



# KDA E-Xpress

Volume 1, Issue 1

July 2004

## A New Format

The KDA would like to update you in regards to information and happenings on a regular basis. We would like to try this newsletter format and would be interested in your thoughts:

- What do you think about our new format?
- What would you like to see in this newsletter?
- Should it be available online on our Web site? E-mailed to our associates?
- Do you want to receive this newsletter?

Send your comments/thoughts to:

Susanne Waite, KDA President and Executive Director [tswaite@sti.net](mailto:tswaite@sti.net)

## 2004 KDA International Conference & Symposium

**Theme:** "Edge of Discovery"

**When:** October 20-22, 2004

**Where:** San Diego, CA – Holiday Inn Select

**Conference Info:**

[www.kennedysdisease.org/conference2004.html](http://www.kennedysdisease.org/conference2004.html)

**Agenda:**

[www.kennedysdisease.org/agenda2004.html](http://www.kennedysdisease.org/agenda2004.html)

**Registration Info:**

[www.kennedysdisease.org/registration2004.html](http://www.kennedysdisease.org/registration2004.html)

!

Come join us and enjoy the area, its warm climate, friendly comraderie, and the 3rd KDA Conference and Symposium packed full of information pertaining to those living with KD. The KDA's Conference Committee has put together quite a line-up at an affordable cost.

The "Early Bird" Registration fee is only **\$160.00 per person through September 1, 2004.**

The Registration fee covers your attendance at the breakout sessions, continental breakfasts, break food and drink and the dinner banquet as well as publication of meeting materials, meeting room, etc.

Southwest Airlines now has a \$39 - \$99 one-way fare special(s) for anywhere they fly - you might want to take advantage of this special and book your flight now. Please also don't forget to book your hotel room- \$109.00 per night (+taxes).

We've even secured a couple rooms at that price for those that want to stay the weekend.

**Special Thanks:** We would like to express our thanks to the following KDA Associates who are serving on the Conference Planning Committee: Michael Buttner, Bill Ericson, Paul Jacobson, Len Janicki, Pat Peper, Paul Hagenbuch, Gail Zittel, and Susanne Waite.

## INSIDE THIS ISSUE

- 1 New Format – the "KDA E-Xpress"
- 1 Edge of Discovery – 2004 International KDA Conference & Symposium
- 2 Grant Recipient Updates
  - ~ J. Paul Taylor, M.D., Ph.D.
  - ~ Andrew Lieberman, M.D., Ph.D.
- 2 Board of Directors Meeting Highlights
- 3 Bright Lights in the KDA – Helping Raise Funds for Research – Alan Jinks, Tara Mills, and Ella Mills
- 3 First Regional Meeting – Northeast
- 4 Neurogenetics – KD'r (Charles Rannells) Volunteers to be Studied
- 4 International KD'rs at Work

## KDA Grant Recipient Research Updates

From **J. Paul Taylor, M.D., Ph.D.,  
University of Pennsylvania, on  
the Drosophila (Fruit Fly)  
Model:**

- We have been proceeding with the new transgenic Drosophila. Meanwhile, the past few weeks have been devoted to establishing two techniques that are important for thorough characterization of the SBMA Drosophila model. The first is called semithin plastic section histology. Basically, this is a technique that allows high resolution analysis of the neuropathology that our animals are experiencing. It is likely that we will be able to detect neuropathology with this technique well before it becomes evident by looking at the whole animal. This is important in determining the earliest events that are occurring at the cellular level when these animals begin to show signs. The second technique is called transmission electron microscopy. This technique allows us to evaluate the pathology at a sub-cellular level. Basically, this allows us to look inside the affected neurons at individual cellular components like mitochondria and see if they are affected by the mutant androgen receptor. The senior research specialist in my lab, Zhiping Nie, has gotten both techniques working very nicely and we are enthusiastic about applying this to the Drosophila model throughout the summer and fall.

From **Andrew Lieberman, M.D.,  
Ph.D., University of Michigan,  
on the Knock-In Mouse Model:**

- We're making steady progress characterizing our knock-in mouse model of Kennedy's disease. We're currently aging the mice that we've got, and following them by monitoring weight and motor activity. We've also

*(continued next column)*

surgically castrated a group of mutant males and treated carrier females with testosterone. Those experiments are just underway. We're also breeding the mutant mice we've got to put them on a uniform genetic background. This should help us interpret the effects of the mutation. All of these experiments will likely take months to complete. At that point, I hope we'll have some interesting data to share with the Association's associates.



