

The Host Defense Program



Safe Living After Solid Organ Transplantation



**NATIONWIDE
CHILDREN'S**

When your child needs a hospital, everything matters.™

Safe Living after Transplantation

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INTRODUCTION



Congratulations on your transplant! We in the Infectious Disease Host Defense Program (ID HDP) want to make sure that you have a full and healthy life after your transplant. Transplant patients are at higher risk for infections because the medicines they take to help prevent transplant rejection weaken the immune system. However, you are able to prevent many infections. We want you to have the tools you need to live a safe and happy life after your transplant. This document gives you the information you need to help prevent infections that can occur after transplantation.

Some examples of medicines that can weaken (suppress) your immune system and make you at a higher risk for infection (immunocompromised) include:

- Calcineurin inhibitors: tacrolimus, cyclosporine
- mTOR inhibitors: sirolimus, everolimus
- Steroids (prednisone, solumedrol)
- Biologic response modifiers: infliximab (Remicade®), adalimumab (Humira®), abatacept (Orencia®), etanercept (Enbrel®), rituximab (Rituxan®), eculizumab (Soliris)
- Other medications: methotrexate, mycophenolate mofetil (MMF), leflunomide, azathioprine, mercaptopurine (6MP), eculizumab (Soliris)
- Chemotherapy or radiation

Our immune system protects us against infections. It is our body's defense against germs that are around us every day. Children, teens, and young adults who have weakened immune systems (are immunocompromised) cannot respond normally to an infection. This makes them at greater risk for common, and uncommon, infections caused by different germs, including bacteria, viruses, fungi, and parasites. Infections in immunocompromised patients may also be more severe since the weak immune system cannot easily clear the infection.

Risks for Infection

Other factors that increase your risk for infection in immunocompromised people include:

- Low numbers of white blood cells, including specific white blood cells, like neutrophils and lymphocytes
- Inflammation of the gastrointestinal (GI) tract
- Having a central venous catheter (also known as a CVC, port, or central line) in place
- Certain environmental exposures

Although there is always a risk for infection while taking anti-rejection medicines after transplant, **you are at higher risk for infection during these times:**

- The first 6 months after your transplant
- While getting therapy for possible rejection
- 3 to 6 months after the therapy for rejection is completed
- When your white blood cell count is very low
- During other infections, like cytomegalovirus (CMV)

Signs of Infection

Some signs and symptoms of possible infection may include:

- Fever - A temperature equal to or greater than 101 degrees F or two temperatures equal to or great than 100.4 degrees F taken one hour apart. This may be the only symptom of infection in immunocompromised children.
- Throwing up (vomiting)
- Diarrhea
- Cough or having hard time breathing
- Pain when urinating
- Sores on your lips, mouth, or throat
- Rashes
- Wounds that are red, swollen, or have drainage

Contact your transplant team right away if there are any signs of fever or other signs and symptoms of infection.

PREVENTING INFECTIONS AFTER TRANSPLANT



Some infections are passed from person to person (transmitted). Other infections happen after eating or drinking contaminated food or water. Some are caused by exposures in the home and environment. **Some basic, ways to prevent infection include:**

- **Always practice good hand hygiene by washing your hands with soap and water or using an alcohol-based hand sanitizer.** Practicing good hand hygiene is one of the most important ways to prevent infection, like spreading bacteria and viruses between people. Always use hand hygiene:
 - before preparing or eating food/drinks
 - after going to the restroom
 - after sneezing, coughing, or touching your nose, eyes, mouth, or any wounds
 - after touching pets
 - when visiting other people
- Avoid contact with people who are sick, including those who have any fevers, coughing, runny nose, vomiting, diarrhea, or rashes.
- Take very good care of central venous catheters by following the instructions from your health care provider.
- Perform daily oral/dental care and have twice yearly dental checkups and cleanings
- If you are very immunocompromised, your doctor may ask you wear a surgical mask when outside of the home to avoid contact with bacteria, viruses, or fungi. Your doctor may also ask you to wear a mask when visiting the hospital.
- Limit contact with animals, including household pets. Avoid bringing new or exotic animals into the home. Scratches, bites, and licks from animals can cause infection.
- Getting recommended vaccines. **You should receive appropriate vaccines after a transplant. Everyone who lives with or cares for you should also get the recommended vaccines to protect you from infection, as well.** This includes getting the inactivated influenza ('flu shot') vaccine every year, as soon as it is available in the fall. Talk to your doctor about what vaccines your immunocompromised child should receive.

