

The SRTTR needs your feedback. User feedback about a patient tool to compare transplant sites for candidates will be an important part of an upcoming research study. And this information will be used to make updates and improvements in the future. Users can visit the site at **transplantcentersearch.org** . Users can provide feedback using the online form at **transplantcentersearch.org/feedback**



www.TransplantAZ.org
Transplant Community Alliance
PO Box 36122
Phoenix, AZ 85067

To:



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Transplant Support & Awareness

Transplant Community Alliance aspires to create a place where anyone in the transplant community can receive assistance. We bridge relationships with transplant organizations and offers support through programs to enhance and protect the quality of life for transplant recipients, caregivers and their families.

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Questions or comments? Call 602-277-2661 or email info@TransplantAZ.org!



Transplant for LIVING

March 2021

Volume 26. No. 3

A life well lived with lung and kidney transplant

By Melissa McQueen.

Jim Cooper was diagnosed in 1991. And so he happened to get some x rays, and his doctor wrote me a prescription for lung rehab. His father had passed from a lung condition, so Jim was doubtful for lung rehab on himself. His doctor prescribed him quite a few medications and told him to keep fit and get as strong as he could. That left him sometimes on oxygen, but he was always able to work himself off of it.



And then in 1996, Jim spent seven holidays in the hospital. During one of these that was an awful episode, the doctor came in. And he said, "The hospital in St. Louis is doing lung reductions. And the director of the medical department has a lot to do with the lungs. You want to give that a try?" It sounded like an excellent chance to Jim, so he had his records sent to St. Louis. After a month or two, they wrote him a letter, and they said, "Mr. Cooper, the disease is so bad there's nothing we can give you to make you better. However, you may be a good candidate for a lung transplant."

They gave him a number to call. He called them back and then took three or four days to evaluate if he was a good candidate. The doctors indeed found he was and put him on the list. They told him that the wait was close to two years. So they sent him home in the fall and in March, they called him back. He flew back, and they still considered him an excellent candidate. But this time, they told him that he needed to stay within two hours to be close when he got the call. He took this as great news because he meant he was further up on the list. So his family went home and loaded up the car. During this time, he had to go to the hospital at the same time each day for an hour and had a walk on the treadmill for 30 minutes. The team didn't care how fast he walked, just that he could walk at all without collapsing. Jim was contacted by his insurance company and was assigned a representative. She called him every couple weeks and made sure he had everything he needed.



From March till August the sixth, he waited, then he got the call. He didn't have his pager on him like he was supposed to, so they had to call and have someone tell him.

That was probably about seven, eight minutes of silence until he went back over there to the hospital. He didn't go into the operating right away. The prep took quite a while, and he could phone all of his kids to come and be with him. They all are actually from all over. One came from Oregon, and another came from Phoenix. Miraculously they all made it in time. The hospital where the procedure was performed is called Barnes Jewish hospital. Dr.

Cooper, who was no relation to Jim, did the first successful lung transplant in Toronto, Canada. And now he was in St. Louis, which is how Jim ended up in St. Louis. Jim says the experience overall was great. He stayed for three months in the area and went to the clinic to ensure everything was okay. It's been 22 years since the initial transplant.

Transplant doctors told him the average time expectancy after transplant was five years. Jim made sure to be pretty careful. They told him he shouldn't fly.

Jim remembers how it felt immediately after surgery and got his respirator out. He had to pull the covers up over his nose and his mouth to restrict breathing. It was too easy to take air in, and it felt odd for awhile!

Before the transplant, he attended support group meetings with other potential recipients. He was in his 50s at the time and found many members younger due to cystic fibrosis, the leading cause of lung problems in transplant. The steroids he took as part of his post transplant regime made him a person with diabetes, which he now treats independently.

For the first eight years 2007, he felt good. In fact, he was volunteering for the fire department for many years. He was able to hike the Grand Canyon both down and back up to the valley.

He used to be in crisis response in the fire department, but these days he is happy to work with the lock boxes. That’s when he also started volunteering for Donate Life Arizona, and he did a lot of speaking engagements. He spoke to the community: all the Lions Clubs, church men’s breakfasts, and anybody that wanted him to speak. He got a lot of people signed up as donors. They just wanted him to tell them his story.

