

LUNG TRANSPLANT

A guide for patients
and families



Sofia, 12,
lung transplant patient



Parker, 2,
transplant patient

CONTENTS

Welcome to the Lung Transplant Program	2
General Information	2
The Transplant Team	
Location	
Phone Numbers	
The Transplant Evaluation	4
The Waiting List	5
The United Network for Organ Sharing (UNOS)	
Donor Matching Process	
About the Donor	
Waiting for Transplant	6
Waiting Time	
Dry Runs	
The Transplant Surgery	6
Preparing for Surgery	
During Surgery	
After Surgery	
Potential Surgical Complications	
After you Go Home	8
Precautions	
Clinic Visits	
Incision Care	
Physical Activity	
Nutrition	
Regular Pediatric Care	
Biopsies	
Medications After Transplant	8
Life After Transplant	11
Returning to School	
Pets	
Piercings and Tattoos	
Transition to Adult Care	
Resources	
When and How to Call the Transplant Team	13

Welcome to Children's
Hospital of Philadelphia

LUNG TRANSPLANT PROGRAM



Hudson, 5,
transplant patient

The healthcare team has told you that your child may need a lung transplant. Lung transplant is a therapy offered to patients who have chronic lung disease or are experiencing lung failure whose chance of survival is poor without transplantation. This is an optional therapy. The goal of lung transplantation is to provide patients with a longer and better quality of life.

Diagnoses that may need a lung transplant:

- Cystic fibrosis
- Pulmonary hypertension
- Pulmonary fibrosis
- Bronchiectasis
- Bronchiolitis obliterans
- Interstitial lung disease

If your child is referred for a lung transplant evaluation, it does not mean that your child needs a transplant or will be listed for one. Pulmonologists refer patients to our program for a transplant evaluation before a lung transplant. Wait times for a transplant are unpredictable. The evaluation process is comprehensive and involves extensive testing, consultations and education. It is best to start the process before the need for a transplant becomes an emergency.

This handbook was designed to:

- Provide you and your family an outline of the transplant process:
 - Evaluation
 - Time frame
 - Transplant surgery
 - Life after a transplant
- Answer common questions about a lung transplant
- Inform you what to expect before, during, and after a lung transplant

The Lung Transplant Team

Our multidisciplinary team will partner with you to care for your child throughout the transplant process.

Transplant Surgeon

A doctor trained in cardiothoracic surgery. The surgeon will perform the lung transplant surgery and follow your child's progress during recovery in the hospital. This doctor works with the transplant pulmonologist.

Transplant Pulmonologist

A pediatric lung specialist trained in lung transplant procedures. This team member will manage your child's care before and after the transplant. Transplant recipients are seen by the transplant pulmonologist for the rest of their lives.

Anesthesiologist

A doctor who monitors your child during surgery and gives your child medications called "anesthesia" that cause a deep, comfortable sleep. Your child will not see, hear or feel anything during the surgery.

Transplant Nurse Practitioner (NP)

An advance practice nurse who will care for you and your child before and after transplant. The NP works with the transplant pulmonologist. The NP will follow your child's progress in the hospital and during outpatient visits.

Transplant Coordinator

A registered nurse (RN) who will coordinate your child's transplant evaluation, manage the transplant listing and provide education. The transplant coordinator works with the transplant nurse practitioners and the transplant pulmonologist.

Respiratory Therapist (RT)

A therapist trained to help your child with breathing treatments and techniques. The RT partners with the inpatient team to provide breathing treatments and oxygen therapy.

Registered Dietitian/Nutritionist

A specialist in nutritional needs for growth and development. Children with lung failure or chronic lung disease are not able to maintain a healthy nutritional status. The dietitian/nutritionist will see your child before and after transplant. This consult ensures that your child is consuming adequate calories, maintaining weight and continuing to grow.

Physical therapist (PT)

The PT is trained to help with exercises to make your child's body stronger before and after transplant. Maintaining mobility and strength is important in transplant recovery. The PT will help your child get out of bed after surgery and provide exercise precautions during recovery.

Occupational Therapist (OT)

The OT is trained to help your child with activities of daily living like brushing teeth, getting dressed and so on. The OT will help your child return to independence after surgery.

