

# KIDZ HELPING KIDZ



DEVELOPED BY THE

**AST**

**PEDIATRIC**  
COMMUNITY OF PRACTICE

Dear Parents, Friends, and Families of Children with a Transplant,

We as healthcare providers are mothers, fathers, aunts, uncles, brothers, and sisters, but very few of us are transplant patients and most of us do not have family members with a transplant. As parents, we can only imagine the joy, mixed with a little anxiety and a tiny bit of fear, the family must feel when they get the call that their child will receive a life changing organ. But what does the child feel? What does the child think?

Depending on the age of the child, there can be many unknowns. As much as we try to prepare them for this event, it can still be quite overwhelming. Over the years, parents have told us that it is so helpful for their child to meet another child who has gone through the same thing. To see the process through another child's eyes. To talk to another child to see what they think.

Since we can't connect all children with transplants, we decided to do the next best thing. The goal of this book is for kids to help other kids going through the transplant process. We did our best to capture their thoughts and feelings. We loved putting this book together. Some answers made us laugh, some made us wonder, and some brought a little tear. But most importantly, we hope it helps support kids in this grand transplant journey. We encourage you to share this book with your transplant families and hope that it brings similar joy to your kids as it has to us in the Pediatric Community of Practice of the American Society of Transplantation.

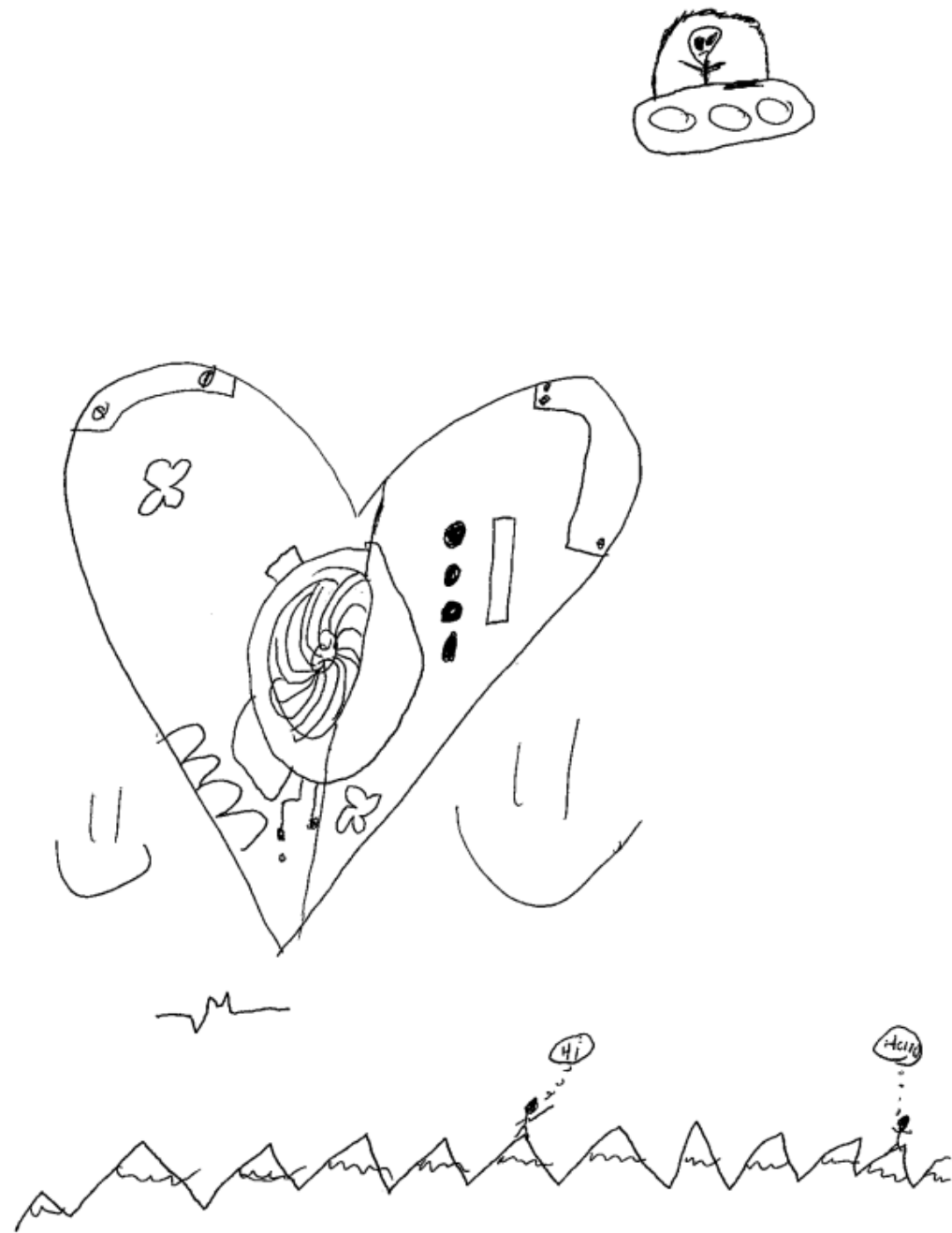
HEY KIDS!

This book was made especially for you.

Do you know that there are a lot of kids just like you with organ transplants?

They want to share their stories with you and remind you that

YOU ARE  
**NOT** ALONE!



What was the easiest part of transplant?

Knowing i wold be healthy

What was the hardest part of transplant?

Leaving my mom

How do you get ready for procedures, such as blood draws, biopsies, etc.?

istay calm and

What do you like most about having a transplant?

it will help me stay alive

What do you like least about having a transplant?

having to take medicine

What is something that you know you should be doing, but you don't always do?