One of his most proud experiences involved a call down to the Indian Reservation with a health fair reservation where he hosted a table. At the time, he was told by a resident that Native Americans don’t believe in organ donation. When he asked, “Wouldn’t you want somebody who could save your life? Or your child’s life?” The resident relented and signed up on the spot, understanding the need for organ donors to sign up.

One warning Jim has for other recipients is to check your skin often for cancer, especially living in Arizona. He found skin cancer to be a problem with regular spots. He goes in frequently to make sure he is taken care of for transplant-related healthcare. Dermatologists would take out stitches and cut another suspicious area. He admits to not being very happy about that, but he still gets around to everything else he has always wanted to do. He considers himself fortunate, “I’m very well blessed. They say it all happened when I had an immune system” Now, at 82, he understands that eventually, skin problems were bound to show up as a result of being in the sun combined with immune suppression. In fact, February is Jim’s birthday month.



When I asked what advice Jim has for others at the beginning of their journey, he says, “Take some work, make yourself strong and healthy. Once you start doing that, you get in the habit of it.”

He especially remembers those support meetings in St. Louis. He remembers those fellows that wanted to drop out of the transplant program because they felt so much better. He convinced others to stay even though they were afraid. He knew everything was going to be okay. Every day he gets to stay here is surplus. He always remembers his faith when he feels anxiety. He knows his strength comes from the Lord. Many patients go through what’s called dry runs. Dry run means that physicians inspect, and when they find out the lungs aren’t good enough, they decide not to transplant. One night he was listening to the radio on the religious station, and he turned it off and knew he had to pray then. Moments later, in his window, there’s an angel. His oldest daughter was with him, and he asked her to come over to see if she could see the angel too. She said she saw it too. Even though he knows that it was a plastic bag shining just so in the light, he took it as a miraculous sign.

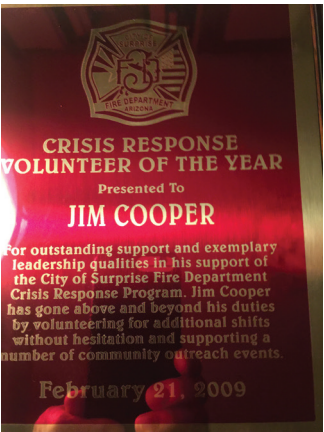
Jim believes in God, his family, and a robust support system. His 83 years of life are a testimonial of this fantastic combination.

Your stories help inspire people to sign up as donors!

Simply sharing your story of being a recipient can help save lives and change the world. By telling others your journey to and after your gift of life, you can inspire others by spreading the word and inspiring others to sign up on the donor registry. Donate Life has statistics of more people signing up in April after Donate Life Month, than any other month. Not only that, but we are time pressed to gather your stories, which are often the very first stories of transplant as a historical record.

Share your story once it’s published on social media. And be a proud volunteer in your community.

If you are interested in sharing more, call Zoe at 602-277-2661 or info@TransplantAZ.org



Want to give back? Some ideas are:

- Sign up organ donors at DonateLifeAZ.org/TCA
- Get a DonateLife license plate for your car at ServiceArizona.com
- Select “Transplant Community Alliance” as your charity on Smile.Amazon.com. It is free for you!
- Go to Frys.com and Community Rewards under My Account. Donate your shopping rewards to “The New Life Society (CD 498)”. This is free for you as well!
- Shop and search the Internet on iGive.com and they send us checks. Try it out!

Join as a Member!

\$25 per year
bit.ly/TCA_Member

or scan the QR Code below & click "Membership"

Member benefits include a monthly newsletter, email updates on important transplant news, invitations to events (virtually) and more!

Simply put, you sustain our work. Solidify your support and ongoing commitment to the mission by becoming a member today.

A DONATION WAS MADE TO
TRANSPLANT COMMUNITY ALLIANCE

In Memory

FRANK GUINTA,
LUNGS, PASSED IN
DECEMBER,
SPENCER HAYES,
KIDNEY, PASSED IN
JUNE 2020

"One who blooms in our heart can never be forgotten."
- Unknown -

RIP Anxiety

We began a new collaboration with local therapist David Phalen of Transcend Personal Development. David has developed an online course about reducing anxiety and has tailored it specifically for the transplant community. This is an additional resource we can offer to our members that is research-based, systematic, and easy to use. If you are interested in learning more, call 602-277-2661 or info@TransplantAZ.org

Welcome, Suzanne Reed to the Transplant Community Alliance Board of Directors!