## Board of Directors Meeting Highlights

### Tissue Donation Program:

- Development of a tissue donation procedure manual. It will be announced when this is complete. Also in development is the idea for a "pre-registration" program

### New and Improved Online Forum:

- Discussion of utilizing a different forum that is easier to use, requires no personal information to obtain an user-id, has no pop-up advertisements and will hopefully foster more forum posts and activity

### Neurologist Mailer:

- Mailer is being prepared to drop through a fulfillment house to approximately 12,000 neurologists - due to the Waite's move to Coarsegold, CA, the brochures and envelopes need to be updated - various methods have been discussed and the board has agreed on a plan of action to move forward

## Regional Meetings

### First one to take place in September 2004 for KDA North- Eastern Associates

This one-day event has been spearheaded by the volunteer work of Paul DeS champ of Maine.

Paul states, " When I was diagnosed with Kennedy's Disease my first thought, (**after will it kill me?**), was, who else had this disease and how are they doing. Well, I found the Kennedy's Disease Association. The KDA, through its national meetings, provided my wife and me with the opportunity to meet, face to face, with other people that were in the same situation we were in. Meeting other KD'rs has been an extremely positive experience for us.

The goal of this Regional Meeting is simple. To provide KD'rs, and their families, the opportunity to meet with other KD'rs from the Northeastern states in a social and unstructured setting. The event will have two dinners, a one day meeting, and hopefully, unlimited networking between the participants. We want it to be fun and rewarding. "

We thank Paul for taking this task on - voluntarily!

Good luck to you all for your first meeting and we hope you walk away with many memories and lifetime friendships!

If you are in the North-Eastern part of the US and would like more information - contact Paul DeS champ:  
[pkdeschamp@capcomp.com](mailto:pkdeschamp@capcomp.com)

If you are interested in volunteering to put together a Regional Chapter and/or Meeting in you area, please notify the KDA at  
[info@kennedysdisease.org](mailto:info@kennedysdisease.org)



## Bright Lights Helping the KDA – Raising Funds to aid Research

**Alan Jinks - England** – a Chartered Engineer by profession works for a large company called National Grid Transco which operates in the UK and the US running gas and electricity systems. Every year there is a award for contributions to health and safety and this year Alan and a colleague have won this award ... the prize is £7500 (\$14,000 US) donated to a charity of my choice .. I have, naturally, nominated the KDA to receive the money. Updates in this regard will be forthcoming.

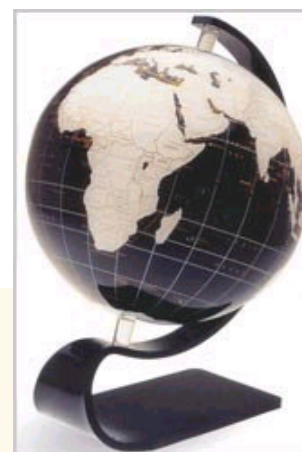
**Tara Mills - United States** - a KD carrier who recently joined the KDA plans on doing some Fund-raising. Her sister (not a carrier) is running her first mini-triathlon on August 15th, 2004 in Harrison, BC and on behalf of their two affected Undes and those in their family that carry the genetic mutation. Tara and her sister are collecting pledges for the KDA and their goal is to raise \$1000. They are currently at the \$400 mark at the moment and they have over a month to go. They also plan to do hot dog and bake sales

## Neurogenetics – Rannels Chosen for Panel Participation

Charles Rannels, a KDA member, will participate in the Neurogenetics Short Course at the National Society of Genetic Counselors ([www.nsgc.org](http://www.nsgc.org)) as a panelist discussing "Individuals Whose Lives Are Impacted By Neurological Disorders".

Charlie and Anna Lea reside in Martinsburg, WV and will travel to the Hyatt Regency in Washington, DC for his participation in this two day course October 6-7, 2004.

He was invited to be one of five panelists nationally by Jennifer Lieb, Ph.D. whom many of us know from the NIH. Also attending this course will be Kurt Fischbeck, M.D., Ph.D. and Charlotte Sumner Ph.D. from NIH.



## International KDA's at Work:

ARMK (France) – Yves Martin, Jean Jacques, and others in France met through the KDA and decided together they could make a difference – they've since put together a Web site and association for Kennedy's Disease in their country: <http://www.kennedyens.com>

SBMA Chat (Australia) – Alistair Fyfe has set up a chat room on MSN.com – the timing for these chats are more convenient for those in that part of the world:  
<http://groups.msn.com/kennedysDisease>

SBMA in the UK – Paul France set up a Web site earlier this year dedicated to Kennedy's Disease and has expressed interest in working together with the KDA:  
<http://www.sbma.org.uk>

## For Additional Information

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