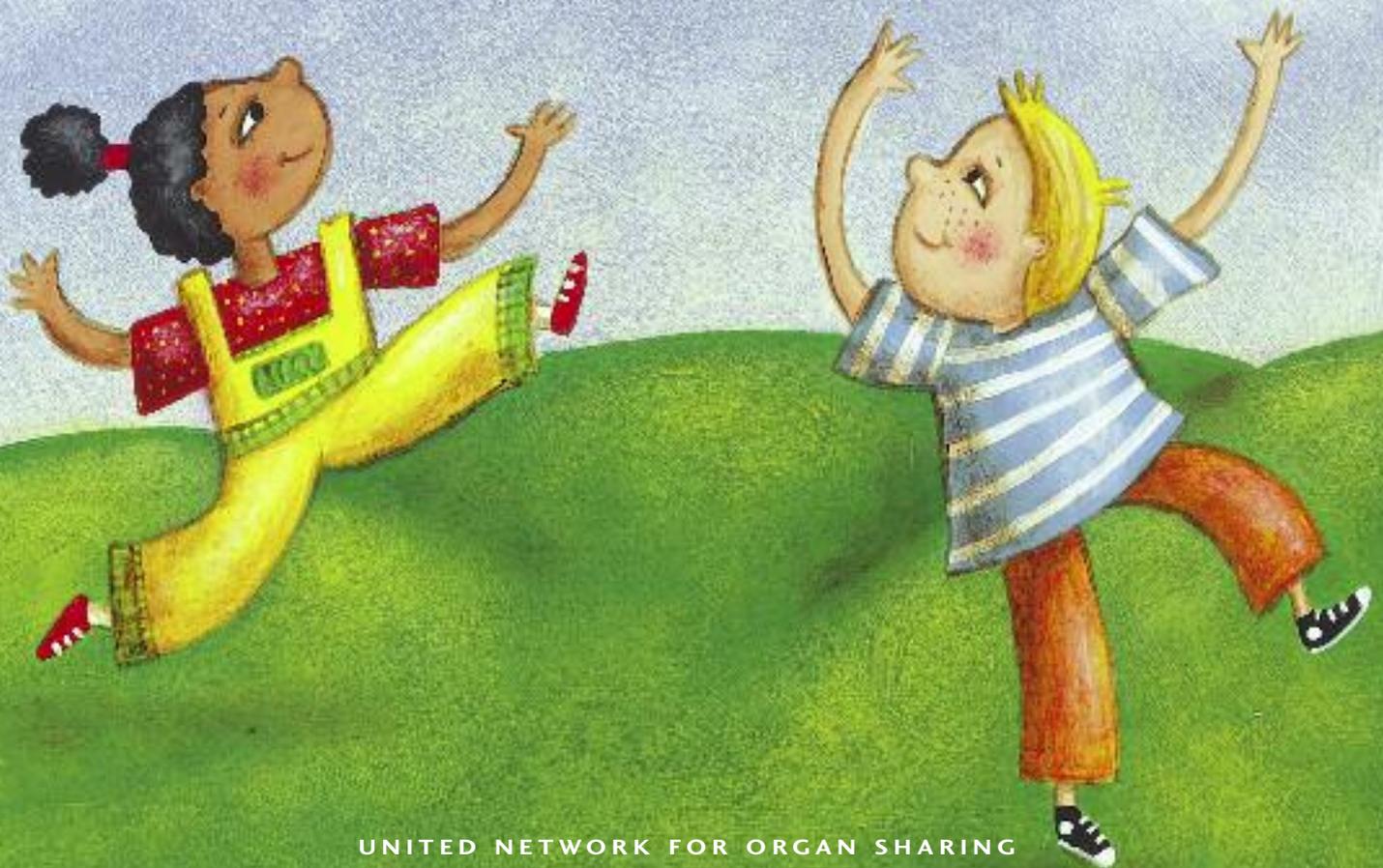


organ transplants

What Every Kid Needs to Know



UNITED NETWORK FOR ORGAN SHARING

UNITED NETWORK FOR ORGAN SHARING

United Network for Organ Sharing (UNOS) is a private non-profit 501(c)(3) organization that operates the Organ Procurement and Transplantation Network (OPTN) under contract with the federal government. For more information about UNOS, living donation, and organ transplantation, please call 1-888-894-6361 or visit www.transplantliving.org.

PARTNERS IN EDUCATION

UNOS gratefully acknowledges our Partners in Education whose generous support helps make this resource possible:

Astellas

Bristol Myers Squibb

Genentech

Novartis

Teva Pharmaceuticals

UNOS would also like to thank the following volunteers for their editorial assistance:

- The OPTN/UNOS Pediatric Committee
- The OPTN/UNOS Patient Affairs Committee
- Marva Moxey-Mims, M.D., FAAP, Director, Pediatric Nephrology and Renal Centers, Programs, NIH, NIDDK, DKUH
- Eleanor Trinkle and Beverley Stone, school educators
- Reagan Montgomery and her 2002–2003 fourth grade class of Cedar Lane Elementary in Ashburn, Virginia.

A note to parents

Since you have received this booklet, *Organ Transplants: What Every Kid Needs to Know*, chances are that your child or a child you know may need an organ transplant now or some time in the future. This booklet has been created to help children and their families feel more at ease with the organ transplantation process by providing general information in an understandable format. Most importantly, it is designed to let the readers know that they are not alone and that there are other children who need a transplant. Since 1988 there have been more than 40,000 children who have received a new organ. Unfortunately, in the United States alone, there are approximately 1,700 children in need of an organ transplant. It is a stressful time for these children and their families. So, we hope that the information that you find here is helpful and provides you with the needed answers to your questions.

