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Heart Recipient

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Waiting for liver transplant

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UPDATE

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A Publication of the Kentucky Circuit Court Clerks' Trust For Life

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Talía Blue 12-Year-Old on a Mission for Organ Donor Awareness

For her bat mitzvah project, 12-year-old Talía Blue chose to focus on organ donor awareness.

She was inspired by Anna Parish, who is awaiting a life-saving liver transplant. (Read Anna's story on page 6.) Talía met Anna's sister, Gracie, in third grade. Talía's sister Tamar and Anna were best friends, and Talía and Gracie became best friends too.

Inspired by Anna, Talía started Talía's Love 4 Life project.

First, she wrote articles for the Voice-Tribune in Louisville. In a clear voice, she described how a virus damaged Anna's liver and wrote: "Even though I've known about Anna's condition for quite a while, it still really surprises me that a girl with such a big, loving heart could be diagnosed with such an awful disease. If it were my sister, I would be scared that something bad could happen to her and it would break my heart."

She adds: "Gracie loves her little sister like I do mine, and even though we all hang out like any other friends, there's always Anna's illness hanging right there, and that's not easy to deal with,



The Blue sisters and the Parish sisters promoted organ donation to runners at the Louisville Sports Commission Half Marathon. Top right, posing with the winner of the marathon. Bottom photo, posing with the Voice-Tribune Crew and other donation supporters.



especially for Gracie. 'It's hard because I'm really worried about her,' (Gracie) told me. 'Anna has a life-threatening disease and needs a life-threatening operation to get better.'

Talía wrote about her visit with Jefferson County Circuit Clerk David Nicholson; with a transplant recipient; and with a living donor. She learned that it's not about signing the back of your driver's license anymore. To join the organ donation registry, it is most important to say yes when visiting your Circuit Court

Clerks office. Or you can register online at anytime – www.donatelifeky.org.

She also set up a station at the Greater Louisville Sports Commission's Half Marathon and Pure Tap 5K last fall, where she and her friends spread the word that joining the organ donor registry is important — and easy.

Talía's passion and commitment are a great example of how one person can make a difference in many people's lives. To explore how you can help raise organ donor awareness, please visit our website, www.TrustForLife.org, or call 866-945-5433.

20TH ANNIVERSARY

TRUST FOR LIFE

The Circuit Court Clerks of Kentucky are action-oriented public servants going above and beyond. Kentucky's Circuit Court Clerks are responsible for handling the records of Circuit and District courts including: recording & providing legal documents, maintaining the jury system, receiving money due to the court, and also issuing driver licenses and state ID cards. In 1992, they began a program to help save lives.

The Vision

The Kentucky Association of Circuit Court Clerks wanted to create a program that would make a difference in the Commonwealth. Around the same time, a Circuit Clerk tragically lost a cousin in need of a heart transplant. The Circuit Clerks vowed to do something about the need for more organ donors so no one else would lose a parent, spouse, child, or friend waiting for a transplant.

The Actions

The Circuit Clerks supported a law that gave every Kentuckian obtaining a driver's license or state ID an opportunity to donate \$1 to promote organ donation. This was the first program of its kind in the US. These dollars are put into a trust, and it is called their Trust For Life.

In 2006, the Clerks worked with other agencies to establish the Kentucky Organ Donor Registry. Now the Circuit Clerks ask every customer if they wish to register as an organ donor.

Continued on page 9

Decades of Dedication



Diane Thompson, Nelson Co. Circuit Court Clerk since 1988

"The Circuit Clerks wanted to make a difference in our communities. This mission had affected several members of our Clerk family; it just seemed like the right thing to do. Now, 20 years later, it's incredible that we've raised more than \$7 million dollars and have helped to educate millions of Kentuckians about the importance of becoming a registered donor."



"I've been Circuit Clerk since 1976, and supporting the Trust is one of my favorite parts of my job. After 20 years, I feel that we have accomplished so much. We have raised money to teach everyone the importance of this mission to help save people's lives."

Mike Mays, Circuit Court Clerk in Owsley County for 6 consecutive terms



"One of my favorite memories of my involvement with the Trust was when I invited transplant recipients and people from our county currently on the waiting list for a transplant. They came to my office and sat around the table and told their stories. That was very special and taught me so much about what it meant to wait for an organ. My favorite Trust For Life awareness campaign slogan was, 'Don't take your organs to heaven, heaven knows we need them here.'"