Drink water

Some children name their transplant. If you did, what is the name and why did you choose that name?

~~Pikachu~~ pikachu

What would you say to a kid that is going to have a transplant and is scared or worried?

IT wold be fine

Age now 12

Age at transplant 4

Race/ethnicity Mexican

Type of transplant ~~kidney~~

kidney



What was the easiest part of transplant?

The recovery from transplant

What was the hardest part of transplant?

waking up to take my medications on time  
and being aware of the kidney.

How do you get ready for procedures, such as blood draws, biopsies, etc.?

I buy a big breakfast from McDonald's  
and coffee :)

What do you like most about having a transplant?

not getting sick as often

What do you like least about having a transplant?

Having to watch what I eat.

What is something that you know you should be doing, but you don't always do?

check nutrition labels on food

Some children name their transplant. If you did, what is the name and why did you choose that name?

no I didn't name my kidney

What would you say to a kid that is going to have a transplant and is scared or worried?

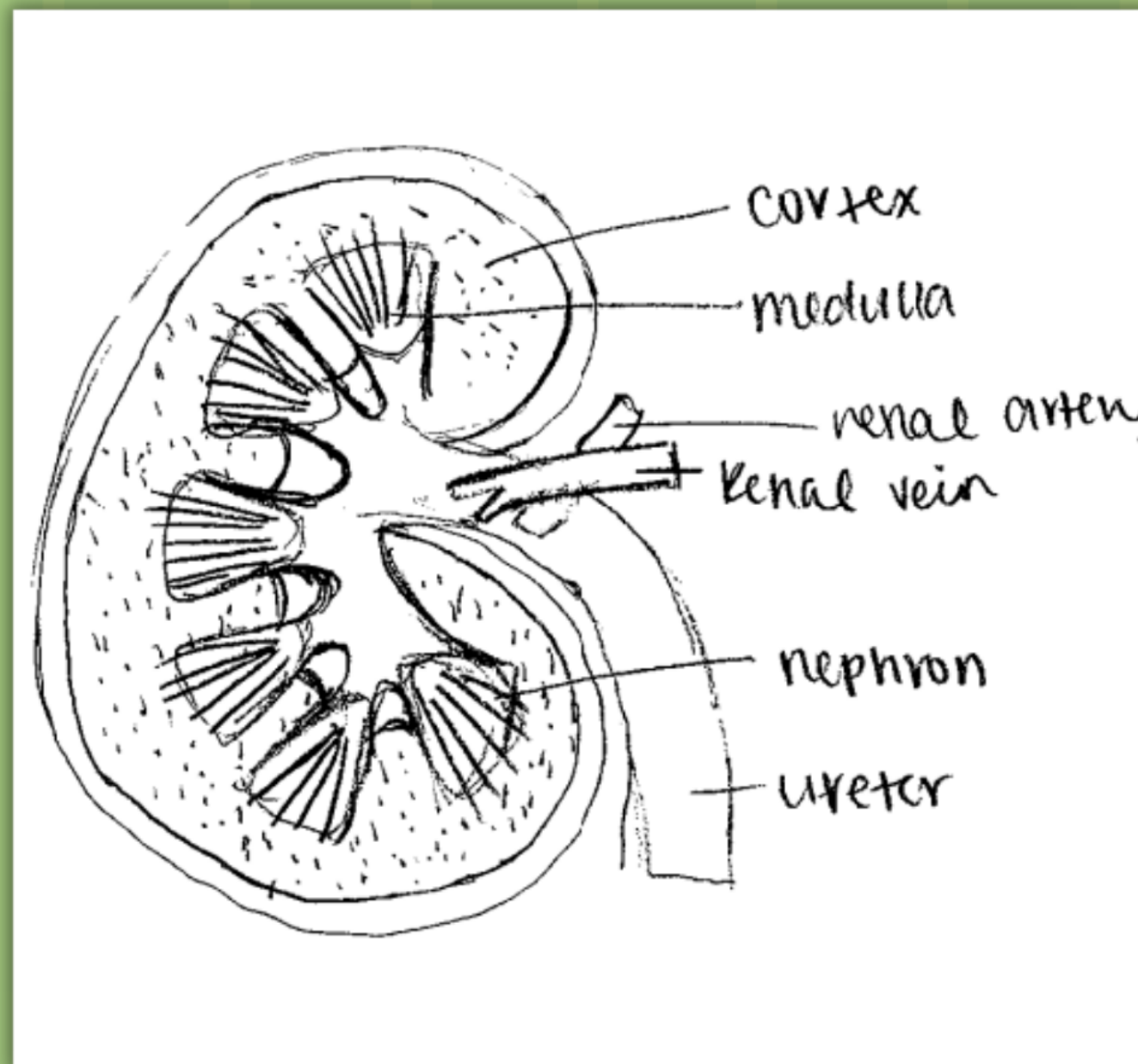
Don't be scared everything is gonna be ok.

