



KDA e-Xpress

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Spring - 2007

2007 KDA Conference and Symposium

“AN EYE ON TOMORROW”

Where: The Golden Nugget Hotel in Las Vegas, NV

- Reservations by telephone: 800-846-5336 (don't forget to mention you're booking for the KDA conference)
- The room rate is \$89/night plus taxes for Sunday (11/04) through Thursday (11/08). The cost for Friday and Saturday will be \$129/night plus taxes.

When: Tuesday thru Thursday, November 6 – 8

Registration Fee: \$200 – on or before September 1, 2007
\$235 – after September 1, 2007

Additional Information:

- The KDA has blocked several rooms for each night of the conference.
- Handicapped rooms can't be held unless booked so they are on a first come first serve basis. Make your reservations early.
- A pre-conference dinner on Monday night, November 3 (cost not included in the registration fee) will be "[Tournament of Kings](#)" **Jousting Dinner Show** at the Excalibur Hotel & Casino.

New Targets Discovered to Potentially Stop Conditions Like Kennedy's Disease

KDA FUNDED RESEARCHER PUBLISHES INITIAL FINDINGS

Note: In 2006, the KDA awarded a \$25,000 research grant to, Chawnshang Chang, Ph.D.

To read the entire article, click on the following link:

<http://www.sciencedaily.com/releases/2007/03/070320103807.htm>

EXCERPT: Scientists who focus on the molecular signaling that underlies prostate cancer have discovered a compound that shows promise against a debilitating neurodegenerative condition known as Kennedy's disease, which is caused by a mutant gene. The compound, a distant chemical relative of a component of the spice curry, dramatically slowed the progression of the disease in mice that carried the mutant human gene that causes the disease. The mice were able to walk much more normally, their muscles were much stronger, and they had near-normal levels of a vital molecule crucial for keeping nerve cells healthy. While a great deal more research needs to be done to see if the compound could be developed into a drug to help people with the disease, scientists say it's a promising development. The research by scientists at the University of Rochester Medical Center appears in the March 6 issue of the journal *Nature Medicine*.

In their search for new treatments for prostate cancer and other diseases, Chawnshang Chang, Ph.D., and his colleagues have taken a few cues from centuries of Asian tradition, where curcumin – the bright yellow spice found in curry powder – has been used to treat a variety of ills. Chang's laboratory, in collaboration with San Diego-based AndroScience Corp., has screened hundreds of compounds for their activity involving the androgen receptor, which is also involved in prostate cancer, acne, and enlarged prostate, as well as Kennedy's disease. Among the compounds tested is ASC-J9, a synthetic chemical compound that is loosely based on a compound found in curcumin.

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- There will be a silent/noisy auction with a real live auctioneer this year so everyone is requested to bring an item to the Wednesday night dinner.

The agenda for this year's conference will include:

- Kennedy's Disease Association up-date
- Paul Martin Dir. & Pres. – Nevada Equal Access
- Dr. Nicholas Di Prospero – NIH Clinical Trial Update
- Ed Meyertholen - Layman's Guide to KD
- Wives/Sign. Others & Carriers Group Discussion with a guest therapist.
- Men's Group Discussion with a guest therapist.
- Doctors and Researchers Updates and Panel Discussion
- Doctors/Researchers Private Discussion Symposium

Friends Who Are No Longer With Us

WE GRIEVE AND WE REMEMBER

The following is a list of KDA associates and friends who left us this last year:

- Denny Neu 1951-2006
- Patrick Griffin 1950-2006
- Patrick Hagarty 2006
- Wolf Kemna 2007
- John Kopycinski 1949-2007
- Jerrold Brown 1955 - 2007

We apologize if we missed anyone.

View several memorials at the following link:

http://www.kennedysdisease.org/disc_memorials.html

If you have a loved one with Kennedy's Disease who has passed away and would like to have them added to the memorial page, e-mail the KDA at info@kennedysdisease.org with the information and a picture. If you do not have a picture on your computer to send via e-mail you can mail it to us via regular US mail at the address below. We will scan the picture and return the original to you.