Vicki Crace Rice, Johnson Co. Circuit Court Clerk since 1988



"When I took office as Circuit Court Clerk in 2001, I was humbled to serve the citizens of McLean County, but I was thrilled when I soon learned I could have an impact on saving lives throughout the nation. Listening to the personal stories of organ recipients and organ donor families over the past years as clerk makes me more committed, as President of the Circuit Clerk's Association, to help build the Trust to make an even bigger impact in each of our communities."

Stephanie King-Logsdon, President, Kentucky Association of Circuit Court Clerks

Timeline:

■ 1954 America's first kidney transplant

■ 1964 Kentucky's first kidney transplant

■ 1984 Kentucky's first adult heart transplant

■ 1992 Trust For Life is created by Circuit Court Clerks in Kentucky.

■ UNOS creates Donate Life America to build public support for organ donation nationwide.

■ 1994 Circuit Court Clerks of Kentucky awarded the Lloyd R Workman Award by KODA. Award acknowledges significant contribution to increasing public awareness about donation by non-healthcare organizations.

■ 2006 Kentucky Organ Donor Registry founded to allow Kentuckians to electronically state their wish to be an organ and tissue donor.

■ 2008 US Department of Health and Human Services – HRSA, Division of Transportation, recognizes KY Circuit Court Clerks' Trust For Life for outstanding achievement in the Workplace Partnership for Life



Helping Kentucky's Kids

provided and the savings from our new office space will go directly back to our educational efforts. Thanks to Kosair Charities, the Trust has significantly increased awareness of organ donation throughout Kentucky.”

The Circuit Court Clerks’ Trust For Life and Kosair Charities were originally linked by Jefferson Co. Circuit Clerk David Nicholson, who is a Shriner. That connection led to a more formal partnership including a \$100,000 grant from Kosair Charities to support the Trust’s public outreach and education efforts. Now, with the generous use of office space, the Trust will save an additional \$15,000 per year.

Incredibly, Kosair Charities awarded more than \$18 million in grants last year to help meet the healthcare needs of children and their families. Rent-free space is provided to several non-profit organizations on The Sam Swope Kosair Charities Centre campus.

“We know there are children in critical need of organ transplants,” Linda added. “Kids are in

“Our missions converge; both organizations are involved in helping save lives.”

H.I. Stroth, Kosair Charities Board Member



hospitals and on the waiting list, and their only opportunity for survival is through the gift of organ donation. We call Kentucky to action. Everyone can express their wish to save lives by joining the Kentucky Organ Donor Registry. The more awareness we extend, the more children who will be saved by the miracle of transplantation. As Circuit Clerks, we spread this message in each of our offices. Thanks to Kosair Charities, our reach is even greater.”



Above, Kosair Charities Centre.

Bottom right, Board Meeting in Community Room listening to volunteers who have been touched by donation.

The Kentucky Circuit Court Clerks’ Trust For Life has a new office. In December, we packed up our Frankfort office and moved into the wonderful Kosair Charities campus on Eastern Parkway in Louisville. And thanks to Kosair Charities, rent and utilities are provided at no cost to the Trust. “It’s a great partnership,” said H. I. Stroth, a Kosair Charities board member who (along with Robert Flowers), serves on the Trust’s board. “Our missions converge; both organizations are involved in helping save lives. It’s in our interest to help them keep their message out there, because often organ and tissue donations go to kids.”

Linda Avery, Calloway County Circuit Clerk and Chairman of the Board of Trust For Life, agreed.

“Kosair Charities has such an excellent reputation throughout Kentucky for helping save lives, and the Circuit Clerks are grateful to be partnered with them,” she said. “The funding they have

Eleanor Westenhofer: happy and healthy after a life-saving heart transplant



As baby Eleanor Westenhofer waited for a life-saving heart transplant, her parents Damon and Lindsey took turns spending the night with her at Kosair Children’s Hospital.

It was Lindsey’s night when that important call came. The cardiovascular nurse-practitioner on the phone asked Lindsey if she was sitting down and told her, “We have a heart.”

Eleanor was put on full life support after her birth on Oct. 12, 2010. Tests had revealed a congenital heart defect. Doctors said a transplant was the only option, and 10 days later, she was added to the national waiting list. Her survival was at stake.