Age now 81

Age at transplant 17

Race/ethnicity hispanic

Type of transplant kidney





What was the easiest part of transplant?

having a good life

What was the hardest part of transplant?

having to take a lot of <sup>meds</sup>

How do you get ready for procedures, such as blood draws, biopsies, etc.?

listen to music

What do you like most about having a transplant?

being active

What do you like least about having a transplant?

going in and out  
of ~~hospital~~ hospital

What is something that you know you should be doing, but you don't always do?

taking blood ~~pressure~~  
pressure

Some children name their transplant. If you did, what is the name and why did you choose that name?

max

What would you say to a kid that is going to have a transplant and is scared or worried?

don't worry about it. your going  
to be big a strong

Age now 14

Age at transplant 13

Race/ethnicity white/hispanic

Type of transplant kidney transplant



What was the easiest part of transplant?

drinking apple juice afterward

What was the hardest part of transplant?

anesthesia needle

How do you get ready for procedures, such as blood draws, biopsies, etc.?

taking deep breaths, staying calm, drinking water

What do you like most about having a transplant?

being alive and telling people I'm better

What do you like least about having a transplant?

having to explain the whole thing to friends/love interests

What is something that you know you should be doing, but you don't always do?

monitoring my blood pressure

Some children name their transplant. If you did, what is the name and why did you choose that name?

Bean, because kidneys are shaped like beans

What would you say to a kid that is going to have a transplant and is scared or worried?

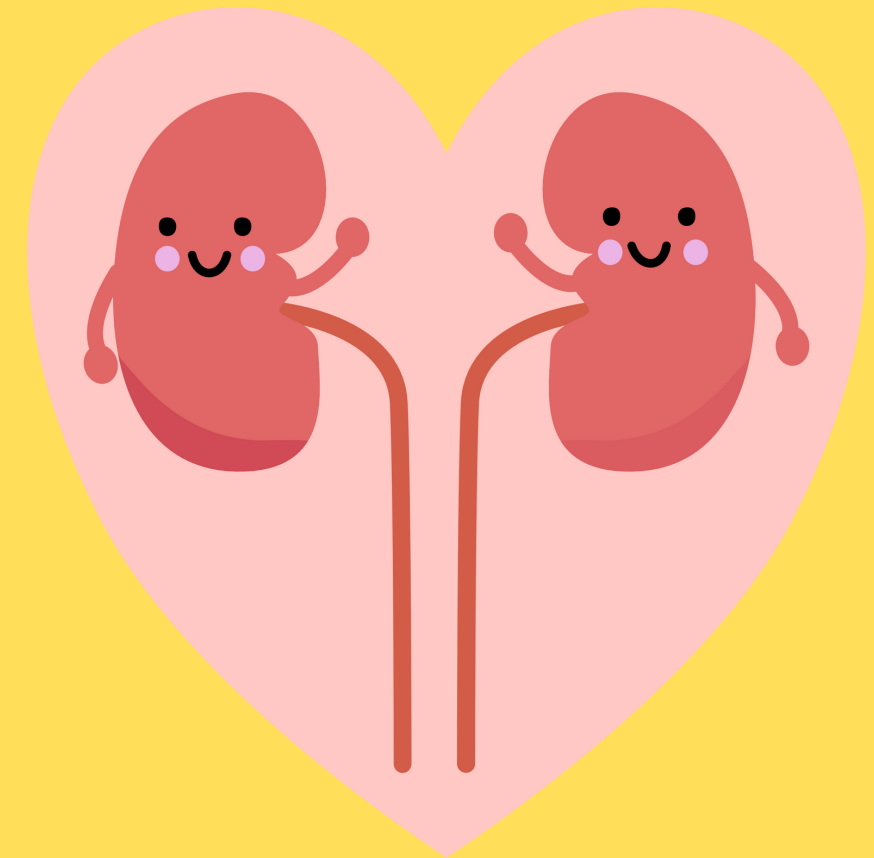
everything is going to be okay! just breathe!

Age now 19

Age at transplant 2

Race/ethnicity Black/African American

Type of transplant kidney



What was the easiest part of transplant?

Honestly everything is ~~easy~~ <sup>easy</sup> just got to be responsible

What was the hardest part of transplant?

~~maintaining~~  
For me is maintaining my transplant healthy

How do you get ready for procedures, such as blood draws, biopsies, etc.?

I just think of them as things that got to get done

What do you like most about having a transplant?

In my case, not having to be connected to a machine for 10-12 hrs

What do you like least about having a transplant?

I get sick very often due to the medication

What is something that you know you should be doing, but you don't always do?

Drink water!!

Some children name their transplant. If you did, what is the name and why did you choose that name?

Mine is named "Frijolito" because it looks like a bean

What would you say to a kid that is going to have a transplant and is scared or worried?

To not be worried, that everything is going to be okay, and to always have hope and a positive mindset

