



Transplantchild

Transplantation (SOT & HSCT) in Children

RECOMMENDATIONS GUIDE FOR TRANSPLANTED CHILDREN

Tips to take care of your health



**European
Reference
Network**

for rare or low prevalence
complex diseases



Network
Transplantation
in Children
(ERN TRANSPLANT-CHILD)

ERN Transplantchild
www.transplantchild.eu



European Reference Networks (ERNs) are virtual networks involving healthcare providers across Europe. They aim to tackle complex or rare diseases and conditions that require highly specialised treatment and a concentration of knowledge and resources.

TransplantChild is a European Reference Network for Paediatric Transplantation, is focused on both Solid Organ Transplantation (SOT) and Hematopoietic Stem Cell Transplantation (HSCT) with **a cross-cutting approach** to support common areas as immunosuppression, rejection, tolerance, infections and psychological wellbeing.

Our main goal is to have a significant impact on the **quality of life of children and their families** in the long term. To achieve it, the methods implemented are giving the patients network access to diagnostic advice and joining with members of the network and stakeholders to increase the information, innovate and expertise in the transplant procedures.



Figure 1. ERN TransplantChild members during the 4th Board of the Network in Madrid.

The Executive Committee in collaboration with the members of ERN TransplantChild have developed this Recommendations Guide for patients and families:

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- Skane University Hospital. Lund, Sweden.
- Vilnius University Hospital Santaros Klinikos. Vilnius, Lithuania.
- Children's Memorial Health Institute. Warsaw, Poland.
- Hannover Medical School. Hannover, Germany.
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Introduction

It is time to come back home after your transplant. Little by little, you will discover that your life has changed from before the transplant and that you can now do many things that were unreachable before.

You will be able to have a pretty similar life to that of the rest of the children or young people your age. To achieve that there are two crucial things that depend only on you:

-
- ✓ Take your immunosuppressive treatment at the right times
 - ✓ Take care of yourself and do not engage in activities that put you at risk
-

Read this guide carefully and ask your doctors and nurses any questions or doubts you may have before you go back home.



What are the chances of me being cured?

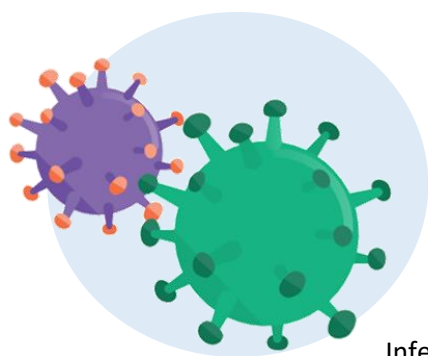
Transplants are a treatment that has changed the survival rate of many digestive, heart, lung, liver, kidney and cancer diseases that did not have any cure. The majority of transplant patients have a quality of life similar to that of the general population but enjoying a good quality of life is linked to following a lifelong treatment. In the case of a bone marrow transplant, this situation will be temporary, until your immune system recovers from the treatment you have received.

The survival rate depends on the type of transplant, but it is also related to your lifestyle and taking your medication. The combination of both reduces complications greatly.

How can I suspect that I have an infection?

Drugs to prevent transplant rejection cause your organism to be less resistant against infections.

The period with a higher risk of infection occurs during the first year after the transplant; after that, the risk lowers but it is always higher than that of people without transplants.



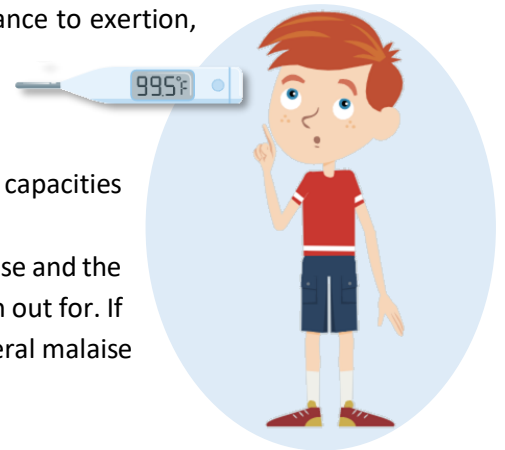
The signs and symptoms of alarm that will let you know when to inform your doctor are: Fever, headache without a justified cause, pain while swallowing, earache, shortness of breath, persistent cough or thoracic pain during breathing, diarrhoea, nausea and vomiting, abdominal pain, and difficulty or pain while urinating.