Her parents felt helpless. “If you allow yourself to think too much about what could happen,” Lindsey said, “I knew I would be in a very bad place.”

The transplant was a huge success, and Eleanor is a happy and healthy toddler.

Eleanor was on the list for exactly two months. Her new heart came from a two-month-old little girl in Pennsylvania. The Westenhofers know few details but have sent a letter of deep gratitude.

“For all we know,” Lindsey said, “that is the only heart that

would have been perfect for Eleanor. Because of their generosity and selflessness, we have our beautiful daughter at home with us. We feel it’s a miracle. There are no words to fully describe the gratitude we have. Even through their tragedy and immense loss, they saw they could help other people.”

Eleanor may have some limitations, no contact sports for example, but the family’s lives have been transformed. They see a bright future.

“Now, we have so much to look forward to,” Lindsey said. “Before, our lives were full of stress and anxiety. It’s agonizing. She could have gotten much sicker very fast. We will do everything we can to keep her happy and to make sure she experiences everything she can. Whatever she



Eleanor, 2010.

wants to be, we will help her make her dreams come true.”

The Westenhofers are huge advocates for organ donation.

“We both feel strongly about spreading awareness,” Lindsey said. “I did not know that 1 in 100 babies are born with a heart



Eleanor today!

Photos by Bethany Billick

defect. Everyone should sign up to be an organ donor. Please make your family aware of your wishes, and make sure you sign up for the registry online. You can help so many people.”



You can give hope to parents like Lindsey & Damon. Becoming a registered organ donor only takes a moment, but gives hope to thousands of kids and adults waiting for life-saving organ transplants.

Here’s how...

1. Say YES when renewing your driver’s license at your Circuit Court Clerk’s office.
2. Donate \$1 to help promote organ donation throughout Kentucky.
3. Encourage your family & friends to register online: www.donatelifeky.org

Anna Parish's hopes and dreams

Charming 11-year-old looks to the future as she awaits her life-saving transplant

"I used to worry when the phone rang. Now I'm worried it won't ring. I worry she won't get one"

Cheryl Parish, Anna's Mom



Imagine laying in bed at night, trying to scratch an itch that you can't reach. That is what Anna Parish deals with. It is part of a liver illness that this charming little girl has lived with for all of her 11 years. Her ammonia levels are high, which causes intense itching from the inside. Despite her best efforts, she cannot really scratch it. It is one of many difficult things she lives with every day.

"She hardly gets any sleep," said her mother, Cheryl Parish. "I don't see how she functions."

Anna's condition is known as biliary atresia. Sometimes the illness is congenital and can run in the family. Sometimes it comes from nowhere. That is what happened



in Anna's case — she was born healthy but a virus attacked her liver. The Parish family had never heard of the disease, and they were not prepared for this sudden, devastating news.

That is one of the most important aspects of organ donation. You never know when the need will arise, and it can happen to anyone.

Imagine your child or grandchild in the same situation, and the fear and anxiety that come with waiting for someone else to say "yes" to organ donation.

Anna was added to the national waiting list on April 1, 2009. The family has no way of knowing when or if a call will come, but they're never farther than five hours from home.

Daily life is a challenge

Anna's charisma and wit jump out immediately. Inspired by her father, Phillip, who has been taking guitar lessons for a couple years, Anna has also taken up the guitar. Her mom and dad bought her one that is the namesake of her musical hero, Taylor Swift.

Anna starts to giggle and talk faster as she tells the story about meeting her idol when Taylor recently performed at the Yum! Center. Through the Make-A-Wish Foundation, Anna got to go backstage and have some personal time with her hero. She

came away with cool photographs and said she felt special. It is something she will never forget.

Her lack of sleep makes school difficult for Anna, and she is often too sick to attend. Her mother said that affects her confidence academically and socially.

Anna loves to play sports, but her endurance is low. But she's enjoying her precious life just the same. She has lots of friends, and loves to have sleepovers. And she loves to hang out with her parents and her sisters, Gracie and Sarah.

Waiting on a 'yes'

Every three months, Anna and her family travel to the Cincinnati Children's Hospital Medical Center where she sees a pediatric gastroenterologist. She is primed to travel to New York for her life-saving transplant.