Age now 19

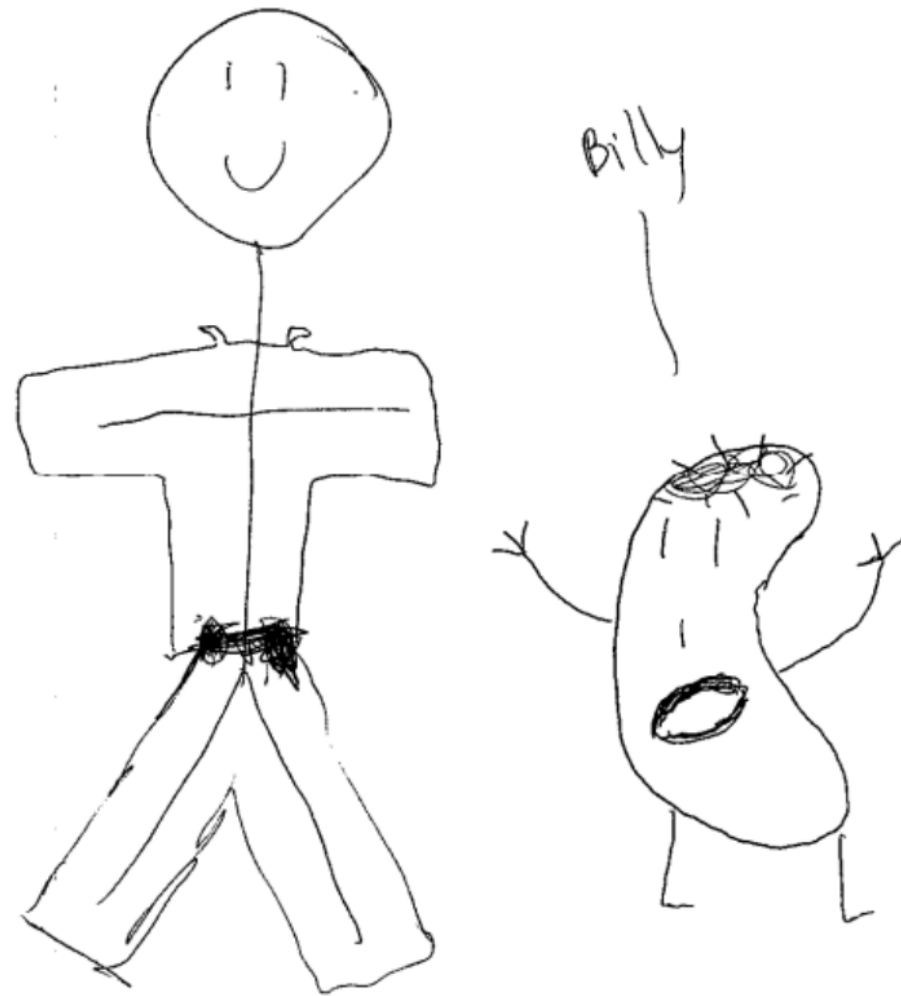
Age at transplant 17-18

Race/ethnicity ~~Latin~~ Hispanic

Type of transplant Kidney







What was the easiest part of transplant?

I would say that the easiest part of the transplant was watching tv <sup>after the surgery</sup>

What was the hardest part of transplant?

Being nervous

Before the transplant

How do you get ready for procedures, such as blood draws, biopsies, etc.?

I would listen to music

What do you like most about having a transplant?

made me taller

What do you like least about having a transplant?

taking meds

What is something that you know you should be doing, but you don't always do?

Drink enough water

Some children name their transplant. If you did, what is the name and why did you choose that name?

Billy the kidney

What would you say to a kid that is going to have a transplant and is scared or worried?

Be brave and you will feel better

Age now 16


Age at transplant 14

Race/ethnicity white

Type of transplant kidney transplant



What was the easiest part of transplant?

I don't think anything was easy other than me getting support 

What was the hardest part of transplant?

Waiting, I knew I needed a transplant and being on the wait list was like a water torture I hated not knowing.

How do you get ready for procedures, such as blood draws, biopsies, etc.?

Honestly I just go even if I don't want to. I realise that this is for the better and it will help my doctors help me.


What do you like most about having a transplant?

Not being on a Renal diet / dialysis  
I felt unordinary from my fellow peers.

What do you like least about having a transplant?

The weak immune system,  
The meds I will have to be on them forever

What is something that you know you should be doing, but you don't always do?

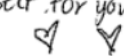
Drink water  (I do it but I have to remind myself)

Some children name their transplant. If you did, what is the name and why did you choose that name?

I heard people do that but I just call it kidney #3

What would you say to a kid that is going to have a transplant and is scared or worried?

Your life is going to change for the better.  
little by little you will heal. This opportunity isn't  
one most people have but you do so take it. You may think  
well why me? I don't have a realist answer than you  
were chosen, you are loved and blessed remember that.

Take care of yourself for you and your donor's organ sake...  


Age now 15

Age at transplant 14

Race/ethnicity Hispanic

Type of transplant

Kidney



What was the easiest part of transplant?

Had a pretty fast recovery -  
I felt good after transplant.

What was the hardest part of transplant?

The pain

How do you get ready for procedures, such as blood draws, biopsies, etc.?

Just by staying calm. I don't look at needles when they go in.

What do you like most about having a transplant?

That I feel great now.

What do you like least about having a transplant?

Not doing everything, but I don't really mind.

What is something that you know you should be doing, but you don't always do?

Eating veggies.

Some children name their transplant. If you did, what is the name and why did you choose that name?

Sunday because I received it on a  
Sunday

What would you say to a kid that is going to have a transplant and is scared or worried?

To not be scared and everything will be great.  
It's worth going through pain through recovery  
but then the better comes.

Age now

Age at transplant

Race/ethnicity

Type of transplant

you've

GOT THIS



You'll  
Do  
GRRREAT!

**What was the easiest part of transplant?**

The easiest part of the transplant was the operation because I didn't feel any pain during the operation.

**What was the hardest part of transplant?**

After the operation my tummy was sore, and it was hard to walk but I got better quickly. I did have to stay in the hospital for a week.

**How do you get ready for procedures, such as blood draws, biopsies, etc.?**

I calm myself down and don't look at the blood draw, and for other operations I close my eyes and think of things I like.

**What do you like most about having a transplant?**

I get to eat foods I couldn't eat before, I got lots of love and support from my family, friends, and doctors and nurses.

**What do you like least about having a transplant?**

I didn't like how sore my tummy was after the transplant.

**What is something that you know you should be doing, but you don't always do?**

I need to drink lots of water but I don't always do that.

**Some children name their transplant. If you did, what is the name and why did you choose that name?**

I didn't name my transplant but I think it's cool to do that.