More information on preventing infection is on the next page. Ask your transplant team or call the Host Defense Infectious Disease Team with any questions or concerns.

WAYS TO PREVENT INFECTION

Prophylaxis antimicrobials

Some infections happen more often after transplant. Some of these infections may be prevented by using antimicrobial medicines. Depending on your past history and infection risk, your transplant team may prescribe prophylactic antimicrobial medicines to prevent new infections or the return of old infections. Make sure to continue taking these medicines until the transplant team tells you to stop.

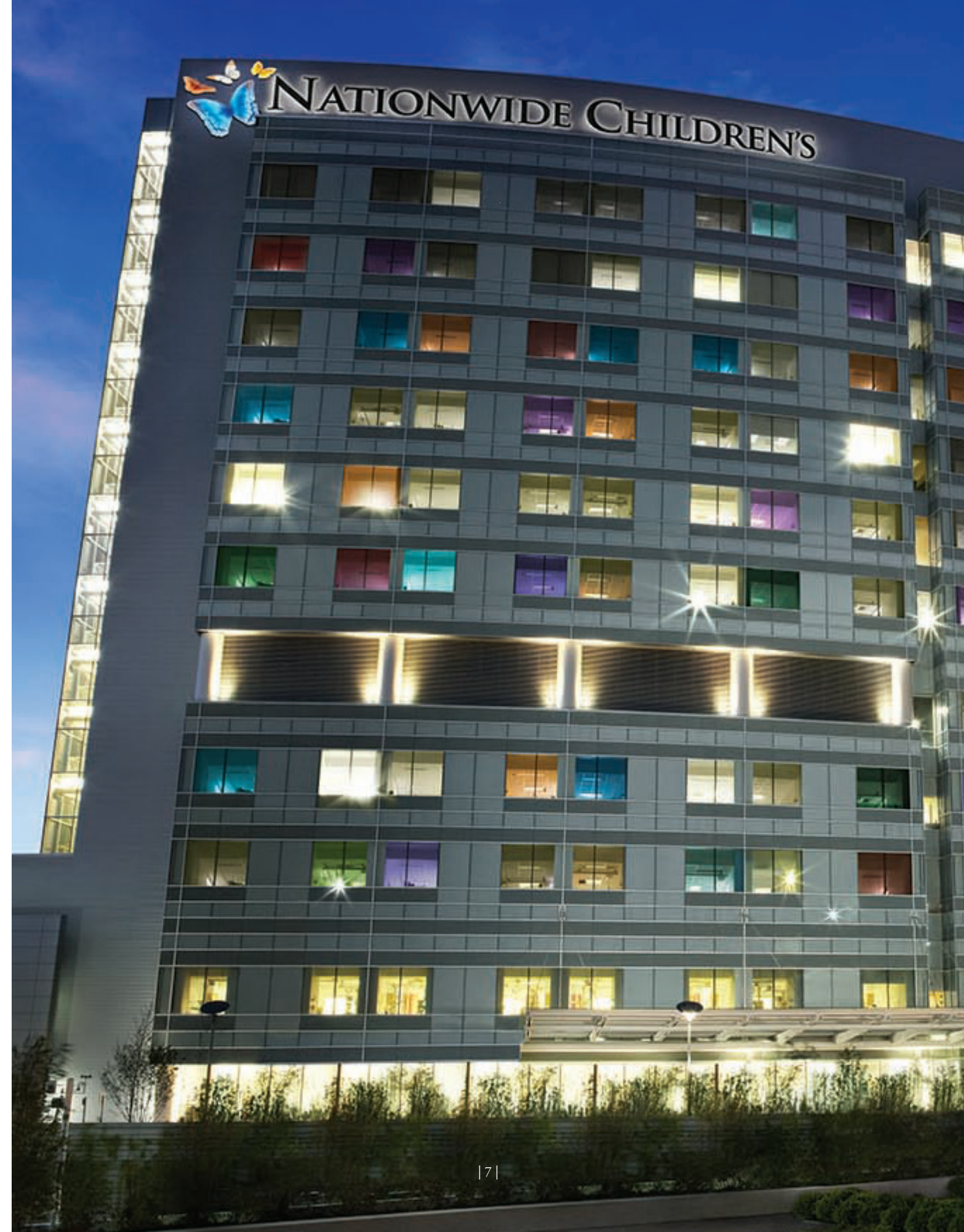
Some of the prophylactic antimicrobial medicines that may be prescribed include:

