

ORA/AR NEWSLETTER



VOLUME 6, ISSUE 1
ORGAN RECIPIENTS ASSOCIATION OF ARKANSAS

Winter 2017

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This month, meet Milton Spooner. He had a heart transplant in 2015 & is doing great now! Read about his "Long Journey" on page 8

See how much fun we had at the Transplant Games in Cleveland June 10 -15, 2016
On Page 7

"Teammates in Life"
Rose Parade in Pasadena, CA
January 2, 2017
See Page 11



Presidents's Message

Hello, Everyone,

2016 was a great year for Frances & I. We attended the Transplant Games in Cleveland, Ohio in June & we both competed in Bocci ball for the first time. Before the games, neither of us had even heard of Bocci ball. We gave it our best shot & we had a great time. We did not win but hey, we had lots of fun competing. Just wait until the next games.....

If you have never been to the Transplant games, you need to go at least once. It is just an awesome time!

If you have anything you would like to share with the transplant community, please let me know by emailing me at webco@tcworks.net & I will be happy to get it in our Newsletter or on our website at www.oraar.org.

Watch for the Upcoming Events in April. **ARDFC** has the **Zoo days on the 7th, Function at the Junction on the 13th** and the **6th Annual Golf Tournament on the 27th** benefiting the families going to the Transplant Games in Salt Lake City in August 2018. Come join us for these events!

Have a blessed day!

Linda M. Weaver

ORA President
ORA Newsletter Editor

Linda Weaver, left with her Kidney donor Frances Griffith at the Transplant Games in Cleveland, Ohio in June 2016



2017 Officers

President:

Linda Weaver

Vice President:

Carolyn Berry

Secretary:

Joani Mott

Treasurer:

Bill Brass

2017

Board Members:

Sue Weeks

Bobby Walker

Karen Scott

Bob Garison

Becky Hogan

Ron Spillers

Michael Williams

If you would like to serve on the ORA Board, please contact Linda Weaver at 501-993-1445. We would love to have you join us.



Support Group Meetings

Central Arkansas

Carolyn Berry
870-329-1368
ccarol20@hotmail.com

Meets the 2nd Tuesday of the month at a local restaurant- location emailed.

Conway

Dale & Debbie Smith
501-472-0461
smithdf1@conwaycorp.net

Meets at 5:00pm the first Tuesday of the month at a local restaurant - location emailed.

Hot Springs

Kay Grubbs 501-767-0426
Kgrubbs60@gmail.com

Meets the 2nd Thursday of each month at 6 pm at various restaurants. Meeting location is emailed or is on "the Hot Springs Facebook Page"

Northwest Arkansas

Milton Spooner
479-212-0872

Meets the 2nd Tuesday of each month at various restaurants. Check their Facebook page "Fayetteville Area Transplant Support Group" for more info.

Russellville

The group is currently not meeting. If you are interesting in starting the group meeting again give me a call & I will be happy to help you get started. Linda Weaver 501-993-1445

If there are any other groups that meet, please let us know so they can be added to this list.

Contact:

Linda Weaver
501-993-1445
webco@tcworks.net

If you have an email address, please get it to us so that we can email these newsletters to you & save on a stamp. To get your name on the email list, call Linda Weaver at 501-796-2301 or email her webco@tcworks.net

Calendar of Events

June 17, 2017
ORA Board Meeting
ARORA Office
10:30 am

September 16, 2017
ORA Board Meeting
ARORA Office
10:30 am

Both Meetings Located at:
1701 Aldersgate Road
Little Rock



Patient Assistance Fund

Many times we, as transplant recipients, are faced with financial challenges. We know what an extended hospital stay, co-pays for medication, numerous trips to doctors, dental costs, food, utilities, etc. can do to our budgets.

In 2008 ORA/AR established the Patient Assistance Fund to help with such financial challenges. The PAF is designed to help pay for medical & other related expenses that are of an emergency or non-insured nature. Your ORA/AR dues help fund the PAF.