Her family has been told Anna's wait time could be 18 to 30 months. It is a scary time for all of them. Anna, who just turned 11, will go on the adult list when she turns 12.

"I used to worry when the phone rang," Cheryl said. "Now I'm more worried it won't ring. I worry she won't get one."

The Parishes have become huge advocates for the cause of organ donation and the Trust For Life, because the need for organs is urgent and crucial. Kids like Anna all over the country are in need of life-saving transplants, and the only hope they have is for everyone to become a registered organ donor.

Saying "yes" at your circuit clerk's office or joining the registry online states your willingness to help kids like Anna. More registered donors means more hope for those waiting. Everyone counts, and everyone can join the registry today. It only takes a moment!

"She could be capable of almost anything if she were given the chance!"

Cheryl Parish, Anna's Mom



A call to action

The Parish family are staying strong and dreaming of a bright future for Anna — maybe with the guitar! They dream of her attending college, getting married and having her own family.

"If she could get her transplant and move on with a healthy liver and body, I truly think that the sky is the limit for Anna," she said. "She could be capable of almost anything if she were given the chance!"

Asked how she would describe organ donation in two words, Cheryl said simply: "Saving lives."

Anna with her family.

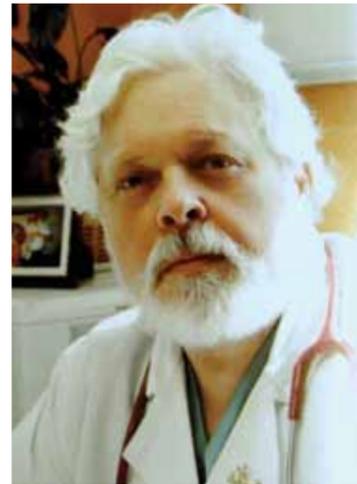
Bottom left, Anna with "Dr. B" Dr. William Balistreri.

1. Say "yes" when you get a license or ID at your county's Circuit Court Clerk's office.
2. Join anytime!
www.donatelifeky.org
3. Tell your family & friends how important it is to register now. Be hope!

Do you have questions about registering?
Call toll-free 1-866-945-5433.

**GIVE HOPE
to kids like
Anna.**





Dr. Phil Aaron

ADAIR COUNTY
RECIPIENT

damaged so badly that I had to have dialysis three days a week. I would travel to Campbellsville in the dark of the morning where I was attached to my dialysis unit for 3 to 3.5 hours, then travel back to my office by noon to see patients.

I was on the transplant list and dialysis for about six months, and was en route home from the dialysis clinic, when I received a call that changed my life forever. I was to go directly to Jewish Hospital — a kidney was available for me.

I received my gift of life (my new kidney), spent only two days in the hospital, and then returned home with a markedly improved

lifestyle. I am extremely fortunate and blessed.

My transplant had been working well for over a year when I received a letter asking if I would like to know who had been my donor. Of course, I jumped at the chance and replied, "Yes."

Sometime later I received a letter from a young woman who now lives in New York City. Her healthy 30 year old construction working husband had died in an accident, and she had compassionately donated his organs.

"The real success and happiness one finds in life depends on how you live and share your life."

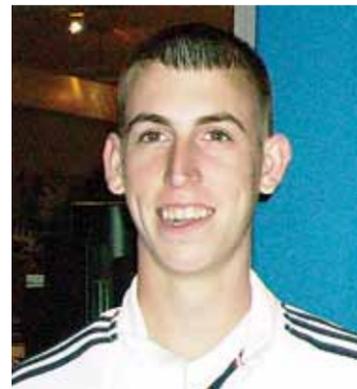
Organ donation saves lives. I am living proof.

Organ donation, take it from me, truly is the gift of life. Our kidneys act as sieves in our body; they trap the needed body-building proteins and keep them in our bodies. They let the wastes filter through a strainer and exit our bodies through our urine.

My own kidneys had been damaged due to diabetes and the punishing lifestyle of a heavy work schedule. My kidneys were

Zachary Hutchens

WOODFORD COUNTY
DONOR



Zachary Hutchens was a giving 22 year-old man. He was a very special, thoughtful person who never met a stranger and always cared for those in need. Zac supported organ donation and shared with his family and friends that he was on the Kentucky Organ Donor Registry. He encouraged everyone he knew to sign up as well.