Antimicrobial:	Possible Brand Names:	Given by:	Preventing infections with:
Acyclovir or valacyclovir	Valtrex®	Mouth	Viruses (HSV)
Fluconazole	Diflucan®	Mouth	Fungi
Nystatin		Swish and spit or swallow	Thrush (fungi)
Pentamidine	Pentamidine®	Intravenous or inhaled	Fungi (PCP)
Posaconazole	Noxafil®	Mouth	Fungi (molds)
Trimethoprim-sulfamethoxazole (TMP/S)	Bactrim® Co-trimoxazole, Septra®	Mouth	Bacteria and Fungi (PCP)
Valganciclovir	Valcyte®	Mouth	Viruses (CMV, HSV)
Voriconazole	Vfend®	Mouth	Fungi (molds)

Vaccines

It is best to get all of your vaccinations before transplant. This is when your immune system will be more active and working best. However, you may still need vaccinations after your transplant. Talk to your transplant doctor and the ID HDP team about vaccines.

- You will only get non-live vaccines after your transplant. Depending on the vaccine, these usually start 2 to 6 months after transplant if you are taking maintenance immunosuppression medicines.
- In general, you **SHOULD NOT** get live vaccines after transplant. These include:
 - VZV (varicella/chickenpox)
 - MMR (measles, mumps, rubella),
 - Oral rotavirus
 - Oral typhoid
 - Oral polio
 - Smallpox
 - Yellow fever
 - Japanese encephalitis
 - Live attenuated influenza vaccine)
- You **SHOULD GET** the inactivated influenza vaccine (the ‘flu shot’) every year, as soon as you can. People that live in your home should also get the inactivated influenza vaccine every year.
- People living in the home and household contact should also get all recommended age-appropriate all the US recommended vaccines as appropriate for age. Household contact can and **SHOULD** receive live vaccines as appropriate for age.
- Transplant patients should not change diapers of infants who have received the rotavirus vaccine for 4 weeks after the vaccine is given.
- Transplant patients should avoid contact with rashes on people who have recently gotten the chicken pox/varicella vaccine. If this happens, tell your transplant team right away.
- Contact your doctor and transplant team right away if you have been exposed to:
 - Chicken pox or shingles
 - Measles
 - Mumps
 - Influenza
 - Whooping cough
 - Bacterial meningitis



WHERE INFECTIONS MAY COME FROM AND HOW TO PREVENT THEM

Infection transmission can happen through contact of skin and mucous membranes (mouth, eyes), breathing (inhalation), eating (ingestion), and recreational activities. The following table summarizes some DOs and DON'Ts to help prevent infection after transplant.