To receive this type of financial assistance, specific eligibility criteria must be met. Once an application is received an evaluation process takes place which will determine whether assistance will or will not be provided. There is a limit as to the level of assistance that can be provided to each applicant each year. If you need emergency assistance, the best place to start is with your transplant coordinator.

Go to the ORA website at oraar.org for the application form under Patient Assistance Fund.

ARORA & ARDFC Events

ARORA Celebration of Life Zoo Night
April 7th, 2017 – Little Rock Zoo Amphitheater

ARORA Function at the Junction Thursday, April 13th, 2017
Clinton Presidential Center
A Bridge Party & Fun Walk to Celebrate
ORGAN DONATION

Get Your Donor Family Team Together and Come Join Us! Check out their website for more details at www.arora.com

Coming up April 27, 2017 Small & Associates Financial
Proudly Sponsors our 6th Annual Arkansas Donor Family Council
Charity Golf Tournament @ the Balboa Golf Course in Hot Springs Village
All Proceeds go to the Arkansas Donor Family Council to help our Families attend the Transplant Games in 2018. Come join in the fun! Brochure to follow soon.



The Harrison House
704 South Valentine
Little Rock, Arkansas 72205

Come stay at our house, your home away from home. The Harrison House is a home for patients receiving kidney dialysis & training for in-home dialysis, chemotherapy, stem-cell transplants, or awaiting organ transplants, & those that just need an overnight stay are served by The Harrison House along with their family members.

Reasonably priced: (\$10 per night/per person)

Conveniently located: (3 blocks from UAMS)

Amenities include: Cable TV
Full Kitchen
Washers & Dryers
Computers & WIFI

No one under 18 years of age
No Pets allowed
No Alcohol or Smoking allowed

Hours: 7 am until 7 pm

To make a reservation or get more information call:

Bobby Walker
House Manager

501-663-5107 or 501-749-5728 (cell)

TGA in Cleveland July 2016

The Transplant Games of America were held in Cleveland, Ohio July 22 - 26, 2016. Team Arkansas had one of the largest groups to attend the Transplant Games! We had lots of fun & fellowship getting to meet other Donor Families & Recipients. The group won several medals.



A Long Journey

By: Milton Spooner

In 1997 I had my first encounter with heart disease. One morning in March I began feeling acid build up, not realizing what it was, I found myself pacing back & forth, taking antacid pills. This continued for about three hours. I finally gave in & my wife Pat took me to the doctor. Ten minutes later I was in an ambulance. Who knew acid reflux could cause so many problems! An artery was 90% blocked. It was the first time I had experienced angiogram & angioplasty which meant putting stents in my arteries.

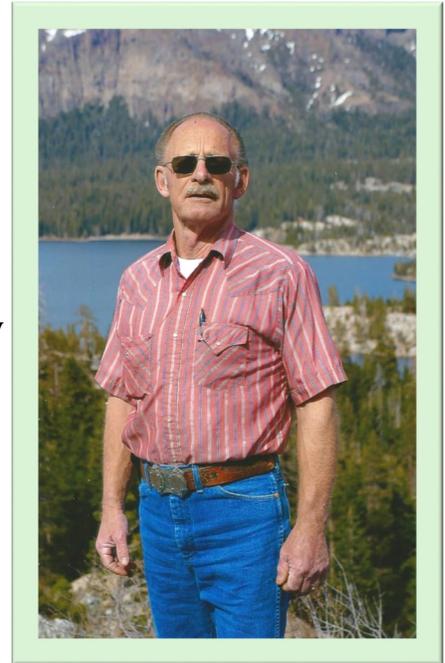
I felt great for the next six years. Of course I hadn't changed my smoking & eating habits. One morning while deer hunting, I had climbed a hill & began feeling nauseas & clammy. I sat there for about 30 minutes & radioed my wife Pat to meet me at the base of the hill. Well, once again I ignored the warning signs & rested for three days without seeing my doctor. You can see where this is going.....???