2ND ANNUAL

Good Deeds for Daisy

It is with great loss when we lose the youngest among us. Recently Transplant Team AZ member and 5 year old Daisy made her way to making heaven a little brighter. Her parents are asking that you

1. Perform a random act of kindness in her honor and take a picture and share
2. Share any pictures or videos that you may have of Daisy at the games or another event and share with her family.

#GoodDeedsForDaisy
Please mail pictures to 1300 N 12th Street #622, 85006 or email to info@TransplantAZ.org

Virtual Support Group!

Support Groups are beneficial to anyone who has been through a difficult time in their life.

Virtual Support Group now available every Thursday 7pm!
New guest speakers and topics each week.

This is a safe and supportive place for you to connect with other recipients and caregivers.

RSVP and Contact:
Zoe Severyn

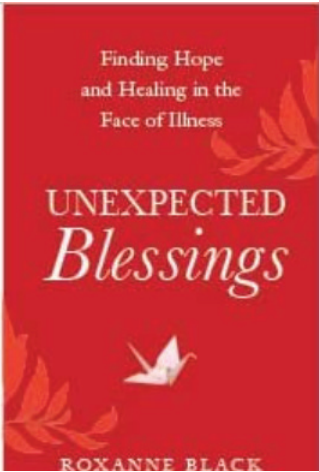
For more information:
info@transplantaz.org
602-277-2661 or TransplantAZ.org/supportgroup

To learn how the Alliance can help you:

602-277-2661

info@TransplantAZ.org
www.TransplantAZ.org

Follow us:



March Story Corner

Unexpected Blessings: Finding Hope and Healing in the Face of Illness (2008)

Author: Roxanne Black
Review adapted from TRIO founder Jim Gleason
<https://www.trioweb.org/resources/book-reviews.htm>

Unexpected Blessings is an extension of Roxanne’s mission to bring a community together. It brings to life not only her inspiring personal story, but also the lessons of courage she s learned from all the people she s met over the years and with her two kidney transplants. From a poignant encounter with Christopher Reeve to her intimate experiences with patients standing strong in the face of extraordinary challenges, these are stories of heroism and hope. They are also reminders of the healing that happens when we can connect together from the heart. Unexpected Blessings offers support and encouragement for anyone touched by illness, or anyone facing a difficult time in his or her life. It is a powerful testimony to the strength of the human spirit.

Note: Unexpected Blessings is available in as audiobook and Kindle version on Amazon.com found at https://read.amazon.com/kp/embed?asin=B00LV9P4C8&preview=newtab&linkCode=kpe&ref_=cm_sw_r_kb_dp_RJQP12NM3K0JJAT5FYNR

Just ask Judy!
Are you struggling with a complex insurance issue?
We offer free insurance counseling!
Go to <https://newlifesociety.org/blog> for the latest



Sign up. Save Lives!
To register to be an organ, eye and
tissue donor, go to [DonateLifeAZ.org/](https://www.donatelifeaz.org/)
TCA

Supporting Your Health and Wellbeing Before, During, and After Transplant

Adapted excerpts from Dialysis Patient Citizen’s Education Center, <https://www.dpcedcenter.org/news-events/news/supporting-your-health-and-wellbeing-before-during-and-after-kidney-transplant/>. Updated 12/24/2020

Life After a Transplant

Take time to care for your mental health. Although mental health can improve after transplant, you can still be at risk for anxiety and depression. About one in four people with a kidney transplant meet criteria for depression. Coping with illness and going through a transplant can be very stressful and sometimes people experience symptoms of post-traumatic stress or PTSD. It is important to care for your mental health because it affects your physical health as well. Feeling depressed and down is related to additional health problems, such as forgetting to take medications or loss of the transplant (graft failure). It may also be helpful to talk to your provider and ask for help from others if you notice problems with your thinking or memory. Chronic kidney disease is related to some cognitive problems over time, but these can improve after surgery.8 However, some problems with learning and memory may remain. It is important to connect with your social supports and medical team if you feel memory problems may be affecting your adherence to medications.