Transplant Psychologist

The psychologist is trained in supporting and counseling children and families throughout the transplant process. You will meet with the psychologist before transplant to assess your family's coping skills. The transplant psychologist will meet with your family after transplant to provide support.

Transplant Social Worker

The social worker helps you access services and resources that you and your child may need while in and out of the hospital. Services include insurance issues, housing, transportation and more. You will meet with a social worker before and after transplant.

Child Life Specialist (CLS)

The CLS is trained in child development. The CLS will help your child and any siblings understand the transplant procedure and life in the hospital. The CLS can prepare your child for transplant surgery and other procedures, and can provide age-appropriate activities and services to help your child cope with hospitalization.

Transplant Pharmacist

Working with the transplant coordinator and transplant psychosocial team, the pharmacist will determine your understanding and ability to adhere to medical treatments before and after transplant. The pharmacist assists the medical team to manage medications at the time of surgery. The pharmacist will provide you with medication education before you go home.

Transplant Financial Counselor

This team member will work with you and your insurance company to determine coverage for the surgery. The counselor will assist with insurance approval for hospitalizations and procedures as well as provide you with counseling.

School Program Teacher

A certified teacher who will communicate with your child's school to help with schoolwork while in the hospital. The teacher will assist with the transition from hospital to school when discharged.

Location

Buerger Center for Advanced
Pediatric Care, 7th floor

Phone Numbers

Children's Hospital of Philadelphia
main number: **215-590-1000**

Children's Hospital of Philadelphia Lung
Transplant Office: **267-426-6629**

THE TRANSPLANT PROCESS

There are many steps in the transplant process: the evaluation, waiting for transplant, the transplant surgery, hospital stay and care after surgery. The following sections will provide information on each step of the transplant process.

The Transplant Evaluation

In order to be considered for a lung transplant at CHOP, your child must undergo a lung transplant evaluation. The purpose of this evaluation is to:

- Perform a comprehensive assessment. Your child must be sick enough to need a lung transplant but well enough to survive the surgery.
- Provide education about transplant. Answer questions to help you decide if lung transplant is right for your child.
- Discuss alternative medical and/or surgical interventions — options other than a transplant.

The transplant evaluation includes some or all of the following:

Routine medical exam: height, weight, blood pressure, review of medical history (family history and previous surgeries), as well as current medications

Blood tests: (1) blood type, which is necessary for donor matching (infants may be eligible to receive a transplant from a donor of a different or “incompatible” blood type); (2) tissue typing and antibody screen; (3) blood counts of red and white blood cells; (4) blood chemistry to check function of the other organs (liver and kidneys); (5) blood gas to assess oxygenation and ventilation; (6) serologies to understand the history of infections (hepatitis A, B, C, HIV, measles, mumps, rubella, chicken pox, Epstein-Barr virus, cytomegalovirus, etc.)

Pulmonary function testing: A breathing test performed in children older than 6 years old that requires taking deep breaths into a mouthpiece

Six-minute walk/exercise test: A test that involves monitoring your child during aerobic activity to determine your child's working capacity. Heart rate, pulse oximetry and blood pressure are monitored.

CT scan: A short test performed by a radiologist to create pictures of the size, shape, and position of lungs

Bronchoscopy: A procedure using a camera that is performed under anesthesia to determine structures of the upper and lower parts of the airway and lungs

Echocardiogram bubble study: To assess the heart for any “holes” or communication between the atria and the top two chambers of the heart.

Multidisciplinary consults: You and your child will meet with many of the transplant team members (see page 2-3) as well as with members of the Pediatric Advanced Care Team (PACT), a unique team that provides support and resources to children with chronic diseases. The PACT can assist families with difficult decision-making.

There may be other consults depending on your child's diagnosis and clinical status.