Infections in the first few months after transplant can become complicated, so it is important to treat them early: do not be alarmed if you are admitted again for fever or other mild symptoms. This is to keep an eye on you, treat the infection quickly, and avoid complications.

What about rejection? How do I know if I am rejecting my transplant?

Usually, doctors will detect it during regular revisions, but there are some alarm signs that you should look out for.

- In hepatic transplants, you may notice a yellow tone in your eyes' sclera and your skin, itching without any zits, darker colour of your urine (similar to that of beer or tea), and lighter coloured faeces.
- In renal transplants your signs of alert will be pain in the area of your new kidney, intense headaches, dizziness, puking, decrease in urine production and change of its colour.
- In cardiac transplants, you will notice a decrease in your tolerance to exertion, fatigue, palpitations, and dizziness.
- In intestinal transplants, the most frequent signs are fever, diarrhoea, general discomfort, and abdominal pain.
- In lung transplants, there is a deterioration of respiratory capacities (persistent cough, fatigue...) and fever.
- In hematopoietic stem cell transplantation, it is possible to relapse and the so-called "graft-versus-host disease" that you will have to watch out for. If you have skin rashes, diarrhoea, fever, severe tiredness or general malaise for no apparent reason, consult your medical team.



Will I need to take medication for life?

From the same day of your transplant you will have to take some drugs called immunosuppressants. They are what protects you from rejecting the transplant. The most used immunosuppressants are cyclosporine, tacrolimus, mycophenolate mofetil, sodium mycophenolate, prednisone, everolimus and sirolimus.

Immunosuppressive drugs should not come into contact with the skin or mucous membranes or be inhaled during their preparation. Therefore, do not open the capsules or tablet fractions and, when it is necessary to prepare them, use gloves and a mask.

You will not be taking all of them at the same time, only two or three depending on the type of your transplant.

You should not worry if other transplant patients do not take the same medication or doses as you. The type of drug and its doses depend on the risk of rejection, the time passed after the surgery, the results from the analysis, and the levels of that drug in your blood. Immunosuppressive treatments are specific to each person and time.



The dose and the number of these drugs are decreased eventually as time goes by, until the minimum dose that prevents rejection is reached.

It is very important that when your doctor makes changes in the medicines you take or the doses of these medicines, you write down all these changes as soon as possible on your medication list to avoid mistakes. If after a change in medication or the dose you see that something is not clear to you, do not hesitate to call and ask your doctor.

Do not stop taking your medication. Any interruption in your treatment, even months or years after your transplant, will cause a rejection that will be very difficult to control. If you have received an HSCT, these recommendations will be valid for the months you are on immunosuppressive treatment.

You must take your drugs every day, making it a part of your daily routine, just like eating or sleeping.

In the case that you are taking tacrolimus, remember that you should not eat anything between 30 minutes before and after taking the drug.

In some cases, the venous line that has been used to administer the treatment in the hospital, needs to be maintained for some time after going home. If that is the case, do not forget to maintain it and seal it as you have been taught. Put an alarm on your mobile phone to remind you when the next treatment or seal is due and do not hesitate to consult the nurses who have taken care of you if you have any doubts. This also applies if you go home with a catheter, drain or stoma for a while.

What should I do after leaving the hospital?



10 things about your treatment that you must not forget

1. Learn the name of your drugs you are taking and what each one is for. Always write down the doses and schedule and carry that information with you (for example in your mobile phone).
2. **Never stop taking your immunosuppressant drugs**, even though you feel good: they are your life insurance. If you stop taking them, even though you may not notice anything at the beginning and your transplant was a long time ago, your new organ will start deteriorating and you may reject it after some time.
3. Take the immunosuppressant drugs every day at the same time. Set up an alarm to avoid forgetting it. When you only take them once, it should be in the morning!
4. If you vomit after taking your medication and you took it less than half an hour ago, take it again.
5. If you missed a dose take it as soon as you remember, as long as there is more time to take your next dose than the time you forgot to take it. If you are doubting whether you took it or not, do not repeat the dose. If you make a mistake in the dosage amount, let your transplant team know, they will tell you what to do.
6. Whenever you have an appointment with a doctor that does not know you, always let him know that you are a transplant patient and show him the medication you are taking as it may interfere with other drugs.