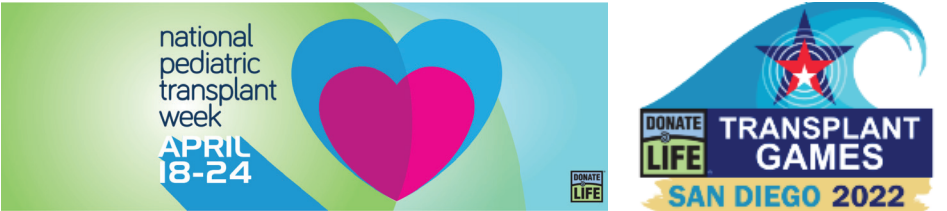
Additionally, some people experience a range of emotions towards their deceased or living donors. Recipients may feel extreme gratitude, but also guilt, especially if their donor was a deceased donor. It is important to discuss these thoughts and feelings with your social supports and your psychosocial team (social workers, psychologists) at your center. Organ procurement organizations (OPOs) can help direct a thank you note to the deceased donor family, if you feel that this would be helpful or important for you. However, there is no expectation that you must be in contact with your deceased donor family, and everyone has their own individual response to the process and journey of being a recipient or a donor.



It is a marathon, not a sprint! Here are some factors for long-term success:

- Meet with your healthcare team regularly. Ask questions and communicate your needs and concerns.
- Build strong social supports and ask for help when you need it. Meet with a therapist or mental health provider to support your emotional wellbeing.
- Eat a heart-healthy diet. Strive for a low fat, low salt diet and drink plenty of fluids. Depending on your medications or if you have diabetes or other health conditions, you may still have some dietary restrictions.
- Exercise regularly and maintain a healthy weight. Ensure adequate sleep. Continue relaxation, meditation, and mindfulness practices. Even one minute of deep breathing can be so helpful during a stressful moment!

U P C O M I N G



Ingredients
½ (55g) red onion, thinly sliced
½ cup apple cider vinegar or red wine vinegar
¼ cup olive oil
1 ½ teaspoons ancho chile powder
1 ½ teaspoons oregano, dried
½ teaspoon cumin, ground
¼ cup cilantro leaves, chopped, plus more for garnish
1 (14g) jalapeño, seeded and chopped
½ pound flaky white fish (such as mahi-mahi, cod, halibut)
8 fresh corn tortillas, 6-inch diameter
2 limes, quartered
Pinch of salt, to taste (optional)
Hot sauce, to taste (optional)

F i s h T a c o s

Fish tacos are a healthier alternative to regular tacos. Marinating the fish will ensure that the fish will be full of flavor. Garnished with red onion, cilantro and lime, this is a dish that will please your senses.

Instructions

1. Add sliced onion to a small bowl and cover the slices with vinegar.
2. Set aside for 30 minutes.
3. Pour olive oil into a separate small bowl. Add the ancho chile powder, oregano, cumin, chopped cilantro, and jalapeño to create a marinade. Mix well.
4. Place the fish in a shallow dish and pour marinade over the fish. Coat the fish on both sides and leave to marinate for 20 minutes.
5. After marination, heat a small skillet over medium-high heat.
6. Remove the fish from the marinade and place in the hot skillet. Season the fish with salt, if desired.
7. Cook the fish for 4 minutes undisturbed. Turn it over and cook for another 2 minutes.
8. Remove the pan from the heat and flake the fish in the pan with a fork. Mix in any marinade that has stuck to the bottom of the pan.
9. Place four tortillas on a plate and sandwich them between two slightly dampened sheets of paper towel.
10. Microwave on high for 45 seconds or place them on a baking sheet and heat them in an oven at 325°F for 4 minutes.
11. Place warm tortillas in a towel-lined basket or plate and cover. Repeat with the remaining tortillas.
12. To serve, divide flaked fish into 4 equal portions.
13. For one serving, place ½ of each fish portion onto the center of 2 warmed tortillas. Top with marinated onions. Serve with hot sauce, if desired, and lime wedges. Enjoy!