Please call UNOS Patient Services at 1-888-894-6361 or visit www.transplantliving.org for additional information.





Did you know that there are a lot of kids like you, who are waiting for a new organ?

So your doctor has told you that you need a transplant.

What does that mean? It means that you have an organ that is sick and not working right. It needs to be replaced by a healthy organ.

You may have to wait before the right organ for your body becomes available. Having to wait is not fun, and sometimes you may not feel so great. It's okay to show your feelings. Talk to your mom, dad, doctor or friends about how you're feeling. Or, draw some pictures to show them.

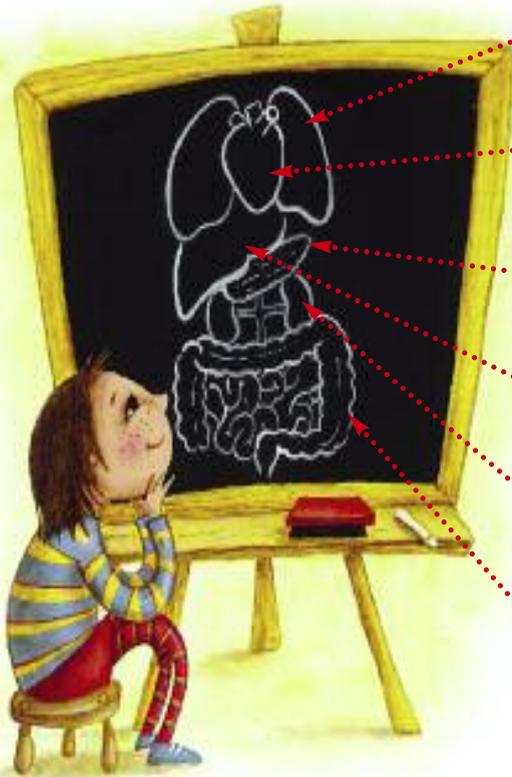
What is an organ?

A body is like a machine. It needs lots of working parts—called organs—to keep it going. Organs come in many shapes and sizes—and some even come in pairs!

If an organ does not work right, it may need to be replaced to keep you healthy. This is called an organ transplant, and your doctor will explain why you need one. But you're not alone! There are lots of kids just like you who need a new organ. Some need a new heart, lung or liver and others may need a new kidney.

Amazingly, one organ donor can save the lives of up to eight other people.

What do the organs do?



Lungs – a pair of organs that help you breathe

Heart – pumps blood through the body

Pancreas – helps the body use the food you eat

Liver – helps break down the food you eat

Kidneys – a pair of organs that get rid of the body's waste

Intestine – takes in water and food for the body



Where do the organs come from?

There are two different places that the organs can come from. Organs can come from a living person or someone who has died.

A living donor is someone who cares about you and wants to help by giving you part or all of one of their healthy organs. They can be related to you, like your mom or dad, or they can be unrelated, like an adult friend. The doctors and nurses will take good care of your living donor and make sure they are healthy when they are ready to go home.

Someone who has died from a serious injury can also be a donor. That person's family wants to help someone else live, so they agree to donate the organs. Your doctor would make sure the organ is healthy and will work well in your body.



Your transplant team includes doctors, nurses and other people, all working to help you feel better.

Your transplant team

You will be meeting a lot of new people who will take care of you at the hospital. They are your transplant team and they understand if you feel scared. When you have a serious illness, your life is different than before. Your transplant team will be there to help you every step of the way and answer any questions you and your family may have. You may want to make a list of questions before you go to the doctor so you don't forget them.

Questions you may have...

Do other children need transplants?

What is wrong with my organ?

Why don't I feel good?

Why do I need a new organ?

How long will it take for me to get a new organ?

Where will the new organ come from?

Why do I have to have so many tests?

Can my family be with me?

How will I feel after I get my new organ?

How long do I have to stay in the hospital?

Will I have to take medicine after my transplant?

Who will take care of me in the hospital?

When it is your turn to receive a new organ...

You will need to stay in the hospital for a while. The doctors and nurses want to make sure everything is okay before you go home. They also want to teach you and your family how to care for your new organ.



Thousands of kids just like you have received transplants. You're not alone.



It's important to remember that your transplant experience may be different from another child's.

If you've had to miss school, you may be nervous about going back.

Friends may be afraid to call or to invite you over because they know you have been sick. Tell them it is okay for them to talk about it and even ask you questions. Remind them that they don't have to treat you differently. It might be a good idea to ask if a speaker can come talk to your class about donation and transplants. This may help your friends get a better idea of what you have been through.

If you have any questions or are upset about your health, you and your family should always talk to your transplant team. They are the ones who know you so well and can help fix what is bothering you.

When you have had a transplant...

Ask questions if you don't understand.

Follow your doctor's instructions.

Keep yourself healthy.

Take your medicine.

Exercise.

Eat healthy foods.

Get plenty of sleep.

Know that you are important.

Set goals for yourself.

The best way to thank your donor is by staying active, happy and healthy.

And remember, you're not alone.

Lots of kids like you need transplants, too!





www.transplantliving.org



P.O. Box 2484 | Richmond, VA 23218

www.unos.org

113k R7.12