After the transplant evaluation is completed, your child will be discussed at our weekly Lung Transplant Multidisciplinary Team Meeting, where a decision about listing for transplant will be made. The result of our evaluation could be one of the following:

- Your child does not need a transplant right now, as other medical therapies or interventions could potentially improve lung function.
- Your child needs a lung transplant, and would be a good candidate. We would proceed with listing for transplant if you agree.
- Your child would be a good candidate for lung transplant but does not currently need it because your child is well. Your evaluation would be closed and we could continue to follow your child as an outpatient.
- Your child would not be a good candidate for lung transplant as your child is too sick to survive the procedure. A lung transplant would not improve your child's quality or length of life. In some cases, certain children have a potential for improvement in clinical status that may make them eligible for transplant.

The outcome of our evaluation and multidisciplinary meeting will be discussed with you in detail. At this time, you will have the opportunity to ask questions.

The Waiting List

If your child is found to be a good candidate for lung transplant and you decide you would like to pursue transplant, your child will be placed on the United Network for Organ Sharing (UNOS) lung transplant waiting list.

UNOS oversees organ transplantation across the country. UNOS maintains a national computerized list of children and adults waiting for lung transplants. UNOS works with Gift of Life, our local organ procurement organization, to recover organs.

In order to be placed on the waiting list, your child's information will be entered into UNOS's secure website. Your child will be assigned a Composite Allocation Score (CAS). The lung CAS determines priority for receiving a lung transplant when donor lungs become available and is individual for each patient and each organ offer. The lung CAS is composed of the following factors:

- medical urgency
- estimated 5 year survival rate
- blood type
- cPRA
- height
- pediatric (under 18 years old)
- prior living donor
- travel efficiency
- proximity efficiency

Once active on the waitlist, your child will be eligible for organ offers.

Status 7/Inactive: In some situations, our team makes children inactive on the wait list for a period. One reason for this would be an acute viral illness. You will be notified if your child is made inactive on the wait list.

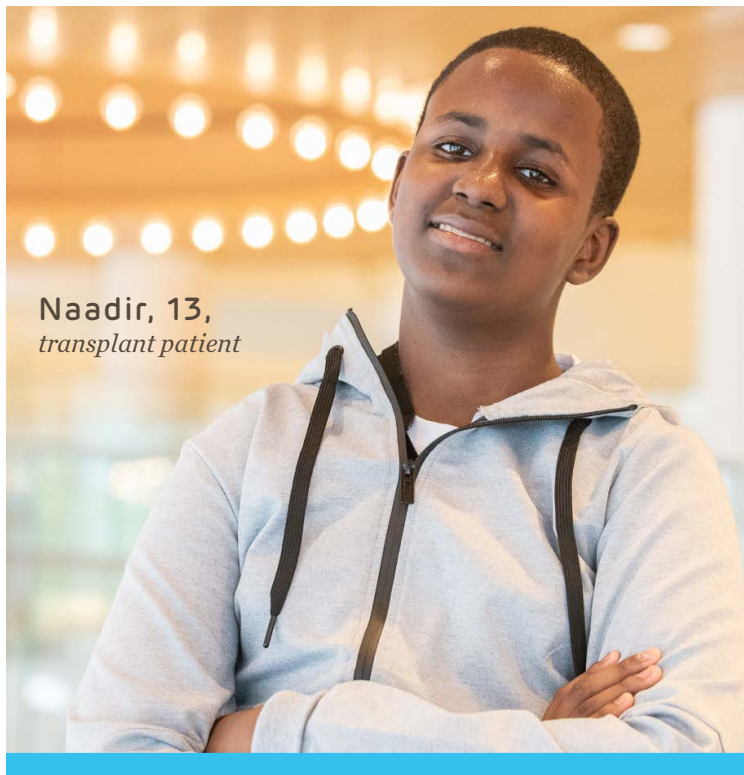
Tzivya, 8,
transplant patient

The UNOS Donor Matching Process

These steps result in an organ match:

1. A child has experienced brain death and his family decides to donate the child's lungs.
2. The donor's medical information is added into the UNOS database.
3. UNOS notifies Gift of Life and CHOP that lungs are available for one of our patients on the wait list. Lungs are offered based on:
 - a. Donor/recipient blood type match/compatibility
 - b. Donor/recipient size: they must be approximately the same height for the lungs to fit
 - c. Recipient lung Composite Allocation Score (CAS)
 - d. Time on the list: Wait time is a tie breaker if all of the above are equal.
4. The transplant pulmonologist and surgeon review the information about the donor lungs and decide whether to accept the organs.
5. If our team accepts the organs, you and your family will be notified.





