



The SRTR 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



The OPTN seeks nominations through September 30, 2021, for people to apply for consideration for open positions on the board and committees for terms beginning July 1, 2022.

Register today: <https://unos.org/news/2022-2023-nominations-optn-board-of-directors-committees/>



Join Power2Save to get the latest updates from the American Society of Transplantation including legislative efforts, bills that are transplant related, and sharing your story. <https://power2save.org/>



To:



DONATE LIFE LICENSE PLATE

Get one for your vehicle today at www.ServiceArizona.com! Only \$25!

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.

2021 - 2022 Board of Directors:

- | | |
|---|----------------------------|
| Gregory Welsh-Board President | Judy Maltz, Vice President |
| Andrew Bombeck- Board Secretary | Ben Wilson, Treasurer |
| Kathryn Crippen, Suzanne Reed, Robert Scanlan, Dan Baran, members | |
| Staff: | Newsletter: |
| Zoe Severyn, Executive Director | Melissa McQueen |
| Catherine Hawxby, Mentor Program Director | |

Opinions expressed in this publication do not necessarily represent the views of Transplant Community Alliance. The Alliance does not endorse any medications, products or treatments described in any of the articles herein.

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



Percerverance bring new purpose and empowerment to both recipient and community

Written by Melissa McQueen



Growing up in Saudi Arabia as the only child of two very amazing parents, Omar Hashem was taught the value of hard work early on. As chronicled in a highlight by his alma mater ASU, he worked for three summers as a teen to purchase photography equipment to pursue his hobby. He also played soccer many hours a day with his friends. Often with many friends that ended up going on to be professional and Olympic players. It was while Omar was playing soccer that he would meet his biggest challenge yet.

When Omar was a teen, he passed out on the field when playing soccer in a different city and was immediately brought to the hospital. This wasn't the first time he was brought to the emergency room for breathing problems, but it was the first time it was taken seriously. While in the ICU, he was given a name for his condition, Pulmonary Veno Occlusive Disease, which is a kind of Pulmonary Hypertension. PVOD is characterized by the blockage of the blood vessels that carry oxygen-rich blood from the lungs to the heart. The medical team told him he would need a lung transplant, but because the program was just beginning where he was, he was advised to go to a more established center.

Omar came to North Carolina to be listed for a lung transplant. He was given a second chance at life on August 16th, 2016. But with so many other areas in life, Omar would be challenged with this as well. His team began to see rejection immediately. Once they got it under control, they would see it again and again. He began to live with chronic rejection and would have to postpone returning to Saudi Arabia, his home.



Because he knew he would be in the states longer, he applied to Arizona State University. He wanted to pursue his dream of filmmaking while also being seen at St. Joseph's for transplant care. He went back home to Saudi Arabia to get his visa changed and his paperwork in order for this big move. While there, he was in a dangerous car accident where his car flipped three times. He was nearly paralyzed. But he took his plight as a sign that he was saved for a reason. He began school at ASU two weeks later.



Once at school, he found that he had a lump on his tongue and went to get it checked out. After going to several specialists, they discovered that the lump was a tumor after being biopsied. The tumor was found to be lymphoma. So on top of being a student and a transplant patient, Omar began chemotherapy. Thankfully, the chemo worked quickly and effectively, and his lymphoma would go into remission.



Now it was the summer of 2019, and Omar traveled back to Saudi Arabia for the summer to be with family. He was filming a short film when he felt an intense temperature coming on, and it felt as if his lungs were on fire. When visiting the emergency room, the doctor's first question after an x-ray was if he was a smoker; Omar assured him he was not and lived a very clean lifestyle. Despite this, his lungs were very cloudy. It was clear that his original transplanted lungs were beginning to fail. He would have to start planning for the path of another transplant.

In early 2020, his lung function was so poor that he couldn't walk anymore. He was taken directly from school to the ICU. For two months, he deteriorated until he was gifted another chance at life. He received his new lungs and went into early transplant recipient protocol of masking, sanitizing, and isolating, at the same time as the rest of the world was being introduced to the same practices for different reasons. Omar was protecting his new lungs. The world was preparing for Covid-19.

Now at 24, Omar has completed his dream of getting a Bachelor's degree in Film and Media Production from ASU. He is continuing with his Master's in Creative

Enterprise and Cultural Leadership. He looks forward to telling the many important stories of those that could illicit positive change in their communities. He saw firsthand the impact of his own story in his native country after making a short film promoting organ donation. It received over 2 million views from Saudi's and got the attention of the crown prince. The royal family is now very favorable to organ donation as a life-saving medical treatment.

Omar credits much of his success to the support of his parents and his Muslim faith. His mother is always there for support. His father is working from halfway across the world to keep providing money for Omar's future. Despite walking through many challenging times, most of us would ask why me? He knew his story would mean that much more with such incredible perseverance powered by peace and faith.

These days Omar dreams a new dream of a possible Golden Globe or Oscar to his credit. We know with the exceptional gift that Omar has to tell other's stories as well as his own; this is entirely possible. Let this audience tell you; we will be the first in line to support you.