Significantly, however, ASC-J9 has been chemically modified compared to its natural counterpart to make it much more powerful. Despite the promise it offers for Kennedy's disease, Chang notes that ASC-J9 must be rigorously screened for side effects and effectiveness, through clinical studies in people, before it can be considered as a possible treatment for any disease. "The compound we are studying has been significantly modified from the original ingredient found in food like curry or ginger," said Chang. "It still must be tested in people. We certainly don't want to mislead people to think these foods themselves have any benefit for Kennedy's disease."

In 1988 Chang was the first to clone the androgen receptor, and he was the first to discover that the protein needs molecular allies called co-factors to accomplish many of its tasks. Now more than 70 co-factors are known, offering many new targets to potentially stop conditions like Kennedy's disease that involve the receptor itself. Chang's work has led to an understanding of the genetic basis of Kennedy's disease, which affects the motor neurons that go from the spine to certain muscles, causing muscle weakness and wasting throughout body.

In the experiments reported in *Nature Medicine*, mice carrying the human gene that were treated with ASC-J9 experienced a remarkable improvement. They were more mobile than their untreated counterparts, walking more normally and dragging their legs less often. Their muscles appeared to work normally, and they lived 40 percent longer than the untreated mice. In addition, the mice treated with ASC-J9 were able to mate and produce offspring, while their counterparts could not.

Chang's team found that ASC-J9 appears to work by breaking up a sort of molecular clog in neurons affected by Kennedy disease. In such diseases, the extra amino acids become part of abnormal proteins that clump up inside neurons, creating a clog that can bring normal molecular activity to a standstill. The clumps of material eventually become toxic to neurons. In Kennedy's disease, a vital molecule known as CREB-binding protein or CBP becomes bound up or entangled by the clumps in motor neurons. As the clumps dissolve, CBP moves throughout the cell as it normally would, producing more VEGF. Ultimately, the work brought about healthier mice whose symptoms were much improved. Chang's team also found that the amount of abnormal clumps in the neurons and spinal cords of the mice was slashed by half, and that VEGF activity in the neurons went up more than four times in the treated mice compared to untreated mice.

To read the entire article, click on the following link:

<http://www.sciencedaily.com/releases/2007/03/070320103807.htm>

Donated Items for Sale

**ALL PROCEEDS GO TOWARDS
KENNEDY'S DISEASE RESEARCH**

These used chairs were donated to the KDA. They are available through Ron Wiker in Lancaster, PA. All chairs require customer pick-up (no delivery available). Call (717) 393-0504 for additional information.

Pronto M71 Electric Chair - \$1,000

- The Invacare® Pronto™ M71™ power wheelchair with SureStep™ offers excellent maneuverability and true centre-wheel drive performance in a compact, stylish design. With its innovative SureStep technology, the M71 drives smoothly over transitions and thresholds up to two inches while maintaining stability.

Jazzy 1113 ATS Electric Chair - \$1,000

- The Jazzy® 1113 ATS offers you everything you need -- all of the "big chair" options and accessories, even full rehab capabilities -- on the most compact frame available. You'll take on tight spaces and narrow hallways without sacrificing a strong outdoor performance never before seen in a chair of this size. For sharp ramp transitions as well as a smooth and stable ride even over exceptionally rough and uneven terrain, this Jazzy is equipped with Active-Trac® Suspension.

The lift below is available through Murray Williams in Katy, TX (Houston area). The lift requires customer pick-up (no delivery available). Call (281) 392-3603 for additional information.

Bruno VSL 670 CurbSider Wheelchair Lift - \$1,500

- Lift is in new condition. New nylon strap.
- Four-point lifting attachment comes with quick disconnect buckles. (seatbelt type)
- Fits all mini vans without fold away 3rd seats.
- Right (passenger) side mounting.
- Maximum load 400 lbs.
- \$2,550 new - It comes with manual and personal three month guarantee.

Funding Research is Critical

**RESEARCH JUST DOESN'T HAPPEN ...
IT HAS TO BE FUNDED BY SOMEONE**

As we mentioned last fall, the federal government has reduced the funding available for medical research. As a result, research projects for Kennedy's Disease, along with other lesser known, lower public profile illnesses are being seriously under-funded.