When Zac became an organ donor he gave the *gift of life* to five people in need, including a mother of two from New York, who had been on the national waiting list for a life-saving kidney transplant for nearly nine years. Zac's kidney was a perfect match.

We miss Zac and his bright smile terribly, but it helps knowing that his heart beats on and his generosity has given others a second chance at life.

We believe in organ donation and the miracle it brings to those in need. Before losing Zac we didn't know much about organ donation. I guess sometimes the child teaches the parents.

- Story shared by Zac's family

Has your family been touched by donation or transplantation?

Share your story. Contact our office 1-866-945-5433 or email info@trustforlife.org.

View more stories on our website: www.trustforlife.org/kentucky-stories

Continued from page 3

The Outcome

With the funds raised, dollar by dollar from the Circuit Clerks and willing residents of Kentucky, the Trust educates the Commonwealth through state-wide advertising and public awareness initiatives.

These programs dispel myths and teach the crucial need for everyone to join the Kentucky Organ Donor Registry to save lives. With more than 113,000 Americans waiting for life-saving organ transplants, the need is greater than ever. Locally, many Circuit Clerks participate in



health fairs, festivals, and school & civic speaking events to raise awareness in their community. Since 1992, the Clerks have raised more than \$7 million to educate Kentucky about this life-saving mission.

Today, more than 1.1 million Kentuckians have joined the Kentucky Organ Donor Registry.

Circuit Court Clerks on the Capitol steps in Frankfort in 1992.

The KY Circuit Court Clerks add over 98% of the names to the Registry. Kentucky is fortunate to have such a generous association of Circuit Court Clerks who are committed to making a difference in our Commonwealth.



Dedicated Circuit Clerks and Deputy Clerks promote this mission every day.

Above Left, Henry Co. Circuit Clerk Mary Lou Roberts' staff.

Right, Carroll Co. Circuit Clerk Laman Stark with staff.

Below, Hopkins Co. Circuit Clerk

Karen McKnight with staff.



You can contribute to this life-saving mission anytime. Text "kytrust" to 72727.



10

TOP 10 in DECEMBER:

1. Magoffin County
2. Morgan County
3. Woodford County*
4. Floyd County
5. Union County
6. Franklin County
7. Ballard County
8. Caldwell County
9. Johnson County
10. Breathitt County

TOP 10 in JANUARY:

1. Magoffin County
2. Woodford County* (tie)
2. Morgan County (tie)
3. Floyd County
4. Johnson County
5. Union County
6. Crittenden County
7. Fulton County
8. Breckinridge County
9. Washington County
10. Franklin County

TOP 10 in FEBRUARY:

1. Magoffin County
2. Woodford County*
3. Floyd County
4. Ballard County
5. Washington County
6. Powell County
7. Johnson County
8. Morgan County
9. Franklin County
10. Oldham County

*Special Thanks to Jack Kain Ford! Jack Kain Ford paid 50% of the difference in \$1 donations for Woodford Co.

Everyone obtaining a license or ID can donate \$1 to raise awareness about organ donation. Congrats to the Top 10 counties in collecting dollar donations!



Sally Jump, Franklin Co. Circuit Clerk, and her hardworking staff in the Frankfort Christmas Parade. The theme was "The Wonder of Christmas Morning" and the office promoted that the gift of organ donation allows patients to experience the wonder of Christmas with their family.

2011 WRAP UP

TOP 10 Counties with the highest percentage of REGISTERED organ donors

1. Clark, Circuit Clerk Paula Joslin
2. Oldham, Circuit Clerk Linda G. Mason
3. Kenton, Circuit Clerk John C. Middleton
4. Woodford, Circuit Clerk Tricia Kittinger
5. Union, Circuit Clerk Sue W. Beaven
6. Campbell, Circuit Clerk Taunya Nolan Jack
7. Marshall, Circuit Clerk Carla Marshall
8. Boone, Circuit Clerk Dianne Murray
9. Scott, Circuit Clerk Karen Boehm
10. Caldwell, Circuit Clerk Danny Hooks

TOP 10 Counties Raising \$1 donations for Organ Donor Awareness Program

1. Magoffin, Circuit Clerk Tonya Ward
2. Floyd, Circuit Clerk Doug Hall
3. Johnson, Circuit Clerk Vicki Rice
4. Russell, Circuit Clerk Tony D. Kerr
5. Laurel, Circuit Clerk Roger L. Schott
6. Washington, Circuit Clerk George Graves
7. Morgan, Circuit Clerk Donna Pelfrey
8. Oldham, Circuit Clerk Linda G. Mason
9. Ballard, Circuit Clerk Holly Oldham Dunker
10. Campbell, Circuit Clerk Taunya Nolan Jack (tie)
10. Kenton, Circuit Clerk John C. Middleton (tie)

Kentucky Circuit Court Clerks' **TRUST FOR LIFE** Organ Donor Awareness Program

To see your county's statistics, go to www.trustforlife.org and click Driver's License Reports.

