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 would 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.?

Stay 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

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

It would be fine

Age now: 12
Age at transplant: 4
Race/ethnicity: Mexican
Type of transplant: 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 my 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?
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: 21
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?

taking a lot of medicine

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 the hospital

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

taking blood 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. You’re gonna be a boss and a strong

Age now 11

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 and family.

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 just got tons responsible

What was the hardest part of transplant?

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 hours.

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 ‘Frisolo’ 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: 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.

What was the hardest part of transplant?
Being nervous

Before the transplant
I would listen to music

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

What do you like most about having a transplant?

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?

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: 11
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 death sentence. I loved it 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 feel that this is for the better and it will help my doctors help me.

What do you like least 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 for (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, why me? I don’t have a ready answer than you where chosen. You are loved and blessed. Remember that.

Take care of yourself for you and your donor’s organs 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.

Its worth going through pain through recovery but then the better comes.

Age now
Age at transplant
Race/ethnicity
Type of transplant
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 had 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 get 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 to get anything you want). It will go perfectly.

Age
11
Age at transplant
10
Race/ethnicity
White
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

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: Unknown
Type of transplant: Kidney
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 don’t 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 couldn’t 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 Don’t worry God got you.

Age now 13
d
Age at transplant
Race/ethnicity
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 with 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
Age at transplant 18
Race/ethnicity Hispanic
Type of transplant Kidney
What was the easiest part of transplant?  
Getting to drink meds

What was the hardest part of transplant?  
the shots hurt

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 the time

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's Kinky

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

It's okay, you got this

Age now: 8
Age at transplant: 8
Race: Asian
Type of transplant: Kidney transplanted
What was the easiest part of transplant?

resting

What was the hardest part of transplant?

I don't think it's about

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

Getting the funny medicine before breakfast

What do you like most about having a transplant?

The healing process

What do you like least about having a transplant?

Water intake

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

Kidney Bean LUC I like it

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?

Don't be scared coz the scars look DORK

Age now

14

Age at transplant

Race/ethnicity

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
Age at transplant: N/A
Race/ethnicity: Hispanic
Type of transplant: Kidney
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 go alone. It is hard knowing you have an organ that doesn’t work. I was very healthy and active before, so I had those issues.

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

I drink water, and I put on my boots for blood draw. 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 what 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 without 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 remembering 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. 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 what’s best for you, and they want to help you. Once you receive the transplant, you will feel better. Your 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) Scared
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?

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 got 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?

Drink a lot 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: __
Age at transplant: __
Race/ethnicity: __
Type of transplant: __

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

3) nothing.

Who did you talk to when you were scared? Mom.

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

What was the hardest part of transplant? Getting blood from veins.

How do you prepare 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? Feeling 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 is special and you’ll feel better after you have it!

Age now: 10
Age at transplant: 12 year old
Race/ethnicity: Caucasian
Type of transplant: Kidney
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?

Simpler team did amazing at all time.

Who did you talk to when you were scared?
Mom - Dad

What was the easiest part of transplant?

Recovery

What was the hardest part of transplant?

Been apart at my family, how do you get ready for procedures, such as blood draws, biopsies, etc. through me, parents, and medical team

What do you like most about having a transplant?

Been alive

What do you like least about having a transplant?

Medicine

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: 5.5
Age at transplant: 5.5
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 was to think about it as just your kid with something after procedures like it is too ex...

What do you like most about having a transplant?

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

What do you like least about having a transplant?

Most adjustments and side effects of them recovery aside 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 it lived out it was a good kidney

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

Just know pain is temporary and its worth it in the long run and better than drugs is.

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) ____________________________
2) ____________________________
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) ____________________________

Who did you talk to when you were scared?

What was the easiest part of transplant?

What was the hardest part of transplant?

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

What do you like most about having a transplant?

What do you like least about having a transplant?

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?

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

Age now
Age at transplant
Race/ethnicity
Type of transplant
THOUSANDS OF KIDS JUST LIKE YOU HAVE RECEIVED AN ORGAN TRANSPLANT.

ALWAYS REMEMBER YOU ARE NOT ALONE!