In March of 2004, I was attempting to push the gate open, unable to, I just stood there. My wife witnessed this and drove her van down to pick me up. Upon reaching me she immediately called 911. I was taken to Gravette Hospital and from there was flown to Springdale. Upon arriving, I flat lined & for about 8 days I was on life support. If it wasn't for my wife, family, & the doctors, not forgetting being blessed by God, I would not be here today.

This was the start of realizing I have to take care of myself & change old habits. I had lost most of my heart muscle. From that time on I had numerous stents, three CHF events & three defibrillators. The last one rebooted my heart. By November of 2014 I was placed on a LVAD (left ventricular assisted device).

On May 31st 2015 I received a call from Baptist Health asking me to come to Little Rock. They had a donor heart becoming available. My daughter Tina & I wasted no time & immediately drove to the hospital. On June 1st I received my donor heart. This was truly a blessing which has changed my life in many ways. Not only is there a physical change but an emotional one which I have never experienced before. To this day, I feel all of the emotions that a transplant recipient faces.

I'm still walking the journey & hope I can for many years to come. Thanks to the sacrifices of a special person who gave their life for many.



NW Arkansas Support Group

If you are in the Northwest part of Arkansas & would like to meet Milt, he is our NW Arkansas Support Group leader. Just give him a call at 479-212-0872 & he will be happy to let you know when they meet & where.

Thanks Milt, for your hard work & dedication to the group!

Central AR Support Group

The Central Arkansas Transplant Support Group continues to meet on the 2nd Tuesday of the month at different restaurants around the Little Rock area. Our group's goal is to provide encouragement, information, friendship, a shoulder to lean on & an ear to listen for transplant recipients & caregivers as we travel this transplant journey together. We have added a few new members in the past couple of months. We are always pleased to have new transplants, caregivers & donors to join our family.

On January 10th we met at Red Lobster on Markham & Rodney Parham. We had 21 members to attend. It was a fun evening catching up after the Holidays.





Conway Support Group

D&Debate Life

The Conway Support Group met at the Whole Hog Café last Tuesday evening. They had a great turnout. If you live in this area and would like to join their group contact Dale & Deb Smith at 501-472-0461 or email him at smithdf1@conwaycorp.net for details.



2017 Rose Parade - Pasadena, CA

“Teammates in Life”



Rodney & Kristie Cotillier
Evan's Parents

Evan Cotillier was sweet and compassionate. Helping others brought Evan joy. Born in Gary, Indiana, he moved to Arkansas in 2006. No matter where he lived, it made no difference in how many people he inspired. He was always asking someone if they were hungry so he could show off his grilled cheese-making skills, but mostly he wanted to just make someone feel loved. One of those friends shared with his family how Evan changed her life and wrote a beautiful poem in his memory. With Evan's donation, his legacy of giving was honored with exactly with what Evan would have chosen.

Evan Cotillier was the ARORA Floragraph for Arkansas on the “Teammates in Life” float at the Rose Parade in Pasadena, CA on January 2, 2017

2017



Organ Recipients Association
of Arkansas, Inc.



Please complete this form if you are interested
in joining ORA/AR and receiving our newsletter.
Send completed form and fees to:

ORA/AR
P.O. Box 250607
Little Rock, AR 72225-0607

New Member Renewal Info Change

Name:

Address:

City:

State:

Zip:

Support Person(s):

Home Telephone Number:

Work Telephone Number:

Cell Telephone Number:

Fax Telephone Number:

Email Address:

Date of Birth:

Local Chapter:

Which organ transplanted or to be transplanted?:

Transplant Center:

Current Status: Recipient Waiting List Support Person
 Health Professional Other _____

Date of Transplantation:

Date Listed:

HOSPITAL RELEASE: I AGREE to allow any hospital I am confined in to release my name to Organ Recipients Association of Arkansas, Inc. so they may contact me.

ORA/AR publishes a directory of recipients and candidates who have given their permission to be included. This directory is available at no charge to members with an email address and \$2.90 for postage if you do not have an email address. It is intended to be used for information and support purposes only.

I AGREE to allow my name, address and phone number to be given to other transplant recipients to form an informal network.