MYTHS & FACTS



MYTH: I've signed my license, that's enough.

FACT: Not true anymore. Become a registered donor through the secure, confidential database called the

Kentucky Organ Donor Registry. Add your name by saying YES at your Circuit Court Clerks' office or anytime at www.donatelife.org.



MYTH: The doctors won't work to save my life if I'm a registered donor.

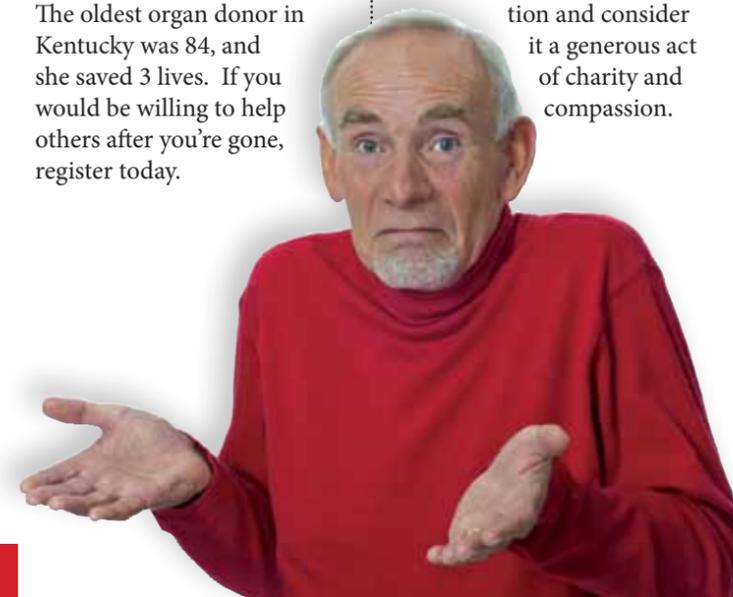
FACT: This is COMPLETELY FALSE. The main priority of any medical team is to save your life. The doctors and nurses working to save your life are entirely separate from the medical team involved in transplantation. To go one step further, ER personnel have no way of knowing you are a registered donor.

MYTH: I'm too old to donate. No one would want my organs.

FACT: No one is too old or sick to join the Registry. The oldest organ donor in Kentucky was 84, and she saved 3 lives. If you would be willing to help others after you're gone, register today.

MYTH: My religion may not support donation.

FACT: All major religions in America support donation and consider it a generous act of charity and compassion.



MYTH: I want to donate my body to science, so I can't be a registered organ donor.

FACT: Anyone can join the Kentucky Organ Donor Registry. Saving a life is the ultimate legacy one can leave. If you can become an organ donor after death, you can save and enhance lives. If you can't donate organs and tissues, you then may donate your body to the medical school you have contacted.

MYTH: Everyone who dies becomes a donor.

FACT: Only 1% of people die in a way they can become an organ donor. It is a rare gift, and that is why we have such a long transplant waiting list. Everyone is encouraged to register and say, "If I could save a life after I'm gone, I would."



982 Eastern Parkway, Box #13
Louisville, KY 40217

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Kosair Charities

SAVE-THE-DATE



**20th Anniversary
Celebration of the Kentucky
Circuit Court Clerks'
Trust For Life**



All Circuit Clerks, Deputy Clerks,
and others touched by donation
are invited to join us on
October 7, 2012
in Louisville for a day of fun,
laughter, & family!

**14th Annual Satterwhite Golf
Outing – Oct. 8.**

Shotgun start at noon.
Persimmon Ridge Golf Club.
Reserve your team today!



KY Circuit Court Clerks' Trust For Life Staff:

Shelley Heavrin, *Executive Director*
Sharon Ernst, *Program Administrator*



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