7. Make sure to always have enough of each drug, especially during weekends and holidays. Get them in advance to avoid problems.
8. **Do NOT self-medicate.** Do NOT take a new drug without consulting your transplant doctor. This includes those over the counter and herbal products (they may interfere with your medication or damage your new organ).
9. Do not switch boxes of drugs or store some of them in the same box. Do not cut out the box in any way that does not allow you to see the name of the drug and its expiration date. All of this can cause you to make mistakes.
10. Store your medication according to the package information leaflet, always protected from light, heat, and moisture and where children and pets cannot reach it.

Measuring the dose and preparing the medicines

Your doctor will indicate your doses in **milligrams**.

In the case of syrup or if you need to dilute a drug in water to take just a part, you will need to calculate the amount in millilitres (corresponding to the milligrams you should take). This quantity will vary depending on the amount of water you use or depending on the laboratory that prepares the syrup.

Therefore, when the drug you usually take changes or you start taking a new one, especially if it is a syrup, always be sure you know two things:

- ✓ How you should take it
- ✓ How much you should take

If you have any doubt talk to your nurse about how to prepare the medicines and the amount you should be taking.



Practical advice

We will now give you some advice about how to take care of yourself to prevent infections and some other risks caused by your medication to keep your new organ healthy and working perfectly. As you will see, the majority of the recommendations are not different from those that every healthy person should take into account to take care of their health. The only difference is that, in your case, the risk of problems appearing if you do not take care of yourself is higher and the consequences more serious.

You will see how everything is really easy as soon as this advice turns into a part of your daily routine.

Personal hygiene

Shower every day. Take care of your teeth: brush them with a soft brush after every meal and visit your dentist at least once a year.



Wash your hands frequently; always before meals and before and after using the bathroom.

Keep your nails clean, as they are a focus of infection. Do not cut your cuticles to avoid wounds that may get infected.

Do not share your toiletries.

Food

You need to be very careful with raw food:

- ✓ Wash fruits and vegetables, peel them when possible and if not, throw away those that present imperfections in their skin.
- ✓ When you eat out, avoid raw food like smoked salmon, carpaccio, or sushi.
- ✓ Avoid raw milk and its derivatives (cheeses made of untreated milk).

Do not eat/drink anything that has not passed a sanitary control.

Do not drink water that has not passed sanitary controls (rivers, wells, fountains, etc.)

Fresh fish may contain a parasite called Anisakis. To consume it you must cook it over 60°C or freeze it under -20°C during at least 5 days. Smoked, marinated, and pickled fish need to be frozen before consumption. This includes octopus, cuttlefish, and squid as well as every saltwater fish.

Freshwater fish, preserves, salted foods, and shellfish do not contain Anisakis and thus these precautions are not needed.

Preserves, once open, can only be stored for 4 hours at room temperature and 24 hours in the refrigerator.

Defrost food in the fridge instead of at room temperature.

Never refreeze something that has already been defrosted.



For food to be well preserved in the fridge you need to follow these rules:

- ✓ Raw food should never be in contact with cooked food.
- ✓ Do not store food too close together because that makes air circulation difficult and they are not adequately preserved.
- ✓ Let cooked meals cool down before storing them in the fridge.

Control your fat intake, since immunosuppressants may increase your cholesterol and fats in the blood. Do not overindulge in sweets either because they can cause high blood sugar levels.

Avoid eating grapefruit, kiwi, and lemon (in juice either) one hour before or after taking cyclosporine and/or tacrolimus because they interfere with the absorption of those drugs.

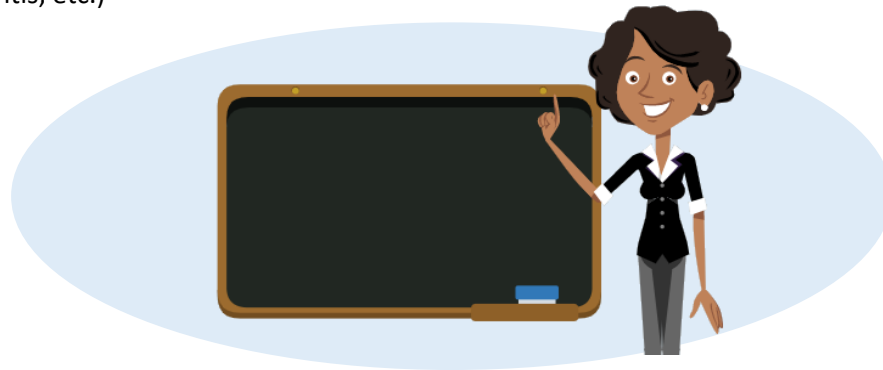
Immunosuppressants can also cause an allergy that you did not have before. Keep it in mind if an aliment starts making you feel unwell. In this case, consult your doctor as it may be necessary to run some allergy tests. The most common food allergies are to legumes, nuts, or white fish.

