

# KDA e-XPress

An official publication of the Kennedy's Disease Association

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*Kennedy's Disease knows no boundaries*

*... It is passed from generation to generation in families worldwide*



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## Avoiding Germs Keeping Colds and the Flu Away

Article by Terry Waite

If you have Kennedy's Disease like me the last thing you need is to get sick and have what is not a real big deal for a non-KD person become a Big Deal for you. You can't really avoid germs because they are everywhere, but there are things you can do to limit your chances of getting bad germs unnecessarily.

You've probably heard dozens of times from your doctor -- wash your hands throughout the day.

Warm water and soap will kill the germs, but be sure you don't rush. Try to wash for 15-20 seconds or sing 'Happy Birthday' to yourself twice. Rub your hands vigorously together and scrub all surfaces, the soap combined with the scrubbing action that helps dislodge and remove germs

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Use a paper towel to dry your hands and to turn off the faucet, especially in public bathrooms.

Colds and flu are caused by viruses, which can easily pass from person to person, or from surface to person. Computer keyboards, telephones, doorknobs, pens that are given to you when you sign for a credit card purchase. I make it a point of carrying around little bottles of alcohol-based cleansers, and I use them all the time after I suspect that I've been exposed.

If using a gel, rub the gel in your hands until they are dry. The gel doesn't need water to work; the alcohol in the gel kills germs that cause colds and the flu. Avoid touching your eyes, nose or mouth. Germs can live for a long time (some can live for 2 hours or more) on surfaces like doorknobs, desks, and tables.

Virus germs need to live inside living things in order to multiply. They can only live a short period of time outside of living things. But when they are outside living things is when the germs are spread – when the germs are sitting on something and you touch it

**Here are five ways to avoid germs while traveling.**

- 1. Sit toward the front of the airplane

"Pick a seat near the front, since ventilation systems on most commercial aircraft provide better air flow in the front of the aircraft

- 2. Don't drink coffee or tea on an airplane

Monitoring by the Environmental Protection Agency shows that water in airplanes' water tanks isn't always clean - and coffee and tea are usually made from that water, not from bottled water, according to Victoria Day, a spokeswoman for the Air Transport Association.

The EPA advises anyone with a suppressed immune system or anyone who's "concerned" about bacteria to refrain from drinking coffee or tea on an airplane.

"While boiling water for one minute will remove pathogens from drinking water, the water used to prepare coffee and tea aboard a plane is not generally brought to a sufficiently high temperature to guarantee that pathogens are killed," according to the EPA's Web site.

According to the EPA, out of 7,812 water samples taken from 2,316 aircraft, 2.8 percent were positive for coliform bacteria. Although that sounds like a small number, this means 222 samples contained coliform bacteria.

- 3. Sanitize your hands after leaving an airplane bathroom

A toilet on an airplane "is among the germiest that you will encounter almost anywhere," said Charles Gerba, an environmental microbiologist at the University of Arizona who's also known as "Dr. Germ."

"You have 50 people per toilet, unless you are flying a discount airline; then it is 75," Gerba said. "We always find E. coli on surfaces in airplane restrooms."

You should wash your hands after using the restroom, but because the water itself might have harmful bacteria (see No. 2 above) and because the door handle on your way out has been touched by all those who went before you, Use hand sanitizer on your hands when you return to your seat.

- 4. Wash or sanitize your hands after getting off an escalator or using the buttons on an elevator

Escalators/Elevators are full of germs.

To confirm these tests, here's a fun activity while you wait for your flight. Look at your watch, and count how many people get an escalator in a five-minute time period. Multiply that by 12, and you have how many people are on that escalator every hour.

- 5. Wash or sanitize your hands after using an ATM



ATM keypads, Gas pumps handles and their keypads are full of germs. Sanitize ASAP after using one.

Keeping your hands clean is crucial when you're spending the day touching surfaces that have been touched by hundreds or thousands of people before you.

Some of the most germ ridden items that you don't think about are;

Restaurant Menus (hardly ever get wiped & cleaned properly, Salt & Pepper shakers, Soft drink dispenser buttons.

# 5 steps to clean hands

An illustration of a pair of hands being washed under a running faucet in a white sink. The hands are covered in white soap suds. The faucet is silver and has water flowing from it. The background is a light blue gradient.