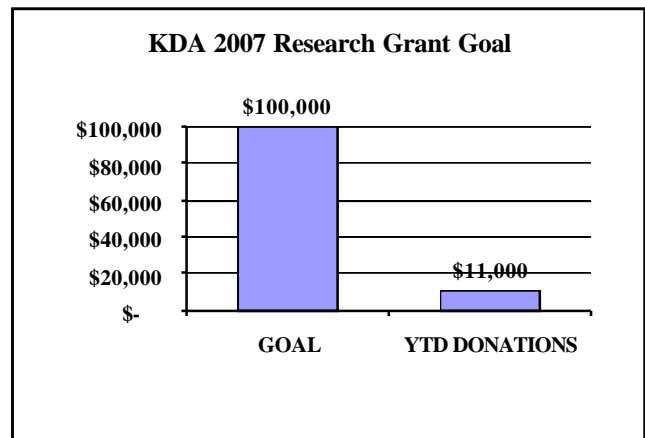
As reflected earlier in the Dr. Chang article, research is crucial to finding treatments and a cure for this disease that has affected all of our lives. From December 2005 through November 2006, the KDA awarded \$75,000 in research grants.

KDA RESEARCH GRANT GOAL FOR 2007

Our goal for 2007 is to award **\$100,000** in research grants. Yes, it is an aggressive goal, but not an unreasonable one based upon the generosity you have shown this past year. Through the first quarter of 2007, however, we have only received \$11,000 in donations. We have a long ways to go to reach our goal, but with you help we can make it.

Please consider making a donation today:

<http://www.kennedysdisease.org/help.html>



If we all continue to work together, there is hope that someday soon, we will have a treatment or even a cure for Kennedy's Disease.

The 2007 KDA Board of Directors and Officers

- Executive Director and Treasurer - Terry Waite
- President - Bruce Gaughran
- Secretary - J. Murray Williams
- 1st Vice President - John Coakley, Sr.
- 2nd Vice President - Ron Wiker
- 3rd Vice President - Paul DeSchamp
- Member at Large - Mike Goynes
- Member at Large - Ed Meyertholen

Other KDA News

2006 ANNUAL REPORT

The KDA Annual Report for 2006 can be downloaded from our web site by clicking on the following link:
<http://www.kennedysdisease.org/2006-Annual-Report.pdf>

COOKBOOKS

The KDA has a wonderful cookbook, "Recipes from around the World." It contains 300 recipes including many contributed from KDA Associates. The books are \$12.00 when shipped within the US. If the books are to be shipped outside the US, please email the KDA for possible additional costs.

KDA Forum

"Have you visited the forum recently?"

The KDA forum is alive and well. There are many topics posted covering a variety of subjects. The benefits of this forum service include: No advertising and Email notification of message replies. Visit the forum on our web site. http://www.kennedysdisease.org/disc_forums.html

KDA Chat Room

Chats are scheduled for the first and third Saturday of each month at 10:30 Eastern Time. If you missed a chat, you can still read the transcripts at:

http://www.kennedysdisease.org/disc_transcripts.html

2007 SCHEDULED GUESTS

- 04/21/07 – Angela Kokkinus – NIH Clinical Trial
- 05/05/07 – Dr. Nicholas Di Prospero – NIH Clinical Trial
- 06/02/07 – Dr. Diane Merry – Gordon Research Conference
- 06/06/07 – Dr. Andrew Lieberman – Research Update
- 08/08/07 – Dr. Paul Taylor – Research Update
- 11/17/07 – 2007 KDA Conference Review

KDA e-Xpress

**A publication of the
Kennedy's Disease Association.**

Editor: Bruce Gaughran

Comments, suggestions, and questions should be sent to:
kennedysdiseaseinfo@gmail.com

For Additional Information

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Coarsegold, CA 93614

Phone: 559-658-5950

Email: info@kennedysdisease.org

Web Site: <http://www.kennedysdisease.org>

The Objectives of the Kennedy's Disease Association

- Sharing information about Kennedy's Disease with those who seek it
- Creating a support system for those living with Kennedy's Disease
- Increasing public awareness of Kennedy's Disease and its effect upon families
- Increasing awareness of Kennedy's Disease in the medical community
- Raising funds, with an aggressive target to earmark at least 70% of every dollar donated to be used for Kennedy's Disease research