School

There is not a set period of convalescence after a transplant. Your doctor will tell you when you can go back to school when your immune system strengthens, and your health improves.

During the first months after the transplant and until you can go back to school, a teacher will go to your house to help you with your studies. Ask your doctor for the form to request this service before leaving the hospital. The signatures of your doctor and your parents will be necessary.

When you return to school/high school, you will be able to live a normal life with the rest of your classmates, taking care to keep some distance from classmates and friends while they are sick (flu, gastroenteritis, etc.)

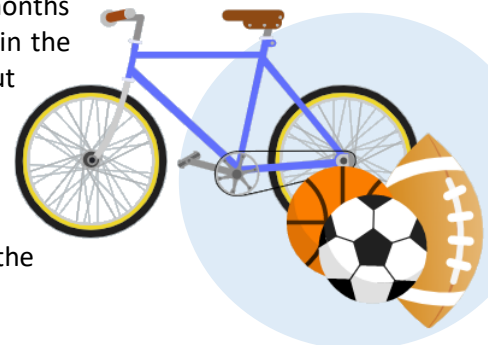


Active life and physical exercise

It is important that you incorporate exercise into your routine when you start feeling better despite the tiredness you may feel at first. In the first weeks after your transplant the best activity is walking. After the first medical check-ups your doctor will tell you when to incorporate other harder activities (running, swimming, cycling, dancing...).

You will have to wait at least 6 months after your transplant before engaging in contact sports because of the risk of getting hit in the transplant area. During these few months you should also avoid public pools, swimming in rivers, lakes or in the sea. After this period of time you can use public pools again but remember to shower before and after swimming and use flip flops and towels that are exclusively yours.

If over time you do intense sport (high performance or competition) it is important that you regularly monitor the mineralization of your bones and the functioning of your heart.



Vaccines

Before getting vaccinated ask your transplant doctor, since you cannot receive vaccines of attenuated viruses (measles, yellow fever, chickenpox, mumps, rubella, and the oral polio vaccine). In some special cases, and always under medical supervision, some transplanted children can receive live virus vaccines.

This type of vaccine may cause that you fall ill with the disease you are being vaccinated against because your body's defences are decreased by your medication, to prevent rejection.

However, some vaccines usually not included for healthy children may be recommendable for transplanted children. Your doctor will tell which one are.

Your reaction to the vaccine before the transplant is higher than after the transplant, so you may need a booster dose.

If you have received a haematopoietic stem cell transplant, vaccination will begin when your doctor considers it appropriate based on how your defences recover, or what complications you have.



It is very important to ensure the vaccination of the people that live with you, especially siblings, because if they fall ill you could do it too. However, remember that when they get a live virus vaccine you will need to avoid contact with them for the first few days after the vaccine.

Sun

Immunosuppressants make your skin more sensitive to the sun and increase the risk of lesions that can progress into skin cancer. That is why it is important for you to **protect your skin** as much as you can:

- ✓ Wear a T-shirt and hat
- ✓ Use high factor sunscreen (SPF 50)
- ✓ Reapply sunscreen every two hours and after swimming

If you have received a bone marrow transplant, keep in mind that the sun can also favour the appearance of graft-versus-host disease.

Trips and holidays

For your vacation you can choose the place that you want, just remember to protect yourself from the sun and avoid public pools during the first six months of your transplants.

It is not a good idea to plan a trip abroad in the first few months after the transplant.

Afterwards, you can travel anywhere, although it is advisable to discuss this with your doctor first.