- 1 Use soap and running water
- 2 Rub your hands vigorously for 10 - 15 seconds
- 3 Wash all surfaces: backs of hands wrists between fingers under nails
- 4 Rinse well
- 5 Dry hands with a disposable paper towel

DEPARTMENT OF HUMAN SERVICES  
Communicable Disease Control Branch

If opening door handles to buildings, Use your wrist if possible. For example, if someone who is sick touches a desk, a pencil, a light switch, a pop can or anything at all, they put their germs on it. If you touch that same desk, pencil, light switch, or pop can the germs are on your hands and fingers. If you touch your eyes, mouth or nose, which are openings into your body, with your hands or fingers the germs go inside your body and you may get sick. Do not eat with your hands without washing them first.

15mg of Zinc daily is a good way to keep your immune system healthy but check with your doctor first before taking to make sure it is ok.

Remember, you cannot avoid touching germs, but you can avoid letting them make a home inside your body and making you sick. Wash those nasty germs away by washing your hands many times a day with soap and water and stay healthy!



# Coarsegold Woman Nominated for Charity

Article by Margaret Carrero

[http://www.kmjnow.com/pages/landing\\_news?Coarsegold-Woman-Nominated-for-Charity=1&blockID=440412&feedID=806](http://www.kmjnow.com/pages/landing_news?Coarsegold-Woman-Nominated-for-Charity=1&blockID=440412&feedID=806)



A Valley woman may soon be inducted into a very special Hall of Fame.

Susanne Waite of Coarsegold was only 27 when she learned that her 35-year-old husband had Kennedy's Disease, a rare and degenerative neural-muscular disease that leads to muscle weakness and atrophy.

"It was tough," recalls Waite of the three years it took doctors to finally produce a diagnosis and even then she says, "...no one knew how long he'd live, how fast it would progress, if we had children what would happen, we couldn't get those answers."

So in August 2000, the Waite's took matters into their own hands by launching the non-profit "Kennedy's Disease Association" where they've been able to connect with others who are suffering from the disease, while raising money to fund research grants.

Waite says there may also be a promising new drug going into clinical trials over the next year, which would be a positive step toward battling a disease with no known cure.

Over the years, Kennedy's Disease has taken a toll on her husband who now has to use a wheelchair because it's grown increasingly more difficult for him to walk long distances.

"He's getting weaker but he has good spirits, and he's trying to do the best he can with what he has available as far as strength goes," adds Waite.

Earlier this year, Waite's mother nominated her for induction into Energizer's 2011 "Keep Going Hall of Fame" which recognizes everyday people for their extraordinary acts.

Waite has since been tapped as one of 100 semifinalists and jokingly alluded to being a "shoe in" because her nickname growing up was "energizer bunny".

Judges are expected to narrow down the pool to 9 Finalists by Thursday, March 17th, at which point Energizer Bunny Facebook fans will get the

opportunity to vote for the 10th Finalist, all of whom will receive a \$1,000 donation to the charity of their choice.

The 2011 Inductee will then be chosen by a public vote on Energizer's website beginning April 4th, with the winner being awarded a \$10,000 cash prize plus another \$5,000 donation to his/her favorite charity.

The winner will be formally inducted into the Hall of Fame by 2006 inaugural inductee, Cal Ripken, Jr., in June.

## BREAKING NEWS

Susanne Waite, KDA President Emerita and co-founder, has made it into the Top 10 and is a National Finalists for the Energizer "Keep Going" Hall of Fame Contest!

Thank you for your votes. The Kennedy's Disease Association will be receiving a \$1,000.00 check for Susanne making it into the Top 10 Finalists!

We need your help again to bring home the big prize. Please take 30 seconds to vote today and every day through May 13th. (A Facebook account is NOT needed) Click on this link to cast your vote now:

[www.energizerkeepgoinghalloffame.com/Finalists.aspx?finalists=SusanneWaite](http://www.energizerkeepgoinghalloffame.com/Finalists.aspx?finalists=SusanneWaite) You can only vote once per day, but you can vote every day through May 13th. The Energizer website will ask for your name and an email address. Energizer states this is not being collected for any marketing purpose, but is their way to verify that only one vote per person is being registered.

