



WE'LL GIVE  
EVERYTHING.  
BUT UP.

Dear Friends,

As a member of the Board of Directors of the Tuberous Sclerosis Alliance (TS Alliance), I am writing to announce the inaugural TS Alliance **Drive for a Cure, a Philadelphia Food and Wine event**. On behalf of the TS Alliance, I am asking for your support as we strive to raise \$100,000 to fund continued medical research and support programs for tuberous sclerosis complex (TSC). Friends, families, and supporters will gather at the Simeone Foundation Automotive Museum on May 8, 2015 for an entertaining evening that will include a tour of some of the world's greatest collection of racing sports cars, a cocktail reception with heavy hors d'oeuvres, live and silent auctions, and informative presentations.

TSC is a genetic disorder that causes tumors to form in organs throughout the body, as well as seizures, and developmental delay. My daughter, Stephanie, was a newborn when our neurologist diagnosed her with TSC. Since then, Stephanie has been continually treated by many specialists at Boston Children's Hospital and at the Children's Hospital of Philadelphia because of the many tumors she has on her brain, heart, and kidneys. Stephanie, now 8 years old, is in second grade at the Woodlynde School, a school known for educating children who learn differently. My daughter is an inspiration to me and to others affected by TSC. Stephanie has worked hard to help advance TSC medical research. She has participated in three medical research studies with Dr. Mustafa Sahin, the Director of the Multidisciplinary Tuberous Sclerosis Program at Boston Children's Hospital and joined Congressman Michael Fitzpatrick on the House Floor where he urged Congress to support continued Federal TSC research funding.

**You can be a part of this year's celebration and participate in this fabulous event by donating an item valued at \$100 or more.** Join a list of TS Alliance compassionate supporters and businesses—such as American Airlines, American Idol, Bacara Resort and Spa, Garth Brooks, Billy Bush, Coach, Dancing with the Stars, Donna Karen, Edina Kiss, Firestone Wineries, Harry Winston, JetBlue, Montage Resort & Spa, Neil Lane, NetFlix, Raymond Weil, Tod's, Oakley, and Waterford—who all donated items previously and stood beside us in the pursuit of a cure.

Your support will continue to fuel dramatic breakthroughs such as two FDA-approved treatments that shrink TSC-related tumors in the brain and kidneys. These treatments, along with new treatments on the horizon, offer hope for effective, non-invasive alternatives to surgery. Your donation will also help to advance additional medical research projects such as studies to identify which infants with TSC may develop autism or infantile spasms, a devastating type of epilepsy. The first-ever preventative study to increase the quality of life by thwarting infantile spasms starts in the very near future.

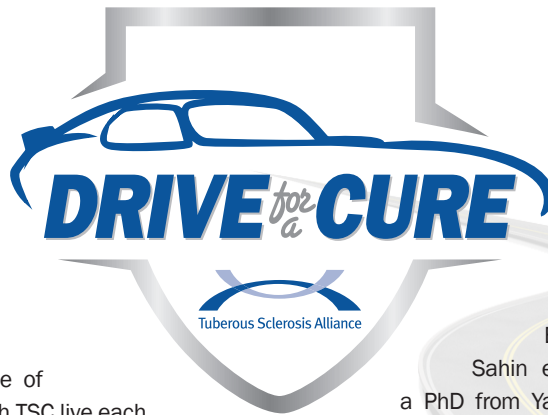
I am enclosing an In-Kind Drive for a Cure Donation Agreement for your consideration. On behalf of the Tuberous Sclerosis Alliance, I want to thank you for your time and support.

Very truly yours,

A handwritten signature in blue ink, appearing to read "C. Johns".

Colleen M. Johns  
Event Chair, Drive for a Cure  
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The **Tuberous Sclerosis Alliance** (TS Alliance) is thrilled to present our inaugural Philadelphia food and wine event, **Drive for a Cure**, which brings a diverse group of supporters together for a night of hope and progress. The TS Alliance is the only national nonprofit dedicated to finding a cure for tuberous sclerosis complex (TSC) while improving the lives of those affected. TSC is a rare genetic disorder that causes tumors to form on vital organs throughout the body and is the leading genetic cause of epilepsy and autism. Children and adults with TSC live each day under unimaginable circumstances, yet they and their caregivers carry on because current TSC-related research proves there's a real possibility their fight is winnable in the near future.



We invite you to be a TSC supporter through a sponsorship for Drive for a Cure. Join us Friday, May 8, 2015 at 5:30 pm at the Simeone Museum for an amazing look inside and inspiring evening.

The award-winning Simeone Foundation Automotive Museum is the result of some 50 years of car collecting by Philadelphia neurosurgeon Dr. Frederick Simeone. Dr. Simeone is the son of a physician who also collected cars – specifically 1950s-era classics.

## DRIVE FOR A CURE

**Drive for a Cure** is a unique event celebrating past advancements in TSC research as well as driving scientific breakthroughs forward in the pursuit of new treatments and improved quality of life for every child and adult living with TSC.