Please keep in mind the following precautions when travelling:

- ✓ When you are travelling, carry enough medication for a longer stay than planned, in case you need to involuntarily push back your return date.
- ✓ Your medication should always be in your hand luggage. Do not let them out of your sight and do not put them in the sun. If one of them needs to be preserved cold, prepare a transport container beforehand.
- ✓ When you travel by plane you will need a medical certificate that justifies their use so that you can take them with you on the plane.
- ✓ Make sure to know beforehand where the closest healthcare centre is and do not forget to bring the phone number of your transplant team in case you have a doubt you need to consult during the trip.
- ✓ Bring with you your sanitary documentation up to date and a copy of the last medical report with the medication you are currently taking.
- ✓ It is important to be careful with the water you drink, especially in the case of an intestinal transplant, as digestive infections have a more serious impact than in the general population. It is advisable to use bottled water, especially if you are travelling abroad.

And for trips to foreign countries:

- ✓ If possible, do not travel outside your country during the first year after the transplant.



- ✓ If you travel to countries where the risk of infections is high, find out if there is any preventive medication or additional vaccines you may need.
- ✓ If possible, hire a health insurance for the trip (admission fees and hospital transfer).
- ✓ Keep in mind the time zone of the destination, so you can adjust your immunosuppressants gradually.
- ✓ When you travel to other countries, always drink bottled water and be very cautious about raw food or street food, including fruits and vegetables.

Friends and social life



During the first six months avoid closed, poorly ventilated, and crowded spaces, as well as places with high air conditioning.

Until your immune system stabilizes, use a mask when visiting the hospital (in the case of haematopoietic transplant must be at least FP2 mask), the air is much more polluted than anywhere else. In some occasions your doctor may ask you to use a mask at other places or times.

Avoid people who present symptoms of infection as much as possible:

- ✓ Cough, mucus, fever
- ✓ Diarrhoea, vomiting
- ✓ Cold sore and other contagious skin lesions
- ✓ Childhood diseases (chickenpox, measles, mumps, etc.)

Talk about your transplant with your friends naturally. It is a good thing that they also know why you take all these precautions.

Emotional health

Living with a chronic illness, as it has happened to you, is something that is not chosen but can condition your day-to-day life and the life of the people around you. Besides the disadvantages, it gives you the opportunity to go through very decisive life experiences (some great, others not so great, right?) and meet people you would never have met otherwise. While you are in the hospital everything is adapted to your needs and you feel safe, but when you return home you may feel a little lost at first.

On one hand, you are eager to go home and get "your life back" and many pre-transplant limitations have disappeared. On the other hand, sometimes you feel afraid or insecure and have to adjust schedules and routines to make everything fit.

Sometimes you may feel sad or anxious without really knowing why and have the feeling that you are not able to control your emotions. Do not worry: **these feelings are normal** after a serious illness or major surgery.

If you are a teenager, they will also come along with the emotional changes associated with this stage of life.

If you feel that you cannot control it or it makes you very uneasy, do not hesitate to comment your situation with your doctor when you come for a check-up. Sometimes it is necessary to get some help to cope with these situations.

Alcohol, smoking, and drugs

Alcohol and drugs are bad for the health of any individual but in your case the risks are higher:

- ✓ Your liver and kidneys already work “overtime” to eliminate the wastes of the medication you are taking to prevent them from harming you. If you add to this the workload of eliminating big amounts of alcohol or any kind of drug, the possibility that your kidney or liver will be damaged is much greater.
- ✓ Alcohol and drugs can also interfere with immunosuppressants, increasing or decreasing their effectiveness. This can cause infections or even rejection.
- ✓ The risk of cancer if you smoke is a lot higher than that of smokers without a transplant and non-smokers with a transplant.

Contraceptives, pregnancy, and sex

In men it is usual that they suffer from erectile dysfunction temporarily after the transplant. In a few months normal function will be restored.

Menstrual cycle should be restored a few months after the transplant.

Your immune system is less resistant to infections than that of other people, so it is very important that if you are going to engage in sexual intercourse you take precautions to avoid a sexually transmitted disease (STD). Use barrier methods (diaphragm, condoms, and spermicides).

Take into account that these methods decrease a lot the risk of contagion but they do not make it disappear completely which is why it is advisable that you limit the number of partners you engage in sexual activities with.

If, despite these precautions, you experience genital or urinary discomfort, consult your doctor as you may require treatment.