If Susanne wins the Grand Prize - an additional \$5,000.00 will be donated to the KDA by Energizer, Inc. The remainder of the \$15,000 prize, Susanne promises to divide up amongst these non-profits: KDA, American Cancer Society, Alzheimers Association, Veteran's Association, SPCA, Central Valley Food Bank - 24% of those living in the Fresno area go without a meal each day, Manna House, Poverello House, Terry's House, Boys & Girls Club, and 4-H/FFA

## The KDA Continues to Grow KDA has 977 associates located in 42 Countries

- 575 are men with the defective gene (59%)
- 108 are carriers (11%)
- 294 are family, friends, and caregivers
- Additionally, 76 doctors and researchers are also registered with the KDA

Source: February 2011 KDA database

## The 2011 KDA Conference and Educational Symposium



**Date**

**November 9, 10, and 11**

**Location**

**Sheraton Baltimore-Washington Airport Hotel - BWI**

1100 Old Elkridge Landing Road  
Linthicum Heights, MD 21090



On Tuesday evening, November 8, there will be an informal (Dutch Treat) dinner for those arriving early. Further details will be made available in the early summer.

Conference Chair: Paul DeSchamp  
Conference Team: John Coakley, Sr.

### **Volunteers are needed**

Paul needs your help. If you are interested in helping to plan the conference, please email the KDA at

[info@kennedysdisease.org](mailto:info@kennedysdisease.org)

## Good News on the Research Front



Over the last few years, ASC-J9 has shown itself to be a potential treatment for Kennedy's Disease.

Background: In 2006, the KDA's Scientific Review Board recommended the awarding of a research grant to **Chawnsang Chang, Ph.D., of the University of Rochester**. Dr. Chang's research was focused on developing a treatment regimen for Kennedy's Disease targeting the poly Q-expanded mutant AR. A few years later, AndroScience purchased the rights to this technology.

In late January, AndroScience and NIH announced a grant to move this potential treatment's research along. Follow this link ([ASC-NINDS](#)) to the PR-Newswire site to read the entire press release. A summary of the release can be found below.

### **“AndroScience Corporation Awarded a \$3.8 Million, 3-Year Milestone-Driven, Cooperative Translational Research Grant from the NIH to Develop an Oral Treatment for Spinal Bulbar Muscular Atrophy (Kennedy's Disease)**

SAN DIEGO, Jan. 25, 2011 /PRNewswire/ - AndroScience Corp. (ASC), based in San Diego, California, announced receiving a \$3.8 Million, 3-year milestone-driven, cooperative translational research grant from the National Institute of Neurological Disorders and Stroke (NINDS) of the National Institutes of Health (NIH).

Through a joint research effort with the Neurogenetics Branch of the NINDS, ASC will use the funding to pursue development of an oral drug treatment for spinal and bulbar muscular atrophy (SBMA) or Kennedy's

Disease, a rare hereditary neurodegenerative disease, which currently has no approved drug available to patients. Key pathological features of SBMA include progressive motor neuropathy and androgen insensitivity syndrome caused by a distinctive mutation within the androgen receptor (AR) gene. ASC has developed a unique platform of therapeutic small molecule drugs, which selectively and potently enhance degradation of the AR protein, termed AR degradation enhancers (ARD enhancers).

"Given encouraging pre-clinical results and the clear need for a new therapeutic option for SBMA patients, ASC is excited to continue advancing preclinical development of this promising novel drug candidate," said ASC President Charles Shih, Ph.D. "The funding provided by the NINDS/NIH will significantly propel our efforts in validating ARD enhancers as a disease-modifying therapeutic intervention against such a rare and devastating neurodegenerative illness."

This \$3.8 Million cooperative translational research grant will leverage expertise from the NINDS and draw upon ASC's innovative approach to targeting the mutant androgen receptor (AR). The goals of the grant will be to first validate an orally administered ARD enhancer drug is efficacious in the SBMA transgenic animal model, and further, to complete preclinical toxicology, safety pharmacology, and ADME studies necessary in supporting of an IND filing to commence human clinical studies. To date, ASC has provided robust proof of concept data using an ARD enhancer compound; demonstrating treatment ameliorates cardinal features of SBMA neuromuscular pathology, restores functional activity, and improves survival in a SBMA transgenic mouse model."