The TS Alliance is proud to honor **Congressman Mike Fitzpatrick** during this special evening for his support and compassionate partnership. Congressman Mike Fitzpatrick is a lifelong resident of Bucks County, where he has been an active member of his community for decades. In the 114th Congress, Mike's number one priority is job creation. Mike recognizes that government does not create jobs, but fosters an environment in

which the private sector can create permanent, family sustaining jobs. Congressman Fitzpatrick is the proud co-sponsor of the Dear Colleague letter in the House of Representatives garnering support for TSC research through the Department of Defense Congressionally Directed Medical Research Program.

Starting at 5:30 pm our sponsors will enjoy a VIP guided tour of the museum followed by cocktails and hors d'oeuvres. At 7 pm, we will make a formal presentation to our esteemed honoree. Then a top expert in TSC research, **Dr. Mustafa Sahin**, will discuss how far we have come and how close we are to preventative treatments, all of which is possible because of supporters like you. The event will also feature silent and live auctions with amazing deals.

Our respected presenters include Mustafa Sahin, MD, PhD, pediatric neurologist, Director, TSC Clinic, Children's Hospital, Boston, MA and TSC champion, Congressman Mike Fitzpatrick.

Dr. Mustafa Sahin is Associate Professor of Neurology at Harvard Medical School.

After receiving his BS degree from Brown University, Dr.

Sahin earned his MD and a PhD from Yale University School of Medicine. He completed a pediatrics residency at Children's Hospital of Philadelphia and a child neurology residency at Boston Children's Hospital.



Dr. Sahin directs the Multidisciplinary Tuberous Sclerosis Program at Boston Children's Hospital. His lab has developed evidence that the TSC/mTOR pathway plays crucial roles in axon specification, guidance, myelination and regeneration. These experiments support the notion that neurological defects in TSC-deficient mice can be blocked by postnatal mTORC1 inhibition. This work underpins the design of a clinical trial investigating the effect of an mTORC1 inhibitor on neurocognition in individuals with TSC.

## THE FIGHT AGAINST TUBEROUS SCLEROSIS COMPLEX

There was a time not long ago when the average life expectancy for individuals with TSC was only 30 years. Since then, we've come a long way, but so much more needs to be done. The TS Alliance is the leading resource for the medical community, parents and individuals with TSC, as well as the driving force behind funding and organizing TSC-related research in the United States. And while progress in research continues, we still have much work to do.

## THE TUBEROUS SCLEROSIS ALLIANCE

Since the TS Alliance was formed by four mothers in 1974, the organization has worked tirelessly to provide fellowship, generate awareness and offer hope to those who share the common bond of TSC. Approximately 50,000 people in the United States – and more than 1 million worldwide – battle TSC every day along with their family, friends and caregivers. Many compare having TSC to walking through a minefield blind-folded because they never know what symptoms or which complications may come next.

But there is hope, and every dollar spent unlocking the cure to TSC may lead to quantum leaps in our understanding of other diseases like autism, epilepsy and even cancer. You can see why your support is so critical at this time.

## JOIN THE FIGHT TODAY

Help make this dream a reality today by securing your sponsorship for Drive for a Cure in Philadelphia. It's an event you don't want to miss. You'll be able to feel the hope and help drive for a cure!

## MORE INFORMATION

If you have questions or need more information about Drive for a Cure, please contact event chair, Colleen Johns, at [colleenjohns22@gmail.com](mailto:colleenjohns22@gmail.com) or 215-266-6089.



WE'LL GIVE  
EVERYTHING.  
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## Drive for a Cure

To benefit the Tuberous Sclerosis Alliance

### IN-KIND DONATION AGREEMENT

I would like to donate the following gift(s) to:  
Drive for a Cure to be held on May 8, 2015

ITEM #1: \_\_\_\_\_

VALUE #1: \_\_\_\_\_

ITEM #2: \_\_\_\_\_

VALUE #2: \_\_\_\_\_

Please list any other descriptive information or conditions associated with the donation(s):

\_\_\_\_\_  
\_\_\_\_\_

**Please identify the type of item being donated:**

Raffle Item  Auction Item  Prize  Supplies (ie: Food & Beverages)  Services (ie: Printing)

CONTACT NAME: \_\_\_\_\_

COMPANY: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

CITY: \_\_\_\_\_ STATE: \_\_\_\_\_ ZIP: \_\_\_\_\_

PHONE: \_\_\_\_\_ FAX: \_\_\_\_\_ EMAIL: \_\_\_\_\_

Authorized Signature: \_\_\_\_\_

**Delivery:** Please return the auction item or gift certificate with this in kind donation agreement to the address listed below. All items should be received with the agreement form no later than **4/17/15**

**Donations should be sent to:**

Colleen M. Johns  
419 E. Wynnewood Road  
Narberth, PA 19072

To arrange a time to drop off an item, call 215-266-6089

Your gift will be gratefully acknowledged  
and is tax deductible to the extent allowed by law.

**(Tax ID #95-3018799)**

If pick-up is required, please complete the following:

Contact Name: \_\_\_\_\_

Date for Pick-Up:(if applicable)\_\_\_\_\_