

800-772-1213

[www.ssa.gov](http://www.ssa.gov)

## Triangle Disability Advocates, Inc.

919-350-8539

Fax 919-350-5626

# Additional Resources

## Transplant Recipients International Organization

(Support for transplant candidates, recipients, their families and donor family members.)

1000 16<sup>th</sup> Street, NW, Suite 602, Washington, DC20036

800-874-6386

[www.trioweb.org](http://www.trioweb.org)

## Transplant Support Group Directory (Updated annually)

Chronimed Pharmacy

13911 Ridgedale Drive

Minnetonka, MN 55305

800-753-5583

## Transplant Times

(Newsletter of the transplant patient partnering program.)

340 Kingsland Street, Nutley, NJ 07110

800-893-1995 [www.tppp.net](http://www.tppp.net)

# Additional Resources

## United Network for Organ Sharing

Post Office Box 2484, Richmond, Virginia 23218

804- 782-4800

[www.unos.org](http://www.unos.org)

## United States Department of Health and Human Services

(Comprehensive web-site on a wide range of healthcare issues.)

[www.os.dhhs.gov](http://www.os.dhhs.gov)

## US Living Will Registry

(Medical power of attorney and living will/advance directives information.)

[www.uslivingwillregistry.com](http://www.uslivingwillregistry.com)

## Ventricular Assist Devices

[www.sts.org/education/faqs/faqvassist.html](http://www.sts.org/education/faqs/faqvassist.html)

# Additional Resources

## Veterans Resource Center

(If you have served in the military and received an honorable discharge, you may be eligible for benefits, including immunosuppressant drugs. )

800-606-2022

## We've Been There National Transplant Foundation

(Provide emotional and social support for young transplant patients 10-35 years old.)

866-938-3233

7713 Fontaine St. Potomac, MD 20854

[www.wevebeenthere.org](http://www.wevebeenthere.org)

## World Children's Assistance Fund

(Private, **nonprofit** organization dedicated to providing financial, social, emotional support.)

818-905-9283

[www.wctf.org](http://www.wctf.org)

# Website Resources

<http://circ.ahajournals.org/cgi/reprint/106/14/1750.pdf>

[http://www.ustransplant.org/heart\\_primer.php](http://www.ustransplant.org/heart_primer.php)

<http://www.tmc.edu/thi/anatomy2.html>

<http://www.shands.org/find/service/transplant/heart/meds.htm>

<http://www.cts.usc.edu/ht-patientguide.html>

<http://www.transplantliving.org/Community/glossary.aspx>

<http://www.niaid.nih.gov/publications/transplant/glossary.htm>

<http://www.nlm.nih.gov/medlineplus/ency/article/003003.htm>

<http://www.nlm.nih.gov/medlineplus/druginfo/medmaster/a601207.htm>

<http://www.itns.org/education/edubooklets.html>

[http://www.thoratec.com/ventricular-assist-device/heartmate\\_lvas.htm](http://www.thoratec.com/ventricular-assist-device/heartmate_lvas.htm)

[http://www.thoratec.com/ventricular-assist-device/thoratec\\_vad.htm](http://www.thoratec.com/ventricular-assist-device/thoratec_vad.htm)