Naadir, 13,
transplant patient

donor and the lungs are no longer good for your child. While this can be difficult for patients and families, it is important to remember that we only want to accept perfect lungs for your child.

About the Donors

Families want to know the age of the donor and how the donor died. We cannot share information about the donor. Information about your child and family will not be given to the donor's family without your consent. There is a letter writing process through which you can reach out to your donor family after the transplant. Our team will provide you with additional information.

Waiting for Transplant at Home

Your child may be able to wait for a lung transplant at home. If you wait at home, you must be within a 3-hour commute to the hospital at all time. If you are going to be further away than 3 hours, you must notify the transplant team. In some special cases, we will allow a child to wait at home that is outside of the 3-hour radius. In these cases, a social worker will work with you to have a transportation plan in place to get your child to the hospital quickly.

Children waiting at home continue to attend school and participate in activities approved by the medical team.

While waiting for lung transplant at home, your child will have monthly (sometimes more frequently) outpatient clinic visits with the transplant team.

Testing may include blood work, pulmonary function testing, laboratory work and physical therapy. During these visits, we will assess your child's need for transplant, transplant candidacy and ongoing transplant education. Team members from child life and psychology are available to help cope and provide support while waiting for transplant.

Tips for "The Call" at home:

- Keep a packed suitcase that includes:
 - shirts that zip or button
 - comfort items (favorite book, toy and blanket)
- Take a bath every 24 hours.
- Keep a list of people to notify about the transplant.
- Plan your transportation to get to the hospital.
- Develop a care plan for siblings.

Waiting for Transplant in the Hospital

If your child needs to wait for transplant in the hospital, you will see a member of the transplant team once a day. A child life specialist will help your child adjust to hospital life, develop a routine schedule, provide age-appropriate activities, and prepare for testing and procedures. In addition, teachers are available to assist your child in school assignments.

Whether you are waiting at home or in the hospital, it is very important that the transplant team be able to reach you at all times. Make sure we have your correct phone number(s) and notify us of any change to your contact information.

THE TRANSPLANT SURGERY

A member of the transplant team will contact you when lungs become available. You and your child must come to the hospital as quickly as possible. Your child should not eat or drink anything. We will give you instructions where to go once at CHOP.

Preparing for Surgery

Before surgery, multiple team members including the transplant pulmonologist, transplant nurse practitioner, cardiac intensive care unit doctor, surgeon, anesthesiologist and bedside nurse will examine your child. Pretransplant testing includes some or all of the following:

- Chest X-ray
- Electrocardiogram (EKG)
- Echocardiogram
- Peripheral IV (a catheter placed in a vein to give

medications and fluids)

- Blood work
- Vital signs (temperature, blood pressure, heart rate, etc.)
- Review of current medications
- Chlorohexidine bath (to decrease the risk of surgical site infection)

We will obtain your consent for lung transplant surgery at this time.

Surgery Details

The transplant surgery takes place on the sixth floor of the Main Building. The surgery lasts 4 to 8 hours. The surgery is performed through either a clamshell incision, which is a surgical incision under the breastbone, or sternotomy incision, which is a surgical incision of the breastbone (see illustrations) and will require the use of the heart and lung bypass machine. A member of the surgical team will provide more details about the surgery. A child life specialist will help prepare your child for surgery and what to expect when they wake up.

You will be provided updates throughout the surgery.

AFTER SURGERY

Cardiac Intensive Care Unit (CICU)