**What would you say to a kid that is going to have a transplant and is scared or worried?**

I would say to not worry, your doctors and nurses will take care, and the operation gets done quick, and there are so many kids just like you. (You will also get I wish, to get anything you want). It will go perfectly.

Age now 12  
Age at transplant 8  
Race/ethnicity South Asian/Indoan  
Type of transplant kidney



What was the easiest part of transplant?

Being done with dialysis

What was the hardest part of transplant?

The feelings of anxiety or questions like am I sure I took meds

Pre transplant: Seeing other kids doing things I couldn't

How do you get ready for procedures, such as blood draws, biopsies, etc.?

I don't really think abt it

What do you like most about having a transplant?

Enjoying life, swimming, the freedom of doing things

What do you like least about having a transplant?

The responsibility and having to grow up quicker/sooner

What is something that you know you should be doing, but you don't always do?

The hardest thing to adjust to is drinking 3L since I used to not be able to drink a lot

Some children name their transplant. If you did, what is the name and why did you choose that name?

What would you say to a kid that is going to have a transplant and is scared or worried?

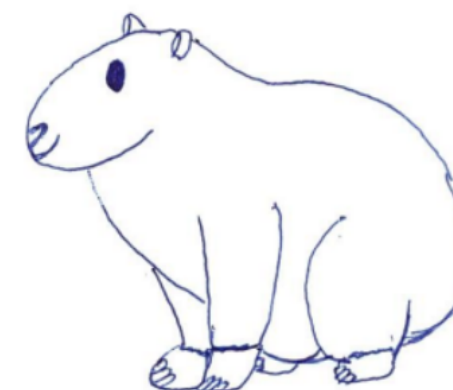
Think about the after/future of things like what you can do or what you can eat

Age now 16

Age at transplant 11

Race/ethnicity

Type of transplant Kidney



Capybara





What was the easiest part of transplant? When they put me to sleep  
During surgery

What was the hardest part of transplant? Not knowing what was going  
to happen

How do you get ready for procedures, such as blood draws, biopsies, etc.?  
BY staying calm and dont ~~worry~~ worry

What do you like most about having a transplant?  
Live a normal life and eat a regular diet

What do you like least about having a transplant?  
i couldnt play football and taking medicine

What is something that you know you should be doing, but you don't always do?  
keep up with drinking water

Some children name their transplant. If you did, what is the name and why did you choose that name?  
The survivor because i survive another day  
and years

What would you say to a kid that is going to have a transplant and is scared or worried?  
keep faith Be strong dont worry god got you

Age now 13y10  
Age at transplant 6  
Race/ethnicity AA  
Type of transplant kidney



What was the easiest part of transplant?

Meds

What was the hardest part of transplant?

fluids

How do you get ready for procedures, such as blood draws, biopsies, etc.?

Make sure everything is set at home and meds are taken at right time

What do you like most about having a transplant?

Telling my story

What do you like least about having a transplant?

People treating me very differently

What is something that you know you should be doing, but you don't always do?

I sometimes struggle w/ fluids

Some children name their transplant. If you did, what is the name and why did you choose that name?

Felipe the third (my dad)

What would you say to a kid that is going to have a transplant and is scared or worried?

That everything will be okay  
you are very strong and you have a cool story to tell

Age now 20

Age at transplant 18

Race/ethnicity Hispanic

Type of transplant kidney

you  
ARE  
Strong

What was the easiest part of transplant?

Getting to drink meds

What was the hardest part of transplant?

the shots tired

How do you get ready for procedures, such as blood draws, biopsies, etc.?

Just be calm and cool

What do you like most about having a transplant?

having a new kidney

What do you like least about having a transplant?

getting tired all lot

What is something that you know you should be doing, but you don't always do?

Nothing

Some children name their transplant. If you did, what is the name and why did you choose that name?

cause it <sup>is nice</sup> kindy

What would you say to a kid that is going to have a transplant and is scared or worried?

"its okay you got this"