## Dutasteride Clinical Trial

<http://www.ncbi.nlm.nih.gov/pubmed/21216197>

NIH published the results of their dutasteride clinical trial in January. The section of the report on "Findings" gives us hope. "At 24 months, the placebo group showed a decrease of 4-5% from baseline in weight-scaled muscle strength as indicated by QMA, and the dutasteride group had an increase in strength of 1-3%; the difference between groups (5-8%, 95% CI -5-9 to 17-6; p=0-28) was not significant."

Also interesting was, "Quality of life, as measured by the physical component summary of the Medical Outcomes Study 36-item Short Form version 2, favored dutasteride (change in score from baseline: placebo, -3-6%, vs. dutasteride, +2-1%; p=0-01), whereas the mental component summary favored placebo (3-3%vs -3-2%; p=0-03). The dutasteride group had fewer patients reporting falls than did the placebo group (9 vs 16; p=0-048); there were no other significant differences in reported adverse events."

The interpretation of the trial from a researcher's perspective reads, "Our study did not show a significant effect of dutasteride on the progression of muscle weakness in SBMA, although there were secondary indications of both positive and negative effects compared with placebo. A longer trial duration or larger number of patients might be needed to show an effect on disease progression. Performance testing, QMA, and quality of life measures were identified as potentially useful endpoints for future therapeutic trials."

Link: <http://www.kennedysdisease.org/>

After months of planning and work, the new Kennedy's Disease Association website was launched at the beginning of February, 2011. If you have been to the site, you will see that it has changed completely from the look of the old site.

It was a major undertaking to update the website to enable the use of the latest technology and software. The new site is "pretty" and navigation is easy. It also took a lot of work to ensure that all the new features that were added worked, and all the necessary files were transferred from the old site and were useable. Even though the site is intended to be almost self-explanatory, there are a lot of features that were added, expanded and moved so there may be a little confusion. Since there have been so many changes, it was difficult to keep this article short unless I focused on just some of them.

The new website functions like many other websites and with similar features. Selecting any one of the headings across the top of the page or along the left side of the page will display a sub-menu to select items from for further investigation. At the bottom of the Home page there is another menu that displays the sub-menus under each of the headings. These are what I call "quick links" to information and features probably used the most like the Chat Transcripts, Chat Room, KDA Forum and the Newsletters. This is my favorite means of navigating around the site.

Some of the new features are obvious, while others are not. They now allow for animation, video, more links to other sites, and conversion to PDF files, printing and email. There is a Search engine and expanded language translation capability. Yes, there is even a link with the KDA on Facebook.

The first thing you probably notice is the Slideshow. There are four slides that you can scroll through that give a brief topic summation. Under each of the pictures you can select to Read More about the topic displayed by the slide. Once the text is displayed, you will see three icons on the right-hand side of the page for PDF,

print and email. These are features that you will find on most other pages as well.

Scrolling over each of the icons provides a brief description of each. Selecting the PDF icon converts the text to a PDF file for saving, printing, etc. I'm not sure what I would use it for, but it's there.

Selecting the print icon prepares selected text for printing in a friendlier format, rather than using the browser print function that would print the whole page. A new window opens displaying the text so you can see what will be printed.

The email icon looks like a little envelope. Selecting the email icon opens a window that allows you to email the link to that page to someone, or yourself.

In the upper-right of the page you will find the language selection feature. The expanded language translation capability now has a drop-down list of over 50 languages to choose from. The most used language selections are still represented by the flag icons. More people, from more countries can now use the website and have most of the information displayed in their preferred language.

One thing I noticed is that once a language is selected, the script on the page translates right in front of you. Select another page and suddenly the text changes from English to whatever language is selected. That is amazing! Even the Chat transcripts get translated. However, the text may not translate completely or accurately in all cases. Many of my funny Chat comments don't appear "funny" in some languages. I guess it does lose something in the translation. I'm not fluent in any language so I just hope the text doesn't get translated to something inappropriate.

The Search engine is like the search found on other sites. A search using a single word will return all instances of that word, which may display more than one expects, and irrelevant information.

It's nice that any previous searches appear in a drop-down when you start to type a word. The search function does have some limitations though.

The search feature is limited to words not less than three characters, and not more than twenty. There is no indication of this limit until you type in your search and select <Enter>. Some medical terms are more than twenty characters so text entry stops when twenty characters is achieved. Basically, keep your search text short and accurate.