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
JAMES TUCKER

Donations made by Kevin Maassen, Sylvia Sundholm, Timothy Davern, Robert Scanlan Ed & Linda Ozier, Sharon Thomas

"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

Executive Director Update
 From Zoe Severyn

The 2021-22 Board of Directions met in June for a Strategic Planning meeting, facilitated by Sara Pace-Jones, VP of Donations Services of Donor Network of Arizona. After much discussion, the board unanimously decided that the three areas of focus for the year would be to increase revenue, develop a referral system to reach transplant patients and families and to build alliances in the transplant community. We are so excited to be able to explore and improve each of these important facets of our organization so that we can improve our positive impact on organ donation and transplantation. If you are interested in learning more, or would like to volunteer, please call or email us. We are always happy to hear from you!

TRANSPLANT COMMUNITY ALLIANCE DONOR DASH

1K RUN 5K DASH 1K WALK

2ND ANNUAL

SATURDAY, DECEMBER 4, 2021
 7:00 AM REGISTRATION 8:00 AM START

www.TransplantAZ.org

KIWANIS PARK, NORTH SIDE
101 W. BASELINE ROAD
TEMPE, AZ 85282

YOUR BEST STARTS HERE

Thank You DONOR! NEW LUNGS



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

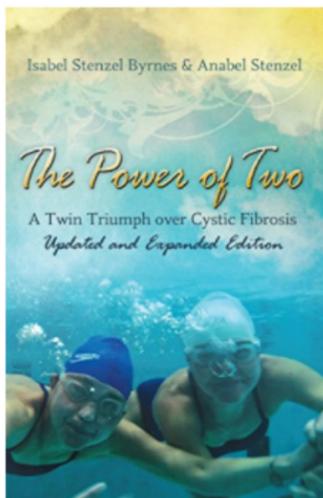
For more information:
info@transplantaz.org
 602-277-2661 or
TransplantAZ.org/supportgroup

To learn how the Alliance can help you:
 602-277-2661
info@TransplantAZ.org
www.TransplantAZ.org

Follow us:



** Additional Source: <https://news.asu.edu/20210419-shining-example-how-survive>



August Story Corner

The Power of Two: A Twin Triumph over Cystic Fibrosis (2014)

Author: Isabel Stenzel Byrnes

The tragedy of CF has been touchingly recounted in such books as Frank Deford's Alex: The Life of a Child, but The Power of Two is the first book to portray the symbiotic relationship of twins who share this life-threatening disease through adulthood. Isabel and Anabel tell of their lifelong struggle to pursue normal lives with cystic fibrosis while grappling with the realization that they will die young. Their story reflects the physical and emotional challenges of a particularly aggressive form of CF and is an honest and gripping portrayal of the daily struggle associated with long-term hospitalization, the impact of chronic illness on marriage and family, and the importance of a support network to continuing survival.

Born in 1972, seventeen years before scientists discovered the genetic mutation that causes CF, the Stenzel twins endured the daily regimen of chest percussion, frequent doctor visits, and lengthy hospitalizations.

But in the face of innumerable setbacks, their deep-seated dependence on each other allowed them to

survive long enough to reap the benefits of the miraculous lung transplants that marked a turning point in their lives: "We have an old life—one of growing up with chronic illness—and a new life—one of opportunities and gifts we have never imagined before."

Note: Available on Amazon through Kindle or softcover https://www.amazon.com/dp/B00O16Q1FM/ref=cm_sw_em_r_mt_dp_T4A7E4PBC8TX1RKVH77H

Just ask Judy!

Are you struggling with a complex insurance issue? We offer free insurance counseling! Go to www.TransplantAZ.org for the latest stories about how Judy saves the day.



Sign up. Save Lives!
To register to be an organ, eye and tissue donor, go to DonateLifeAZ.org/TCA

I have been hearing a lot about equity in transplant. What does that really mean?

Adapted from OPTN/UNOS

What is equity?

Equity in social terms is defined as being equal and fair; and addressing that people may need differing treatment to make their opportunities the same as another's.

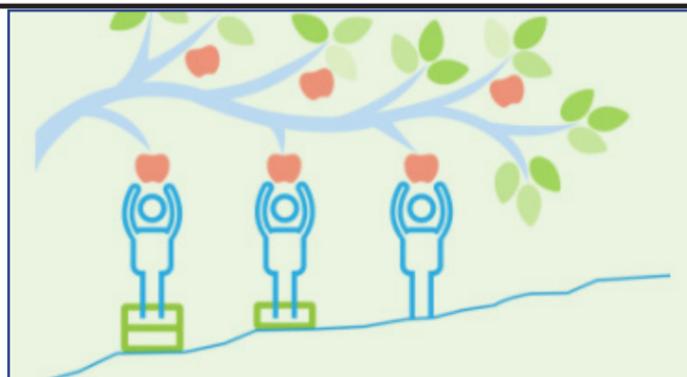
What is equity in transplant?

Our current transplant waiting list is based on an algorithm set by policy developed by administrators, transplant clinicians, and recipient/donor patients and families.

