

Transplant World

2021 | Issue 1

Journal of the



World Transplant Games Federation
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The facts about vaccination

5K AnyWay wrap-up



Sharing The Love

TX the Teddy Bear providing hope for
kids waiting for a transplant

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Front cover: 'TX the Teddy Bear'
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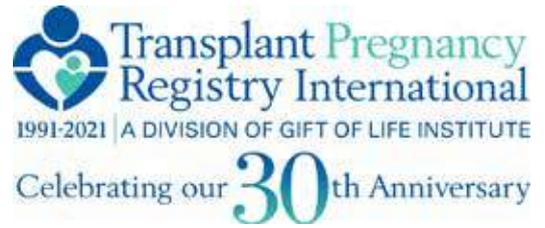
Website: www.wtgf.org

Registered Address: World Transplant Games Federation, Basepoint Business Centre, 1 Winnall Valley Road, Winchester, Hampshire, SO23 0LD, UK

Registered Charity No.1179470

Company limited by guarantee No.10323481

Registered in England



TPRI

Parenthood after transplantation

Lisa A. Coscia on Transplant Pregnancy Registry International (TPRI)

The story of the Transplant Pregnancy Registry International (TPRI) begins with a compassionate doctor and his quest to help transplant recipients who wanted to start a family. When speaking with a patient in 1991, Dr. Vincent Armenti realized there was almost no information available about the possibilities for pregnancy after an organ transplant. He then established the National Transplantation Registry (NTPR) at Thomas Jefferson University in Philadelphia, Pa. to study pregnancy after solid organ transplant.

In 2016, the NTPR became the Transplant Pregnancy Registry International (TPRI) to reflect the need for our Registry to expand to include eligible recipients from around the world. The TPRI was started because no single transplant center would have enough outcomes to adequately study pregnancy after transplantation. The TPRI now has enrolled more than 2,880 transplant recipients with 4,900 pregnancies (includes multiple births) enrolled. The TPRI has now reached recipients in more than 27 countries.

“It is important to know that following a successful transplant, pregnancy is possible.”

The TPRI includes all types of transplant recipients including men who have fathered pregnancies and women who have had pregnancies. We collect all different types of pregnancy outcomes including live births, miscarriages, terminations, ectopic and stillbirths. Each recipient has a unique story that enriches our research, which in turn will also help other transplant recipients in the future.

In addition to gathering data, every year the TPRI fields hundreds of questions from transplant recipients and healthcare providers worldwide who are seeking answers to post-transplant parenthood questions. Each request is personally answered by our team. With help from their own healthcare team and with information provided by the TPRI, recipients can make the best decision about parenthood for them. Our database has pregnancy information that we have collected over decades. This helps us to provide vital data to those considering parenthood after a transplant. We continue to study pregnancies in all transplant recipients, now including uterus transplant recipients.

Voluntary pregnancy registry

The TPRI is a unique voluntary pregnancy registry. It not only seeks to include new post-transplant pregnancies, but also continues ongoing follow up with our recipients over the long term. Key questions that we have asked are – How might pregnancy affect the mother, her transplanted organ, and her baby? Our goal is to call recipients every 2 two years for this follow-up, to see how the recipient, their child(ren) and their transplant are doing over time.

Based on TPRI studies we have observed that it is especially important to have a planned pregnancy, as there may need to be changes in some medications prior to conception and for establishing stable transplant function. It is important to know that following a successful transplant, pregnancy is possible. Based on TPRI research and other studies, there are general

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TPRI

recommendations for women who have had a transplant to follow prior to planning a pregnancy. These general recommendations include:

- good general health for at least 1 year post transplant, to allow for sufficient time for transplant function to stabilize
- immunosuppression at maintenance levels
- low risk of infectious complications
- no rejection in the last year prior to pregnancy
- no high blood pressure or high blood pressure that is well-controlled
- no or minimal protein in urine

The babies born to women after transplant are generally born about 4 weeks early and weigh approximately 5 1/2 pounds. Mothers are at greater risk for high blood pressure and preeclampsia during pregnancy. During pregnancy there is not a great risk of transplant problems when pregnancy is started with a well-functioning organ. However, each organ recipient (kidney, liver, heart, lung, etc.) faces different challenges and to reiterate careful planning is encouraged and needed. Regarding fathered pregnancies based on TPRI studies, the overall outcomes appear to have outcomes similar to the general population.

The TPRI staff and collaborators have participated in more than 500 professional presentations around the world. Additionally, we are pleased to say that we have written more than 200 professional publications based on our study data. Each year, the TPRI also publishes an annual report that

How to participate:

Participation is easy and you can do it from anywhere in the world! Anyone who has had a transplant and then had a pregnancy or fathered a pregnancy can enroll. There is a 2-step process: first complete a short questionnaire to tell us about you and your transplant. Then we will call you if you are in North America or if you are elsewhere, we send another survey for you to complete. We also follow-up with recipients every 1 -2 years! We want to see how you, your child, and your transplant are doing long-term. We look forward to hearing from you!

The link to register can be found here:

www.transplantpregnancyregistry.org/participation

Our website link:

www.transplantpregnancyregistry.org

provides an overview of our pregnancy data, as well as the latest information from the studies we have conducted over the previous year. This report and our professional publications are available by request by emailing the TPRI team.

The TPRI currently stands as the longest-running voluntary pregnancy registry of its type in the world. Some of our early participants have now even become grandparents! We encourage all recipients to participate (see the box on how to participate). It is easy and it will help other transplant recipients in the future!