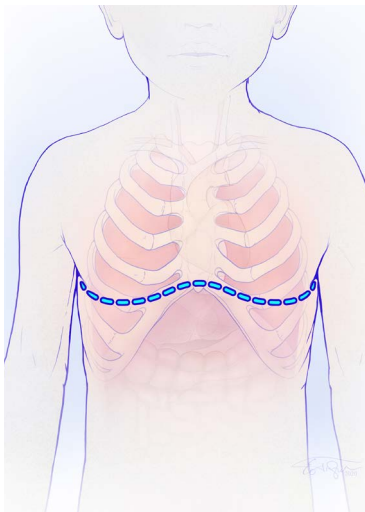


Illustration of clamshell incision

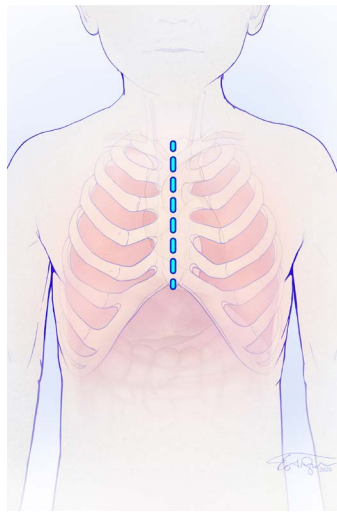


Illustration of sternotomy incision

The CICU is located on the sixth floor of the Main Building. This is the unit where your child will recover from surgery. Your child will be in a private room. One parent may sleep overnight in the room. After surgery, your child will be sleepy from the anesthesia medication.

Your child will be monitored post-surgery and may require the following medical devices:

- **A breathing tube:** A tube connected to a ventilator to help your child breathe while he wakes up from anesthesia. This tube usually stays in for 24-48 hours but can be in longer if needed.
- **Chest tube(s):** Flexible tubes that pass through the skin and into the chest to help drain fluids after surgery. They are usually removed a few days to a week after surgery.
- **PIV's:** Catheters to give your child medications, fluids, etc.
- **Cardiac monitor:** Keep track of your child's heart rate, blood pressure, breathing rate, and amount of oxygen in the blood.

Physical therapy and occupational therapy will be consulted after surgery. Your child will get out of bed and start walking within a day or two after surgery.

You may visit your child 24 hours a day in the CICU. To protect your child from exposure to infections, we ask that you minimize visitors. Family members who have colds or have been exposed to infections cannot visit.

The Pulmonary Floor (8 South)

When your child no longer needs intensive care, your child will be transferred to the pulmonary floor to prepare for discharge. The room will be a private one and one parent may stay overnight. On 8 South, your child will be able to participate in activities. The healthcare team will continue to monitor your child's progress for discharge to home.

Your child may feel well enough to go to the playroom. Because your child will be on medications to suppress the immune system, a mask must be worn whenever out of their own hospital room.

On 8 South, your child will continue with physical therapy, occupational therapy and cardiac rehab. A nutritionist will work with you to ensure your child receives proper nutrition. You will receive detailed transplant education about medications, side effects, follow-up care, life after transplant and more.

When your child is ready for discharge, the transplant team will order medications. You will receive a medication schedule.

If you live more than two hours away from CHOP, we require that you and your child remain local for a period of time, as you will return for required outpatient appointments. Social workers can recommend temporary housing such as the Gift of Life or Ronald McDonald House. The transplant team will let you know when you are able to return home.

In some cases, children are transferred to inpatient rehabilitation at Seashore House at CHOP. The goal of rehab is to improve strength prior to discharge.

MEDICATIONS AFTER TRANSPLANT

After transplant, children need to take “immune suppression” or “immunosuppression” medications for the rest of their lives. These medications are necessary to prevent the body from recognizing the new lungs as foreign and attacking them. This process is called rejection. It is extremely important that your child take these medications as prescribed. Missing doses or taking them off schedule can lead to organ rejection. This can cause irreversible damage to your child’s transplanted lungs and lead to death. The transplant team will monitor the level of these medications in your child’s blood to ensure there is enough medicine to prevent rejection but not so much that it would increase the risk of infection.

In addition to immune suppression, there will be other medications to help your child prevent infection, to recover from surgery and reduce medication side effects. You should expect your child to go home on approximately 10 to 15 medications after transplant. Over time, as your child recovers from surgery and gets further out from transplant, this list should get smaller.

Prior to discharge from the hospital, you will receive detailed information regarding your child’s medication regimen including doses, schedule, indications, side effects and more.

AFTER YOU GO HOME

Precautions

For the first six months after transplant, we recommend that your child wear a mask when outside the house, in public places or returning to CHOP for Transplant Clinic. You should avoid taking your child to crowded public places such as malls and restaurants. Because your child’s immune system is weak, we recommend you limit visitors to your home after discharge.