Membership Fee: (select one)

- Waive Fees - Financial Hardship
- Individual/Friend of ORA/AR - \$10.00
- Patient - \$10.00
- Family - \$20.00
- Corporate - \$100.00
- Other - \$50.00

\$

Donation to Transplant Patient Assistance Fund

\$

Memorial For _____

\$

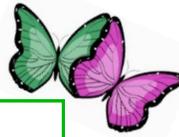
Total

\$

Signature _____

Date _____





Bruce Jordan	3/29/2016
Lonnie McNatt	1/28/2017
Nancy Pyle	2/09/2017

If you know of someone within the transplant community that has recently passed away & would like to spread the word please let us know. This information can be sent to Linda Weaver at webco@tcworks.net

New License Plate Anyone?

Most of you have seen the license plates that have a fish or hunting dog on them supporting the Game & Fish Commission. You've probably also seen the ones that have a razorback on them to show support of the University of Arkansas. But did you know that you can get an Organ Donor license plate? The next time you go to renew your tags ask for this special license plate. It will cost more than your normal renewal but it's worth it! Your money goes to a good cause because the Organ Donor Awareness Education fund actually receives \$25.00 for each plate purchased. If you would like to purchase the license plate early here are the steps to take:

Tell Us Your Story!

Your personal transplant stories are the most interesting part of our newsletters. They are uplifting & encouraging. It is a joy learning about the journey that each & every person takes to have their 2nd (& sometimes 3rd) shot at life. The experiences that one person has can even be beneficial to someone who is just now beginning their journey. So, please share with us your story so that it may help others. We would like to have at least one in every newsletter that we send out. If possible, please send pictures along with your story. Some things that you may want to include:

- Name, Age
- Organ Transplanted,
- Place & Date of Transplantation
- Marital Status, Children, Grandchildren, etc.
- Hobbies
- The road to transplantation
- What went well & what didn't go well with your transplant
- Life after transplant
- Advice for someone beginning the process

- Go to www.dfa.arkansas.gov
- Under **Vehicles** on the far right, click *Specialty License Plates*
- On **Page 8** you will find the Organ Donor Awareness License Plate.
- Once you click on the Organ Donor Awareness License Plate, it will take you to a page with the forms to fill out to get the license plate & the info on how much it will cost to purchase it.

If you would like to purchase a **license plate frame**, you can go to www.cafepress.com & type "Organ Donor" into the website's search bar. There are many different ones available, most for only \$15 plus tax & shipping.



Pass it on..... Be an organ donor!

RECYCLE YOURSELF! BECOME AN ORGAN DONOR!

Our Mission

The Organ Recipients Association of Arkansas, Inc. (ORA/AR) is dedicated to the enrichment of the lives of transplant candidates, recipients, & their families through advocacy, education, services, & support.

The Challenge

Members of the transplant community face continual challenges. Transplant candidates endure disabling illness, long waits & anxiety hoping to receive a life-saving organ. Recipients cherish their gift of new life but then are confronted with a regimen of life long medications, huge medical expenses & public misunderstandings. Families & friends, the caregivers, bare the burdens of supporting the patient & the entire household for extended periods. Throughout their transplant experience, these people need access to information, assistance & understanding to help them face these challenges.

Advocacy & Education

We stay attuned to legislation affecting recipients & educate our membership to its maximum potential effects. We work with our legislators to encourage legislation which we believe benefits the transplant community. We serve as a facilitator in helping candidates & recipients meet their needs. We encourage the strong support of family & friends.

ORA/AR provides information on:

- Developments in transplantation
- Medications
- Organ & Tissue donation
- The personal transplant experience
- Governmental initiatives in transplantation

ORA/AR also provides the patient's perspective on the transplant experience to the general public & the professional medical community.

ORA Newsletter Editor Kidney Recipient 8/9/11

**Linda Weaver
P.O. Box 60
El Paso, AR 72045**

**webco@tcworks.net
501-993-1445**

Helpful Links:

www.arora.org
www.arkdfc.org
www.unos.org
www.oraar.org
www.aakp.org



Give thanks. Give life.