Lisa A. Coscia, RN, BSN, CCTC

Transplant Pregnancy Registry International



The TPRI Team

TPRI

Meet Erin

I'm so grateful for the Transplant Pregnancy Registry International (TPRI). I don't think we would have our precious son if I had not found out about the organization.

To start my story, I was diagnosed with kidney disease when I was in junior high school. I had lived so long with kidney disease, that I never thought I would need a transplant. But after almost 20 years, the slow steady damage from the disease caught up with me and I was shocked to hear the doctor say that I needed a transplant. At the time, I was just engaged, planning my wedding and my future, so I felt like I had been hit by a freight train.

I was beyond blessed that my amazing husband Ken was an excellent match. We always knew we were meant to be together, but him giving me his kidney and saving my life was a miracle. I received his kidney in 2014, a couple months before my 33rd birthday.

The recovery was tough, but I was soon in the best health of my entire life. We wanted to have a baby someday but were very concerned with putting my body through a pregnancy especially while taking immunosuppressants. We decided to speak to my doctors and look into if it was realistic to have a baby of our own. My doctors are wonderful, and they all said it was possible, they have had pregnant transplant recipients, and that they were there to help us through. But I needed to know more about the risks that could be associated with pregnancy after transplant, and I wasn't getting many confident answers.

I had always thought pregnancy after transplant would be too dangerous. I thought it would be highly likely that my child could have health problems from the medications I was taking. I needed to know what the probability of having a child with a birth defect was? I'd heard pregnancy is hard on your kidneys, would I lose my new kidney? Or worse, what was the chance my baby or I wouldn't make it at all?

I tried to find answers, but it wasn't until I found the TPRI that I finally had real answers to my questions. They sent me the most recent study and charts with information.

I had additional questions about some of the data, so I decided to call them. I was surprised at how easily I was able to speak with someone from the TPRI. One of the nurse coordinators, Lisa, answered all my questions. I remember tearing up on the phone because I was so relieved to finally have the information that I needed to make an informed decision. Additionally, I found out that the percentages of risks were much smaller than I had ever imagined. TPRI had so much valuable information and Lisa even gave me some post-transplant emotional support that I desperately needed.

After speaking with Lisa about



Erin and family

the TPRI data, we had the confidence to faithfully pursue having a baby.

My husband and I experienced several years of unexplained infertility, in part due to me running a high stress business. We wanted to get pregnant without IVF because of the expense and from wanting to have the extra assurance that my body was ready on its own. But months of trying turned into years and years of waiting. Ken turned 41 and I was almost 39, and we were very close to giving up our hopes of getting pregnant. But as soon as we made the decision to close my business and focus on me living a more peaceful life, I finally got pregnant!

Being pregnant and delivering during the Covid 19 pandemic had enough uncertainties, and since I was of advanced maternal age, it was wonderful being able to see the TPRI stats broken out by maternal age to give me confidence that even at almost 40, we still had a wonderful likelihood to have a healthy baby. We had our son in October 2020, and he is our healthy and happy little miracle.

The day I was able to contact Lisa again and add my own pregnancy experience to the TPRI database was a very special day. I was so happy to know that my information might help another recipient who has questions about parenthood after transplant. I encourage anyone who has had a pregnancy to contact the TPRI.



Erin and baby

TPRI

Meet Lisbeth

My name is Lisbeth, I am 35 years old, and I live in Denmark. My husband, Tobias, and I have two children; Eva who is 3 years old and Alfred, that was born a month ago. Both were born after my kidney transplant which is why it was never a matter of course that we would be able to have our own, biological children.

Here is more of my story, in 1999, when I was 14 years old, I was diagnosed with an autoimmune kidney disease. I was able to have a normal childhood until the day came, when the love of my life and high school boyfriend Tobias and I wished to start a family.

At that time in 2013 my kidney function, even though stable, had decreased to a point where my nephrologist strongly advised against pregnancy. Furthermore, we found out that my fertility was very poor (which is common in women suffering from kidney disease). We were told that it was very unlikely if not impossible - even if my kidney function improved - that I would ever get pregnant. This was a great, great sorrow for us.

However, six years ago, in 2015, my kidneys failed due to an infection and I had to start dialysis. This period of my life is a blur. I knew all along that I would probably need a kidney transplant one day, but still it came as a shock when the time actually came to have a transplant. It suddenly dawned on me that I was critically ill. I was fortunate to have Tobias by my side during this entire time, but I couldn't help but feel that I had put his life on standby as well. The uncertainty about his, mine and our common future numbed me.

On May 27th, 2016, I received my dad's left kidney and with that a whole new life. Even though I had some issues with regulating the immunosuppressive medications, frequent infections, and hospital admissions in the first month's post-transplant, I soon felt energy that I hadn't felt for years rushing through me.

In 2017 Tobias and I celebrated my new life by getting married. And then the honeymoon came. I consulted with my doctors and with that, out of the blue (well, not entirely out of the blue...!) and against all odds I got pregnant. I delivered a healthy baby girl!

Well, here we are three years later. I was able to get pregnant a second time! This time I had a baby boy. Both pregnancies resulted in healthy, beautiful children. We have become what we always dreamed to be: nothing more than an average Danish family.

“ Out of the blue (well, not entirely out of the blue...!) and against all odds I got pregnant.”



Lisbeth and family



Eva and Alfred