Handwashing is important in preventing infection.

You, your child, and family members should frequently wash your hands. Hand-sanitizing gels prevent the spread of infection and should be used before eating, taking medications and after playing outside.

Clinic Visits

After discharge, your child will be seen in the outpatient Transplant Clinic. Clinic visits will happen one to two times per week for the first month after discharge, then every other week for a month. Approximately eight weeks after discharge, visits become less frequent.

Eventually your child will come to clinic once a month and continue to do so for the first year after transplant. If there are complications or clinical concerns, we will schedule visits more frequently. At each clinic visit, blood will be drawn to check for signs of infection or rejection, to check organ functioning, and to monitor the amounts of immunosuppression medication in your child’s blood. We will check vital signs and perform PFTs. A transplant nurse practitioner and/or pulmonologist will perform an exam. The transplant psychologist and social worker are available to help with any behavioral or coping concerns. Your child may also be seen by physical therapy on clinic days. You can expect clinic visits to last approximately two to three hours.

Once a year out from transplant, your child will come to visits less often, usually once every three months. This schedule will continue until your child is old enough to transition to an adult transplant center.

Important things to remember about clinic visits:

- Do not give your child medications in the morning before coming to clinic. There has to be a 12-hour gap between the time your child takes medications and the time we draw blood to test drug levels. Bring all the medications with you to clinic and have your child take them after the blood tests.
- Be on time for your child’s appointment. If you are having difficulty making it to your appointments, let the team know.

Incision Care

When your child goes home, it will be important to keep an eye on their surgical incision.

Getting wet: Your child can take a shower while the incisions are healing. Your child should not take a bath or go swimming until incisions are healed.

Itching: As the incisions heal, they may itch. This is normal. Scratching can cause an infection. Keep your child’s fingernails short and have your child wear a T-shirt.

Keep the area clean and dry: Pat dry after bathing.

No lotions or creams: Do not use lotions or creams on the incisions. They can trap bacteria and cause infection. Once the incision becomes a scar, lotions and creams are fine.

No talcum powder: Do not use baby or talcum powder on or near the incisions. The powder can keep the incision from closing and healing.

Call the transplant team if you see redness, drainage or opening of the incisions.

Once the incisions are healed, use sunscreen on the scar when your child is out in the sun. The scar is sensitive to the sun and can burn.

Physical Activity

After surgery, exercise will be an important part of recovery. A physical therapist will work with your child in the hospital. Therapy may continue on clinic days for the first month after discharge. There are few restrictions on physical activity.

After surgery, we require at least 12 weeks of scheduled physical therapy and exercise. Your child will work with a physical therapist in outpatient clinic two days a week and will also work with an exercise physiologist in the cardiac exercise lab two to three days a week.

Regular exercise is important for all children who have had lung transplants. It is important in order to maintain a healthy weight, lower blood pressure and improve well-being.

After returning to school, your child should participate in gym class. Your child may feel tired at first, but will gradually build up their endurance.

Your child may swim in the ocean or chlorinated pools after the incision has healed. Because your child's immune system will be weakened life-long, we recommend not swimming in lakes or ponds because they have higher levels of bacteria. This could cause your child to become sick.

Nutrition

Your child's diet will have some limits but gradually return to normal. Maintaining a healthy weight after transplant is important as obesity increases the risk of diabetes and other complications. Some guidelines for your child's diet:

- Avoid foods high in cholesterol and saturated fat.
- Fast food is OK but only occasionally.
- Avoid eating raw meats or fish (for example, sushi), because these foods can carry bacteria and viruses.
- Avoid buffet-style restaurants. There is a risk of bacteria from food that is sitting out.



- Wash fruits and vegetables.
- Lunchmeat is safe to eat as long as it is fresh and eaten by its expiration date.

Water is very important to drink after transplant. The medications given to suppress the immune system can be harmful to the kidneys. Your child should drink water to stay hydrated. Your child should carry a water bottle to school and drink throughout the day. If you have well water, you must use a filter system or use bottled water due to the risk of bacteria in well water. If you have city water, it is filtered and safe to drink. If you are unsure of your water source, reach out to your local water department.