Age now 8

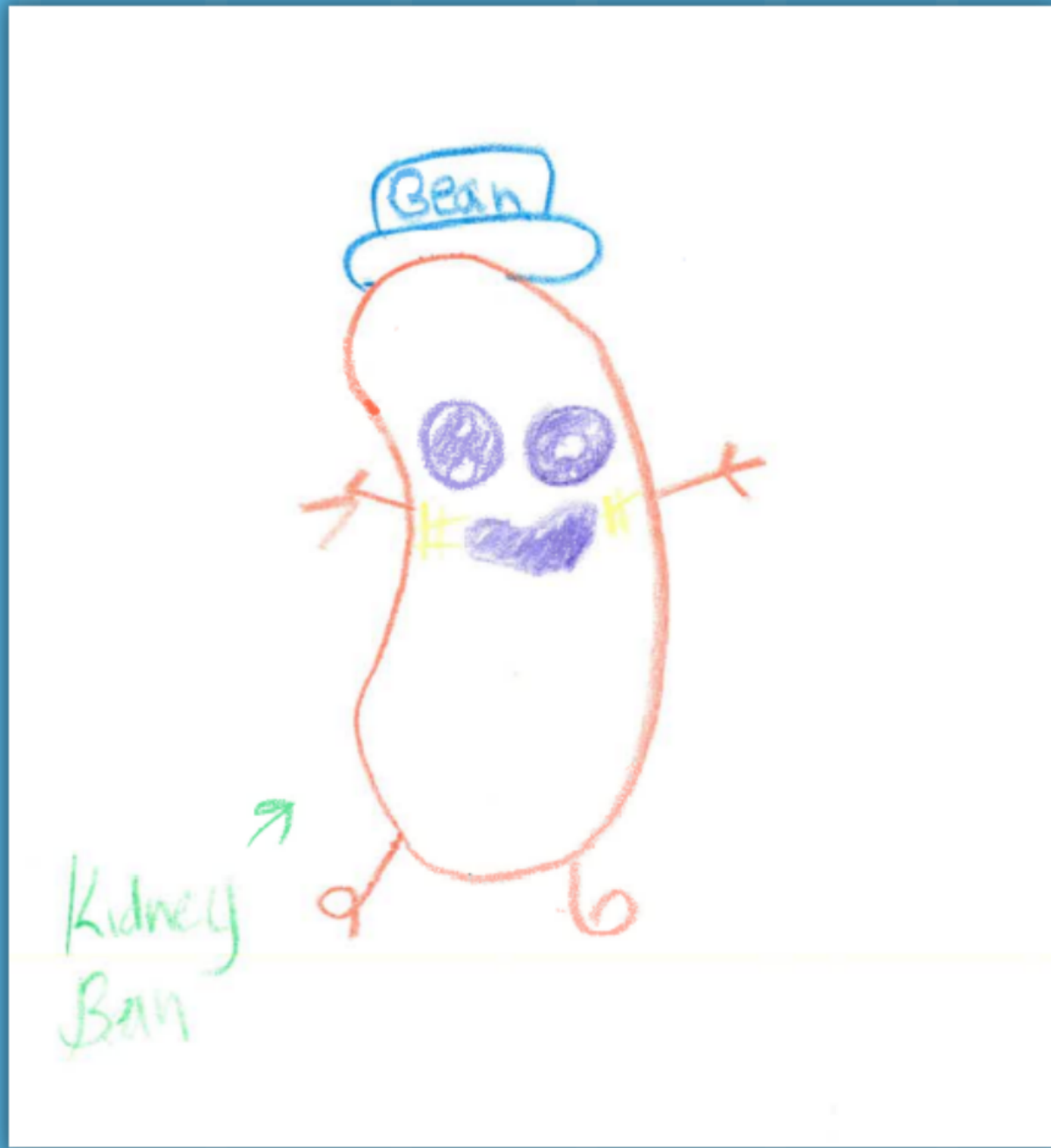
Age at transplant 8

Race/ethnicity

Type of transplant Kidney transplant







What was the easiest part of transplant?  
 resting

What was the hardest part of transplant?  
 P.T

How do you get ready for procedures, such as blood draws, biopsies, etc.?  
 I don't think is about it

What do you like most about having a transplant?  
 Getting the funny medicine before the doctor

What do you like least about having a transplant?  
 The healing process

What is something that you know you should be doing, but you don't always do?  
 water intake

Some children name their transplant. If you did, what is the name and why did you choose that name?  
 Kidney Bean cuz I like it

What would you say to a kid that is going to have a transplant and is scared or worried?  
 Don't be scared cuz the scars look K  
 Dope

Age now 14  
 Age at transplant 12  
 Race/ethnicity white  
 Type of transplant Kidney



What was the easiest part of transplant?

Coordination and organization of the event.

What was the hardest part of transplant?

Seen my daughter going under surgery.

How do you get ready for procedures, such as blood draws, biopsies, etc.?

Communication with transplant clinic team

What do you like most about having a transplant?

Life !!!

What do you like least about having a transplant?

medications.

What is something that you know you should be doing, but you don't always do?

N/A

Some children name their transplant. If you did, what is the name and why did you choose that name?

N/A

What would you say to a kid that is going to have a transplant and is scared or worried?

Life is awaiting ... the best is yet to come.

Age now 6.5 yrs

Age at transplant 2.5 yrs

Race/ethnicity -> hispanic

Type of transplant

Kidney



Sam



DOCTOR



What was the easiest part of transplant?

That I knew what my doctors were doing, and that they knew what was best for me. I knew my parents were with me throughout the whole time. I had a lot of support.

What was the hardest part of transplant?

It was knowing I had to get one. It is hard knowing you have an organ that doesn't work. I was very healthy and active before I had those issues.

How do you get ready for procedures, such as blood draws, biopsies, etc.?

I drink water, and I put arm out for blood draws. Honestly, I trust the doctors, so I really don't care.

What do you like most about having a transplant?

That it is a blessing because without it, I wouldn't be here. I am so happy it happened, and to look back knowing I did that is incredible.

What do you like least about having a transplant?

That I have to go to appointments because I just want a normal life w/out procedures, etc.

What is something that you know you should be doing, but you don't always do?

I should be taking my meds on time because I am really bad at timing when I am not at school.

Some children name their transplant. If you did, what is the name and why did you choose that name?

I named Avatar. ~~Avatar~~ The reason I chose that name is because my donor and I called it that.

What would you say to a kid that is going to have a transplant and is scared or worried?

Don't be scared. The doctors and nurses want best for you, and they want to help you. Once you receive the transplant, you will feel better. Your transplant

Age now

Age at transplant

Race/ethnicity

Type of transplant

is your hero, and you get superpowers that others won't get.





List 3 words that described how you felt when you first found out that you needed or already had a transplant.

- 1) Shocked
- 2) Scared
- 3) nervous

Knowing what you know now, list 1 thing that your doctors/nurses and/or family could have been done to make finding out about your diagnosis easier?

- 1)

Who did you talk to when you were scared?

My friends

What was the easiest part of transplant?