If at some point you would like to get pregnant, talk to your doctor beforehand because some immunosuppressants, such as mycophenolate are toxic for the baby and must be substituted by others during pregnancy.

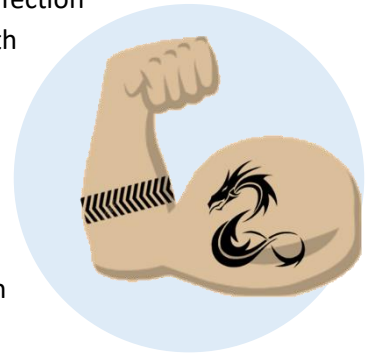
When you decide to use a long-term method of birth control, discuss it with your transplant physician to decide which method is best for you: the birth control pill can, in some cases, damage your liver or alter clotting or medication levels; intrauterine devices (IUDs) can cause infection. Also, keep in mind that both contraceptives can prevent pregnancy but do not protect you from sexually transmitted diseases.

Piercings and tattoos

Both piercings and tattoos are open wounds, with the consequent risk of infection they present for immunosuppressed patients. Think about if the risk is worth taking.

In the case that you decide to follow through notwithstanding the risk it presents, keep in mind the next precautions:

- ✓ Talk with your doctor. He will tell if there is any contraindication or if you must be especially careful about something. He may even prescribe a preventive antibiotic, like when you go to the dentist.
- ✓ Make sure all the material is one-use-only and that they open it at the moment to use on you, and that all the instrumentation is sterilized. Ideally the procedure would be carried by a trustworthy person that knows what a transplant is, and the risks it presents.
- ✓ It is important that they use an antibiotic ointment on you afterwards and that you use an antibacterial soap while caring for it.
- ✓ If you notice any signs of infection inform your transplant team immediately.



Cleaning at home

Make sure your house is always clean, in particular your bedroom and any space where dust may accumulate. Use a damp cloth to dust (so that it does not end up suspended on the air) and a vacuum cleaner instead of a broom.

Ventilate your house daily.

You should not start any constructions at home, at least during the first year after the transplant.

Eradicate insects and rodents.

Avoid damp spots in walls and ceilings because they contribute to the development of harmful fungus and bacteria.

Pets

It is advisable to avoid direct contact with animals for the first three months after the transplant. After that, if you have pets, they should be cared for, vaccinated, and free of parasites. Avoid sleeping with them or that being licked by them.

There are some limitations on the pets you can have at home:

- ✓ Birds are hosts for Staphylococcus and other bacteria. Moreover, when they shake their feathers, they contaminate the surrounding area of their cage. Parrots and related birds also transmit psittacosis.
- ✓ Turtles can transmit salmonella, so they are not a good option either.
- ✓ Cats can transmit toxoplasmosis, bear that in mind.
- ✓ Avoid wild or sick animals.
- ✓ Avoid exotic animals, they may carry parasites, virus, or bacteria that your organism has not encountered before, and your immune system may fail.



Plants

Plants may be a source of infections due to the microbes found on soil. The "old" stagnant water in the vases is also a source of infection.

Do not have plants in the kitchen or in the bedroom.

During the first six months after the transplant do not practice gardening, and if you do, use gloves and a mask, and remember to wash your hands thoroughly afterwards.

With young children, be careful of them putting their hands in their mouths while playing at the park and remember to wash their hands thoroughly afterwards.



Teenagers: healthcare age of majority and medical decision making

From 16 years old onwards you are recognized to present the healthcare age of majority which means that you have *“full ability to accept or reject clinical information, choose an available clinical option, accept or reject medical treatments, and maintain or revoke informed consent”*. This means that you will be able to make the decisions concerning your healthcare.

In order to be prepared for this responsibility it is important that from the age of 12 years old you start taking responsibility for your own care. Your parents will gradually allow you to take care of things. First you will need to know the names of the drugs you are taking, their doses and what each one is for.

Eventually, you will be responsible for taking your medication and caring for your health. You should also know what steps to take to prevent infection and other complications.

When you go to the doctor you will tell doctors and nurses how you have been since the last visit and ask them about your doubts. All the team will be there to answer your questions and help you with whatever you need.

Do not forget that when you turn 18 you will switch to an adult health team and you should be prepared to take responsibility for yourself and your health.



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Main collaborators:



ERN TransplantChild Patients Associations:



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