Nutrition Info		What Does This Mean For Me?	
Makes: 4 servings Serving size: 2 tacos			
Calories	307	Fat	16 g
		Saturated Fat	2 g
		Trans Fat	0 g
Carbohydrates	26 g	Protein	16 g
Sugar	2 g		
Fiber	4 g		
Calcium	68 mg	Phosphorus	245 mg
		Potassium	338 mg

The new Mentor Program matched 37 transplant recipients or caregivers with trained, experienced Mentors in 2020. The Mentors provide hope, inspiration and a safe space to for mentees to share their concerns and fears about transplant.

Donate to the Fund at www.aplos.com/aws/give/TransplantAZ/donate

We believe transplant recipients and caregivers need support groups as a way to navigate through stressful self-quarantine. We host weekly online meeting to bring together fellow recipients and people on the waitlist.

Learn more at www.TransplantAZ.org



Transplant Games of American: Honor the Journey Coast to Coast

Future registrations will be offered at a reduced rate and individuals already registered will receive a partial credit toward the 2022 Transplant Games in San Diego. Every individual registered will receive a commemorative gold medal in celebration of this unique one-of-a-kind event and be shipped a SWAG box that will include a souvenir credential, a modified program, official 2020 commemorative t-shirt, TGA pin, and more.

www.TransplantGamesofAmerica.org



Transplant for LIVING

March 2021

Virtual Support Edition

Meetings are now online or by conference call. To get zoom info, call 602-277-2661 or email info@transplantaz.org

Virtual Events

Anytime

MayoConnect is a peer-run forum where transplant recipients can post Q & A to help each other. <https://connect.mayoclinic.org/group/transplants/> Call your transplant social worker to set a 1:1

Monday

March 8 6PM Transplant Team AZ meeting via Zoom

March 15 10am Banner Tucson Heart & Lung Transplant Support Group Ande Burkholder (520)694-5168

Wednesdays

1pm Mayo patients Heart-Lung Support Group online. Contact Tiffany 480-342-2161 for info.

5 pm - Every Wednesday - Phoenix Children's Hospital caregivers and parents support group online run by Transplant Families. Contact Melissa McQueen 623-217-5875 or melissa@transplantfamilies.org for info. **March 31** - Telling your families transplant story provided by Donor Network of Arizona

March 10 6 pm - TCA Board Meeting

Thursdays

10:00 am 1st and 3rd Thursday - POSTPONED: The Unity For Life Coffee and Gab group meets every 1st and 3rd Thursday of the month at 10am at Panera Bread on Grant Road at Swan.

10:30 am - Lung Support Group at Dignity-Online for lung transplant patients and caregivers. Contact social workers Kathy Lam (602) 406-7009 or Mandy Cornelius (602) 406-8374 for information.

12 pm Mayo Liver Support Group online. Contact Jenna 480-342-1010

7 pm Transplant Community Alliance Support Group Meeting

Friday

March 19 11 am - Banner Phoenix Lung Transplant Support Group Ande Burkholder (520)694-5168

March 19 6 pm - DNAZ Volunteer meeting

Saturday

March 27 6:30 am - Transplant Team Arizona Pro Auto Fundraiser

Sunday

March 14 2pm- Kidney Warriors Support Group: Kidney Disease, contact Sachi Kuwahara for more information <https://www.facebook.com/skuwahara1>



Transplant for LIVING

March 2021

Other Events

March - Kidney Month, Social Work Month

3/12 World Kidney Day

3/30 Doctor's Day

3/27 & 3/28: ProAuto Fundraiser in Litchfield. Shifts 3 hours each from 6:30 am through 4 pm. <https://www.trackitforward.com/site/371660/event/512625>

April - Donate Life Month

4/16 National Donate Life Blue & Green Day

4/18 - 4/24 National Pediatric Transplant Week

5/28/2021 5KAnyWay for World Transplant Games <https://runsignup.com/Race/Info/TX/AnyWay/5kAnyWay>

6/28 American Transplant Congress Meeting

**7/16/2021 2021 Transplant Games of America, NJ - Now Virtual
Registration now open: www.transplantgamesofamerica.org**

12/4/2021 2nd Annual DonorDash at Arizona Boardwalk. www.TransplantAZ.org/DonorDash

Welcome New and Re-newing TCA Members

Lela Alston

Alcurtis Robinson

Deborah Taylor