The easiest part was becoming BFF's w/ my transplant team!

What was the hardest part of transplant?

how it affected my family, and the diet

How do you get ready for procedures, such as blood draws, biopsies, etc.?

I just get it over with

What do you like most about having a transplant?

The scar

What do you like least about having a transplant?

having to keep up w/ medicine.

What is something that you know you should be doing, but you don't always do?

drinking alot of water + eating healthy

Some children name their transplant. If you did, what is the name and why did you choose that name?

What would you say to a kid that is going to have a transplant and is scared or worried?

Age now 14

Age at transplant 13

Race/ethnicity

Type of transplant

you will find out you have a bigger support system when than ever!! (and you won't be "afraid" of medes!)



List 3 words that described how you felt when you first found out that you needed or already had a transplant.

- 1) I felt like I was special.
- 2) I felt lucky to be alive.
- 3) I was happy my dad was a match.

Knowing what you know now, list 1 thing that your doctors/nurses and/or family could have been done to make finding out about your diagnosis easier?

- 1) nothing

Who did you talk to when you were scared? Mamma!

What was the easiest part of transplant? That I was a baby and don't remember.

What was the hardest part of transplant? Getting labs every few months

How do you get ready for procedures, such as blood draws, biopsies, etc.? Tell myself it's not going to hurt.

What do you like most about having a transplant? I feel special that I have one and my sisters don't.

What do you like least about having a transplant? Having to drink huge cups of water to hydrate sometimes.

What is something that you know you should be doing, but you don't always do?

Drinking enough water.

Some children name their transplant. If you did, what is the name and why did you choose that name?

Beanie

What would you say to a kid that is going to have a transplant and is scared or worried? It's okay. It

Age now: 10

Age at transplant: 1.5yo

Race/ethnicity: Caucasian

Type of transplant: Kidney

Mamma is special and you'll feel better after you have it!

My dad and Mom who helped me get through it!





List 3 words that described how you felt when you first found out that you needed or already had a transplant.

- 1) Desperate
- 2) Fear
- 3) \_\_\_\_\_

Knowing what you know now, list 1 thing that your doctors/nurses and/or family could have been done to make finding out about your diagnosis easier?

- 1) Sumi's team did amazing at all time.

Who did you talk to when you were scared?

mom - daed

What was the easiest part of transplant?

Recovery

What was the hardest part of transplant?

Been apart of my family.

How do you get ready for procedures, such as blood draws, biopsies, etc.?

through my parents and medical team

What do you like most about having a transplant?

been alive

What do you like least about having a transplant?

medications

What is something that you know you should be doing, but you don't always do?

Some children name their transplant. If you did, what is the name and why did you choose that name?

N/A.

What would you say to a kid that is going to have a transplant and is scared or worried? Have faith, everything is going to be ok.

Age now: 5 1/2

Age at transplant: 2 1/2

Race/ethnicity \_\_\_\_\_

Type of transplant: Kidney transplant



What was the easiest part of transplant?

post transplant

What was the hardest part of transplant?

finding a match for a working kidney!

How do you get ready for procedures, such as blood draws, biopsies, etc.?

try not to think about it + treat your self with something after procedures, like ice cream ex...

What do you like most about having a transplant?

Some what normal again feel good and have your energy back!

What do you like least about having a transplant?

med: cut, ons and side affects of them recovery after transplant

What is something that you know you should be doing, but you don't always do?

you should be doing everything that your doc tells you very important

Some children name their transplant. If you did, what is the name and why did you choose that name?

no name but if i had one it would be good kidney

What would you say to a kid that is going to have a transplant and is scared or worried?

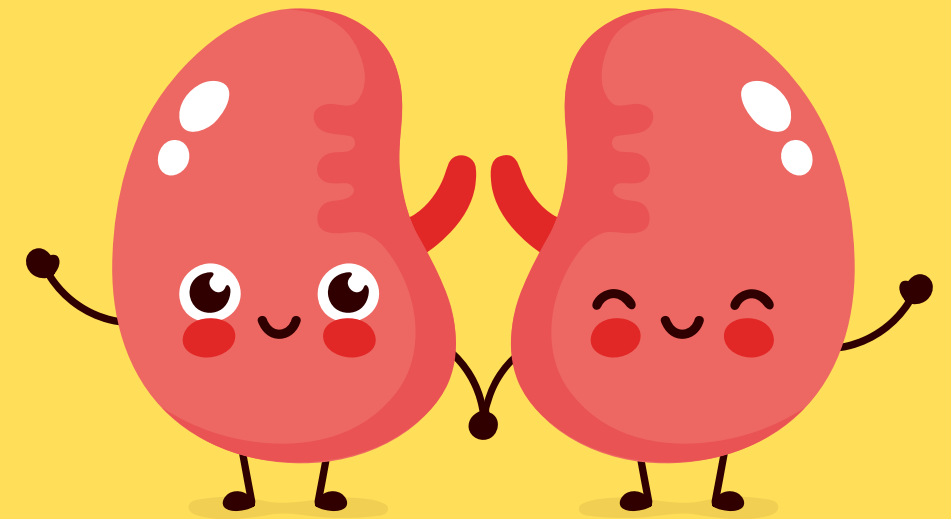
Just remember pain is temporary and its worth it in the long run and better than dialysis.

Age now 20

Age at transplant 20

Race/ethnicity white

Type of transplant kidney



What was the easiest part of transplant?

Ride in cars at hospital.

What was the hardest part of transplant?

Tummy hurting.

How do you get ready for procedures, such as blood draws, biopsies, etc.?