Regular Pediatric Care

After transplant, your child will continue to be seen by your pediatrician for "well" checkups and routine illnesses. Your child should see the pediatrician within one to two weeks after discharge. The pediatrician will examine your child and update their chart with your child's new medications.

Your child should not receive vaccines the first six months after transplant. Your child should get the flu vaccine even if it is less than six months after transplant. Because the immune system is suppressed, vaccines may not be effective.

Some vaccines are "live" and others are "non-live." Live and non-live vaccines are made differently. After transplant, your child must never receive live vaccines. Examples include measles/mumps/rubella (MMR) and chicken pox/varicella. Your pediatrician and the transplant team will tell you which vaccines are live and which are non-live. While your child should not receive live vaccines, it is safe to be around other people who have received live vaccines. Siblings can and should be vaccinated.

Regular dental visits are an important part of your child's post-transplant care. Dentist visits should occur every six months for regular cleanings and checkups. Speak to the transplant team prior to any dental visits.

Bronchoscopy and Biopsies

After transplant, your child will have bronchoscopies and lung biopsies to monitor for infection and rejection. Bronchoscopies and biopsies occur in the operating room. A pulmonologist will insert a thin, flexible camera called a scope into your child's airway to assess the lungs and surgical sites. The pulmonologist uses a tool at the end of the scope to take small pieces of lung tissue. The tissue is looked at under the microscope by a pathologist (a healthcare provider who specializes in tissues) to look for rejection. This procedure will be done with sedation or anesthesia.

Your child will have five to six scheduled bronchoscopies with biopsies performed during the first year after transplant. The number of biopsies performed may be more than six. This will be determined by how well your child is doing and whether a rejection has occurred. After 18 months, we no longer perform routine bronchoscopies and biopsies unless there is a new clinical concern.

The day or two before a bronchoscopy with biopsies, your child will come to CHOP for "pre-visit testing." This includes blood work, a chest X-ray and a physical exam performed by the nurse practitioner. You will receive a phone call the night before to let you know what time to arrive at CHOP. On the morning of the biopsy, bring your child to the preparation unit. This unit is on the fourth or sixth floor of the Main Building. You will be told where to report the day before the procedure. After the procedure, your child will return to the recovery unit for about two hours and then be discharged home. The results of the biopsy are available in three to five days. The transplant team will notify you of these results.

COMPLICATIONS AFTER TRANSPLANT

Rejection

There are three types of rejection: acute cellular, antibody mediated and chronic or bronchiolitis obliterans.

Acute cellular rejection: This is a process in which the immune system recognizes the transplanted lung as being "foreign" and tries to attack or reject them. Acute rejection is common in the first 12 to 18 months after transplant. Having rejection does not mean that your child will lose the transplanted lungs. It does mean that your child will need more immunosuppression therapy to treat the rejection. After 12 to 18 months, the risk of rejection decreases as long as your child

takes the immune suppression medications regularly. Missing doses or not taking the immune suppression medications will result in serious, and sometimes irreversible, damage to the lungs and/or death.

Rejection is treated with steroids (prednisone). This medication can be given orally or through an IV. The treatment of rejection depends on how severe it is. There may or may not be symptoms of rejection.

Signs and symptoms of rejection may include:

- Sudden, unexplained tiredness
- Shortness of breath
- Increased cough
- Change in secretions
- Decrease in home FEV1 monitoring

Although things other than rejection may cause these symptoms, it is important to inform the transplant team.

Antibody-Mediated Rejection: An antibody is a protein created by the immune system in response to foreign materials. These materials include a virus, bacteria and tissues (such as transplanted lungs). Antibodies work with the immune system to detect foreign objects in the body. This response is good to fight off infection but bad for transplanted lungs.

After transplant, we will check your child's blood for signs of antibodies against the new lungs. We also look for antibody-mediated rejection on the biopsies during bronchoscopies. Missing doses of immune suppression medications or not taking them as directed increases your child's risk of antibody-mediated rejection. Antibody-mediated rejection can be more difficult to treat than acute cellular rejection and can damage the transplanted lungs.