POTENTIAL SOURCE OF INFECTION			
	DO	DO NOT	
Skin <i>(if not intact)</i>	<ul style="list-style-type: none"> Wash your hands often, especially after touching people, animals, plants, dirt or possible feces Wash any open cuts right away with soap and water Use sunscreen with 30 SPF or higher 	<ul style="list-style-type: none"> Touch your port, PICC, or catheter Go barefoot Get tattoos or piercings Get fake nails 	<ul style="list-style-type: none"> Put fingers in your mouth Use injection drugs Use community sandboxes
Air	<ul style="list-style-type: none"> Wear a mask if your transplant team instructs you to do so 	<ul style="list-style-type: none"> Have close contact with ill people or people with sneezing, coughing, runny nose, or red eyes Go around large crowds, like the mall, especially during flu season Smoke or be around smoke: Bonfires, fireplaces with wood logs, tobacco. Use or be exposed to marijuana. 	<p>Smoking marijuana can cause a serious fungal lung infection.</p> <ul style="list-style-type: none"> Breathe dusty air: gardening/landscaping/farming, cleaning attics/basements, construction or remodeling in the home, chicken coops/roosts Go around molding food, plants, wood, or hay
Food	<ul style="list-style-type: none"> Wash fruits and vegetables well with clean water Cook beef and pork to an internal temperature greater than 165°F. Cook the inside of poultry greater than 175°F and seafood greater than 145°F. Wash utensils, cutting boards/surfaces, and hands often when cooking Drink prepackaged teas, already in bags Thoroughly recook prepackaged foods, like hot dogs or sausages Refrigerate food made at home right away. Your refrigerator temperature should be below 40°F and the freezer should be at 0°F or below. Eat refrigerated leftovers within 1 to 2 days and reheat to steaming hot temperatures greater than 165°F. Let the transplant know about any food outbreaks you may have been exposed to 	<ul style="list-style-type: none"> Eat food past the expiration date Share utensils, cups, or food with other people Eat soft cheeses: blue cheese, feta, queso blanco fresco, etc. Eat or drink unpasteurized/raw milk products Eat foods with raw or undercooked eggs: soft boiled or over easy eggs, cookie or cake dough, or some salad dressings (Caesar) Eat raw or undercooked proteins: meat, poultry (chicken or turkey), fish, tofu, 	<p>sushi, smoked salmon (lox), beef jerky, smoked proteins, patés.</p> <ul style="list-style-type: none"> Eat raw alfalfa sprouts, raw honey, or miso products Drink loose leaf teas Eat at street food vendors, public salad bars, standing buffets, or foods sitting at room temperature or sitting out for a long time, like at a picnic. Eat deli meats, deli salads, cold cuts, or salad dressings with cheeses or raw eggs
Water	<ul style="list-style-type: none"> Always drink clean water. When there is a 'boil advisory', use bottled water or boil water on high for 1 full minute before consuming. Use boiled water for any eating, drinking, teeth brushing and bathing! When traveling, use only bottled water Wash toys weekly in the dishwasher. Let toys dry between baths. 	<ul style="list-style-type: none"> Drink well water (if possible). If you must drink well water, filter it and screen it often for germs. Use filters should that remove cryptosporidium and are labeled NSF 53 or NSF 58 and must say 'cyst removal' or 'cyst reduction.' For more information, refer to: the NSF International consumer line at 800-673-8010 and http://www.nsf.org/consumer/drinking_water/contaminant_cryptosporidium.asp Swallow water from rivers, lakes, ponds, or water rides 	<ul style="list-style-type: none"> Use hot tubs Use public pools or water parks in the first year after transplant and whenever possible. Do not use your private pool for 2 weeks if you have any illness causing diarrhea. Use toys that hold water Be around standing water in the house, basement, or outside places where mosquitos can breed. Drink fruit juice, water, or ice cubes when traveling to areas with more sanitation
Pets, Animals & Insects	<ul style="list-style-type: none"> Make sure your pets are healthy and get regular check-ups, vaccines, tick and flea prevention medicine. Talk to the vet about how to prevent spreading illness to humans. Always wash your hands after touching pets Take all measures to prevent mosquito and tick bites from early spring to early fall by: wearing long pants and sleeves and using insect repellent with DEET. Remove sources of standing water from the home that can breed mosquitos with West Nile virus 	<ul style="list-style-type: none"> Get a new pet during the first year after transplant Get or keep a kitten Get or keep a reptile: snakes, turtles, lizards, iguanas, frogs Get or keep any birds: including baby chicks, ducklings or eggs Get or keep non-traditional or exotic pets: hamsters, guinea pigs, rabbits 	<ul style="list-style-type: none"> Be around or keep a stray animal Kiss any animals or let animals lick you. Avoid all animal secretions. Get scratched or bit by animals. If you do, wash the area right away and get medical care. Feed your pet raw, contaminated, or spoiled food Clean kitty litter or fish aquariums
Activities & Hobbies		<ul style="list-style-type: none"> Go hunting Go fishing 	<ul style="list-style-type: none"> Do activities that throw up dirt, like dirt biking or 4-wheeling, landscaping Go hiking in caves