Get dressed and talk about it.

What do you like most about having a transplant?

get to eat; macaroni + cheese.

What do you like least about having a transplant?

NO IV'S

What is something that you know you should be doing, but you don't always do?

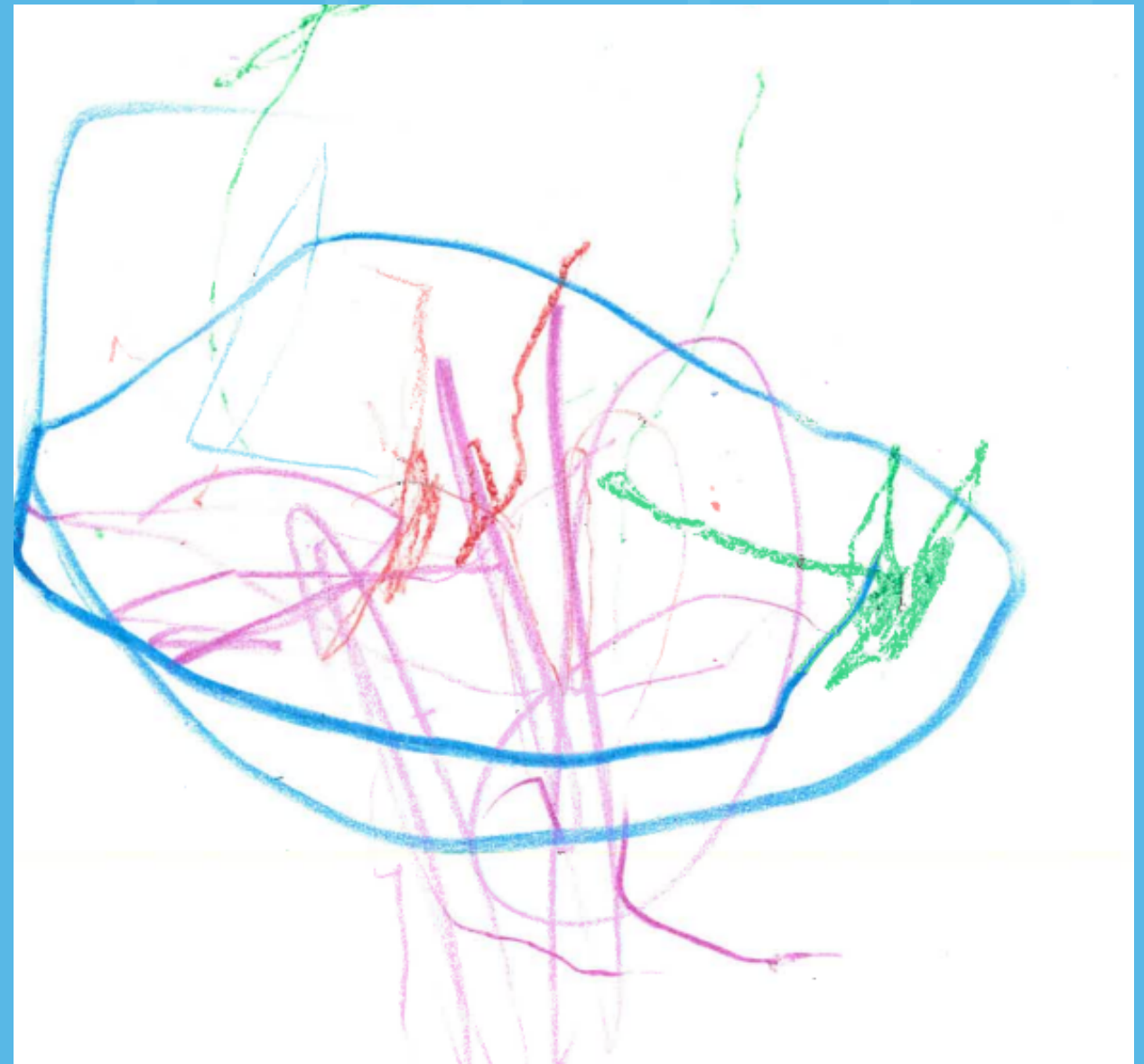
DRINK

Some children name their transplant. If you did, what is the name and why did you choose that name?

Sara Nana Kidney

What would you say to a kid that is going to have a transplant and is scared or worried?

Be Brave





List 3 words that described how you felt when you first found out that you needed or already had a transplant.

- 1) Shocked
- 2) scared
- 3) confused

Knowing what you know now, list 1 thing that your doctors/nurses and/or family could have been done to make finding out about your diagnosis easier?

- 1) explained what surgery was for

Who did you talk to when you were scared?

my mom + child life nurse

What was the easiest part of transplant?

the surgery

What was the hardest part of transplant?

diagnosis being in the waiting

How do you get ready for procedures, such as blood draws, biopsies, etc.?

I pray + trust God!

What do you like most about having a transplant?

No dialysis + regular diet

What do you like least about having a transplant?

all the appointments

What is something that you know you should be doing, but you don't always do?

eat more veggies

Some children name their transplant. If you did, what is the name and why did you choose that name?

Charlie ~~for~~ for Charleston + good for a boy or girl

What would you say to a kid that is going to have a transplant and is scared or worried?

trust and believe that God will carry you through it all.

Age now

Age at transplant

Race/ethnicity

Type of transplant

15  
15  
white  
kidney





THOUSANDS OF KIDS JUST LIKE YOU HAVE  
RECIEVED AN ORGAN TRANSPLANT.

ALWAYS REMEMBER YOU ARE NOT ALONE!