Correct spelling of a word or term is important using the search feature too. Every effort was made to make sure words were spelled correctly. By that I mean the American English spelling. Medical terms can pose a problem like, Guillain-Barre. I prefer to use the Medical Dictionary selection at the bottom of the Home page for finding those words.

If you are really curious about how much information is on the site, select the Sitemap. There you will find a list of everything on the website. It's like the index in the back of the book. That is a lot of information! It can also be a good way to search for and locate what you are seeking rather quickly. Just scroll down and select the item you want to view.

Though there have been many changes, you will find that some of the familiar links like Contacts, List of Doctors, Donate and KDA News still exist. Online shopping through the KDA is still available and has been increased.

I could go on about more of the items on the website, but it would take too long. I will say that I think the new site is a success. If the numbers listed in the visitor's log is any indication, I think other people like the new site as well. I should mention that those numbers also represent something the KDA has discussed many times: how to get more visibility. It appears the numbers show that we have achieved that goal too. Happy browsing.

# Green Thumb

Article by Mary Goynes

The one with the greenest thumb wins...

How many times have you heard someone say, "I don't have a green thumb" or, "I have a black thumb when it comes to plants."

For me, I think the gardening trait is passed from parents to child – and depending on your affinity for digging in the dirt, you will exhibit the trait – and develop a green thumb!

According to the Old Farmer's Almanac, the origin of the phrase is linked to the reign of King Edward I of England, who enjoyed fresh green peas so much that he had half a dozen serfs working to keep him supplied, a prize going to the one with the greenest thumb.

I think I inherited the gardening trait: I love to garden. And in my family I'm in good company. I would say that just about all of us love to garden. My brothers and their kids all have gardens, and most of my cousins also like to garden. Each of my three children is into gardening too.

Looking back, my mom, sister and brother all gardened and joined clubs in their communities to beautify – using their green thumbs. Looking even further back, her mom, my grandma, might have been the most famous in the family, winning prizes for her mums, spider lilies and victory gardens.

Grandma Bering, in fact, was featured in the Houston Post newspaper frequently with articles about her skills in the greenhouse.

She wasn't the only one though. My cousin Matt White (from the Bering and Foxes side of the family) is a professional gardener, and he's booked with clients year round, and has a waiting list. His family tree has the green thumb on both sides. His great-grandfather Hugh McLeary built the original gardens for Sam Houston Park, the first park established in Houston. Today the park includes the historical house built around 1847 that was the birthplace of Hugh's daughter – Matt's grandmother.

My grandpa Goynes, on my dad's side, was a farmer too, so you could say my family traits were passed down from two clans of Irish and German immigrants who worked the soil.

So, I'm talking with my cousin Gene Bering (volunteer editor for KD publications/newsletter committee) and he remembers his dad Cy as a gardener:

"Dad grew everything, from roses to tomatoes to bougainvillea," Gene said. "But he really loved azaleas, and cultivated a bunch of them around the yard. He had a small greenhouse, and for years, his Christmas list would always be the same: Potting soil, clay pots, mulch and compost. That says it all about his love for growing things."

My brother Mike Goynes, vice president of the KDA Board of Directors, thinks this is all pretty intriguing.

"I never thought of it but there may be others that can confirm that our families are very good at growing things. I remember, when we had our garden in South Carolina, how my neighbor used to come over and marvel at how good our corn, okra, beans, peas, and tomatoes would be compared to his. And he was the one who showed me how to do it!"

Mike and I compare notes and share seeds on every kind of flora that grows between Texas and Florida.

Gardening can be many things. It's an opportunity to learn about how to prepare, how to cultivate, how to nourish – and how to be patient.

In our language, we're all gardeners: We plant ideas, branch out, put down roots, have a family tree, try to nip things in the bud, and reap what we sow. We're like two peas in a pod, our kids grow like weeds, and what at first looks like a tough row to hoe often turns out to be small potatoes.

But maybe some gardening talent has to be genetic – just like some people have an affinity for music or numbers, or language or art. It has something to do with ability. And I think it also has to do with affinity, a desire to work at something until you're good at it – or until your thumb gets greener.