Sexual activity

If you choose to have sex (intercourse), some infections can be passed along (transmitted) during sexual contact. You can protect yourself against many sexually transmitted infections (STI).

It is important to know that:

- You are more likely to get an STI if you have more than one sexual partner if your partner has had other partners before you.
 - You can get the same STI more than once, even if you have been treated for the STI in the past.
 - You can get an STI even if you have sex just one time.
 - The “withdrawal” method does not prevent STIs.
 - Some patients with STIs may not have symptoms you can see. For example, patients with a history of mouth herpes may have no active lesions, but can transmit the virus to you during oral/genital sex.
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- Always use latex condoms during every sexual encounter.
 - Avoid exposure to feces during sexual activity, including anal sex.
 - If you think you may have a STI, contact your doctor right away. Some symptoms may include:
 - burning or pain when urinating
 - discharge
 - burning
 - pain
 - sores or blisters from the vagina, penis, or anus.
 - Make sure your vaccines against hepatitis B, hepatitis C, and human papillomavirus (HPV) are up to date.

Travel

- Contact your transplant team if you are planning to travel.
- If you plan to travel to another country, you may need certain preventative medicines or vaccines, depending on where you go and what you will be doing. These medicines or vaccines can protect you against certain infections, like malaria.
- Take a letter with a list of your medicines and make sure to take enough medicine for the entire trip, plus some extra. Store the medicines and letter in your carry on luggage. Do not put them in your checked luggage.
- Find out the nearest hospital to you while on vacation in case you get ill or there is an emergency.

RESOURCES



The ID HDP team finds the following resources very helpful:

- CDC, Transplant Safety
<https://www.cdc.gov/transplantsafety/index.html>
- FDA, Food Safety for Transplant patients
<https://www.fda.gov/downloads/food/foodborneillnesscontaminants/ucm312793.pdf>
- FSIS, Food Safety for Transplant patients
https://www.fsis.usda.gov/shared/PDF/Food_Safety_for_Transplant_Recipients.pdf
- FDA, Food and Transplant Recipients
<https://www.fda.gov/Food/FoodborneIllnessContaminants/PeopleAtRisk/ucm312570.htm>
- U.S. Department of Health and Human Services, Organ Procurement and Transplantation Network Patient Education
<https://optn.transplant.hrsa.gov/learn/patient-education/>
- American Society of Transplantation, Education
<https://www.myast.org/patient-information/patient-education-packets>
- CDC, Organ Transplant Patients and Pet Safety
<https://www.cdc.gov/healthypets/specific-groups/organ-transplant-patients.html>
- CDC, Immunization Schedules
http://www.cdc.gov/vaccines/schedules/index.html?s_cid=cs_001

We are always here to help! If you have any questions or concerns about infectious diseases after your transplant, please do not hesitate to contact the ID HDP team at 614-722-4452.

We wish you all the best!