Chronic Lung Allograft Dysfunction (CLAD): This is a form of slow, progressive chronic organ rejection that occurs after transplant despite adherence with immunosuppressive medications. Over time, the airways become stiff and scarred. This process can cause shortness of breath and coughing.

CLAD does not usually occur until years after transplant, but in some cases, it can occur earlier. It can occur even if your child takes all medications or has no episodes of acute rejection. If your child develops CLAD, there are treatment options that can slow down the process, but there is no way to reverse it, and a second transplant may be needed. Progression of CLAD has been associated with the cytomegalovirus. We will test your child's blood for this virus after transplant.

Infection

After transplant, your child will be at an increased risk for infections because of the immune suppression medications. These medications must be taken for the lungs to keep working properly. The risk of infection is highest in the first 6 to 12 months after transplant. Because lungs are exposed to air, there is a high risk of infection. In addition, common colds and viruses can cause irreversible damage to newly transplanted lungs.

How to prevent infection:

- Wash hands: Teach your child to wash their hands after using the bathroom, playing outside, playing with pets, and before eating or taking medications.
- Avoid sick people, particularly during the first three months after transplant.
- Avoid public places, such as malls, restaurants and movie theaters.
- Do not share straws, utensils, toothbrushes or other similar items.

Signs and symptoms of infection may include:

- Fever
- Vomiting
- Diarrhea
- Cough
- Runny nose
- Rash

Post-Transplant Lymphoproliferative Disorder (PTLD)

PTLD is a form of cancer. Children who are immune suppressed after lung transplant are at risk for PTLD. Approximately 10%-12% of children after solid organ transplant will get some form of PTLD. It can be a minor disease that resolves with decreasing immune suppression or can be severe enough to require chemotherapy or radiation.

PTLD has been associated with high levels of immune suppression, the Epstein-Barr virus (EBV) or mononucleosis virus. After transplant, we monitor your child's levels of immune suppression. We will prescribe the lowest dose possible of medication while still preventing rejection. Your child's blood will be tested for EBV.

LIFE AFTER TRANSPLANT

Returning to School

Because the immune system is weak after transplant, we require your child to stay out of school for the first six months after surgery. During this time, we will help you set up homebound education in which a teacher will come to your home to provide instruction. Once back at school, your child will no longer need to wear

a mask and will be able to participate in all activities including sports and physical education (gym class).

When your child is ready to return to school, we will send the school a letter explaining the following:

- Your child's immune system is weak.
- They should notify your child's healthcare team of any outbreaks of infectious diseases (such as chicken pox) in the school.
- Your child cannot receive live vaccines.
- We will provide the school with emergency contact numbers for the transplant team.

Pets

After transplant, your child is at a high risk for infection. Family pets are safe to have in the house and for your child to be around. Cats and dogs should be kept up to date on vaccinations. After transplant, your child should not clean or handle the cat litterbox as there is a risk of transmitting a certain bacteria called toxoplasmosis.

We recommend that you do not have any reptiles as pets. They may carry bacteria called salmonella, which could cause your child to get sick. Reptiles or other animals can be handled at a zoo or museum, but your child must wash their hands after touching them.

Piercings and Tattoos

Your child should not get any ear or body piercings or tattoos until you speak with the transplant team, because these could involve a risk for infection.

Transition to Adult Care

When your child becomes a teenager, we will begin to explain what they need to know to manage their own healthcare. This education will continue until your care is transferred to an adult lung transplant team. There are many adult lung transplant programs in the country. CHOP will help you find one.

WHEN TO CALL THE TRANSPLANT TEAM

You should call the transplant team with any signs of illness. Fever, cough, decreased energy, decreased appetite or change in behavior are all reasons to call the transplant

team. You should also call with any questions about your child's care or before starting any new medications prescribed for your child by someone not on the transplant team.

IMPORTANT PHONE NUMBERS

If you have questions or concerns:

- Monday-Friday 8 a.m. to 4 p.m.: Call the Lung Transplant Office at **267-426-6629**
- After 4 p.m. and on weekends: Call the hospital operator at **215-590-1000** and ask for the Pulmonary fellow on call

Learn more:
[CHOP.EDU/TRANSPLANT](https://www.chop.edu/transplant)