**Working together to find a cure ...**  
For our generation ... and for our children  
and our grandchildren



**The KDA's mission is to inform, support,  
communicate, educate, research,  
and find a cure for Kennedy's Disease**

# Get Involved....Make a Difference!

Article by Lou Tudor

We are so fortunate to have the Kennedy's Disease Association (KDA) to help us, to guide us and to provide friends who truly understand the trials and tribulations of this neuromuscular disease.

I realized after attending my first KDA conference last November that we have gained a whole new family. We help each other and do whatever we can for the good of the group. In ten short years, this Association has made a huge difference in our lives with worldwide outreach and important discoveries toward finding a cure for Spinal Bulbar Muscular Atrophy. (SBMA) (aka Kennedy's Disease)

I am extremely pleased to tell you about some of our current members, friends and family making a difference...

- Carla and Stan Highe and family have been busy planning for their May 15, 2011 swap meet space at the Gilmore Car Museum (located midway between Kalamazoo, Grand Rapids, Lansing and Battle Creek, Michigan). The attraction is the "Dust Off" Car Show. They'll be selling KDA shirts printed "Show us YOUR Muscle!" Great creativity to bring in much needed funds and public awareness!
- Sean Blasko has turned his hobby into a fundraiser for the KDA! This Austin, TX neighborhood has a yearly community garage sale and Sean sold plants and trees from his greenhouse. His signage "All Proceeds Benefitting the Kennedy's Disease Association" helped to create public awareness... and he had printed handout KDA brochures ready.
- I'm very proud of my husband, Bill Tudor! Instead of accepting a business consulting fee, he instead asked for a donation to be sent to the KDA. The Florida company president was pleased to learn about Kennedy's Disease and all the fine work being done by the KDA to find a cure.
- A Kennedy's Disease Golf Tournament will be held October 1, 2011, at the Jersey Village Golf Course in Houston, TX! The committee members working hard toward the 8:00am shotgun are Murray Williams, Ed Noack, Mike and Verna Noack and Charlie and Louise Goforth. All proceeds will benefit the KDA and we hope this will be an annual event!
- Californian, Beth DuVall, is at it again. Last year, Beth raised \$4,000 in donations for her "Running for a Cure" for the KDA! She is hoping to top that amount this year and is asking for everyone's help to get the word out! Please support Beth in her run that will take place in May. You can make a donation directly to the KDA, PO Box 1105, Coarsegold, CA 93614 or via the Razoo Website which will add your donation to Beth's page which shows if she is on track to meet her goal...  
<http://www.razoo.com/story/Running-For-A-Cure-Part-Deux?1299045182>

## The 2010 KDA Conference and Educational Symposium

The first two videos are now available for viewing on YouTube.

(1) [The role of the KDA in Kennedy's Disease Research](http://www.youtube.com/watch?v=TbXJZpZdA58) is presented by Ed Meyertholen.

(<http://www.youtube.com/watch?v=TbXJZpZdA58>)

(2) [Family Planning: Kennedy's Disease Free Children through IVF](http://www.youtube.com/watch?v=2yV5-eJ2-Q4) is presented by Cliff Johnson from Australia.

(<http://www.youtube.com/watch?v=2yV5-eJ2-Q4>)

- Paul Buck from Millbrook, Ontario, Canada, Kimberly Rife from Hainesport, N.J. and Tiffany Beck-Ortner from Duluth, MN are working together to organize the KDA Cookbook II. Version I was a complete sellout! Submit your favorite food dishes by April 30, 2011 and get published! All recipes may be e-mailed to [pbuck@nexicom.net](mailto:pbuck@nexicom.net)
- Sarah Myers is doing her High School Senior Project to benefit the KDA! She has organized, promoted and will serve a 6:00pm Tri-Tip Dinner at the Raymond General Store in Raymond, CA on May 22, 2011. Pre-sale tickets are \$12 and \$15 at the door.
- Nancy House is the founding president and current member of the Central Square, NY Lioness Club. Each year the club members host various fundraisers to benefit local charities and those affecting member families. For the past two years the club has sent a check to the KDA to help fund research!

We are extremely thankful to all the friends and family doing their part to raise money for a cure. Hopefully their enthusiasm is contagious!

Lou Tudor  
Fundraising Chair  
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*"Working together to find a cure"*

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