Math can't be biased, right? What was found by researchers developing the equity dashboard with UNOS is that the algorithm was skewed to prefer groups. The most pronounced of these groups were African Americans with regards to kidney transplant. These algorithm changes were a result of well intentioned policy that had unintended consequences. To read more about specific case examples of this please read: <https://unos.org/voice/the-road-to-racial-equity-in-kidney-transplantation/>

Why is it important?

All patients should have equal access and opportunity to the gift of life despite race, orientation, or age.



Where is this equity dashboard I have been hearing about?

UNOS researchers have developed a data dashboard that provides transparency about how the Organ Purchase and Transplantation Network monitors equity in access to transplants. Through an Access to Transplant Score (ATS) the Equity in Access Transplant dashboard allows users to explore how different factors in how long waitlist candidates have to wait to receive a transplant. <https://insights.unos.org/equity-in-access/>

What is being done about inequity?

Join UNOS Aug. 26 for a meaningful exploration of equity in access to transplant. Our three expert panelists will discuss the social and racial factors that can cause disparity in organ transplantation and what the organ donation and transplant community is currently doing to combat inequity.

<https://app.mobilecause.com/e/EQs1RQ?vid=kewuz>

Coming Soon!

BE A SYMBOL OF HOPE FOR THOSE WHO ARE WAITING.
NATIONAL DONOR SABBATH • NOVEMBER 13-15, 2020



DonateLife.net

WE'RE HIRING PROGRAM MANAGER



Looking for a dependable, self-starter who is passionate about helping people who have received a life-saving transplant. APPLY NOW

Apply: www.TransplantAZ.org/Staff

Charity Bowl

Benefiting Transplant Team AZ

Bowlero Christown

1919 Bethany Home Rd,
Phoenix, 85015

\$20

/game

Saturday Noon bi-weekly

August 28 through May 21



Contact Irene to signup
480-228-3159
demindave@aol.com

Pediatric News

Upcoming events for our younger recipients

written by Melissa McQueen

Transplant Families is so excited to welcome all of our students back to school whether that be in person or virtual. We welcome your back to school stories and pictures to be sent to hello@transplantfamilies.com to be shared with other families and all of our friends at Transplant Community Alliance.

If you are a transplant family with a recipient under 18 stay tuned in August for a webinar on Nutrition and how to make the most variety and fun out of packable lunches that are transplant recipient safe.

In August, we are also starting our "Bedtime Stories" series written by children's authors. The books are written for kids to inspire, dream, and empower them to make the most out of their new superhero transplants.

Both of the above series will be viewable on our YouTube channel, along with all of our other content from this year and many years past from us and our partners.

Save the Date in September for a crafting night out with HopeKids.

Events calendar listed at <https://transplantfamilies.org>



2021 National DMV Appreciation Month

Thank you to our Driver License Partners for saving lives every day.



DonateLife.net



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



Transplant for LIVING

August 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

August 16 10am Banner Tucson Heart & Lung Transplant Support Group Ande Burkholder (520)694-5168

Fourth Monday 11 am- Saddleback Kidney Support Group Bill & Helen Mills at 949-412-3210

Tuesday

5 pm Referral Committee Meeting.

Wednesdays

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

Every Wednesday (1st - 9am, 2nd - Noon, 3rd - 5pm, 4th - 5pm) - Phoenix Children's Hospital caregivers and parents support group online run by Transplant Families. Contact Melissa McQueen 623-217-5875 or melissa@transplantfamilies.org or visit <https://www.facebook.com/groups/818356851624575> for info.

August 11 6 pm - Transplant Community Alliance Board Meeting / Revenue Committee Meeting

Thursdays

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, facilitated by a licensed AZ transplant social worker

August 12, 1 pm - Abdominal Support Group - Banner TUCSON: For Patients and Caregivers (pre/post-transplant)

Please contact one of the abdominal transplant social workers for more information: Fritzi Dillon, LCSW at 694-2958, Charisse Radnothy, LMSW at 694-5092 or Caitlin Yost, LMSW at 694-6149



Transplant for LIVING

August 2021

August 26, 3 pm - DNAZ Volunteer Meeting

August 26, 6:30 pm - Banner Liver Support Group: 1441 N. 12th St, Phoenix, 85006 Classroom #1 – First Floor Contact: Charlie 602.521.5841/602-521-5830

Friday

August 20 11 am - Banner Phoenix Lung Transplant Support Group Ande Burkholder (520)694-5168

Saturday

Second Saturday 1pm- Saddleback Kidney Support Group Bill & Helen Mills at 949-412-3210

Sunday

August 8 & 15 2pm- Kidney Warriors Support Group: Kidney Disease, Kiwanis Park, Tempe, contact Sachi Kuwahara for more information <https://www.facebook.com/skuwahara1>

Other Events

12/4/2021 2nd Annual DonorDash at Kiwanis Park, Tempe, AZ. www.TransplantAZ.org/DonorDash

Welcome New and Re-newing TCA Members

Art Adams
Jill & George Bowers

Chuck Haneberg
Carol Inman
Sherelle Knight