



KDA e-Xpress

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September 2004

Letter from the President

Dear KDA Associates,

It has now been 5 years since we started the KDA and began to get to know you. It has been an amazing time of learning and growing.

You have been very supportive of what we set out to do, not only financially, which is necessary to help us continue on the road seeking a cure or treatment, but also in your kind comments, suggestions and emails.

We truly appreciate your help and sharing along the way – without you, there is no KDA.

Sincerely,
Susanne Waite,
KDA President & Executive Director

Dr. William Kennedy to be Keynote Speaker at 2004 KDA International Conference & Symposium

We are pleased to announce that Dr. William Kennedy, University of Minnesota, of whom Spinal Bulbar Muscular Atrophy's common name is named after, plans to join us at this year's Conference & Symposium and will be our Keynote Speaker at the Dinner Banquet.

Other prominent researchers from around the World will also be joining us – including:

Dr. Kenneth Fischbeck, Chief of Neurogenetics
NIH/NINDS,
Dr. Albert La Spada, University of Washington,
Dr. Diane Merry, Thomas Jefferson University,
Dr. Lenore Beitel, Lady David Institute,
Dr. Andrew Lieberman, University of Michigan,
Dr. Paul Taylor, University of Pennsylvania
Dr. Lisa Ellerby, Buck Institute of Aging
Dr. Patrick Weydt, University of Washington
Dr. Richard Smith, Center for Neurologic Study

We **currently have 36 individuals living with Kennedy's Disease registered** to attend the meeting and are looking forward to others registering now that we are down to the last month before the conference.

Theme: "Edge of Discovery"

When: October 20-22, 2004

Where: San Diego, CA – Holiday Inn Select

Conference Info:

www.kennedysdisease.org/conference2004.html

Please don't forget to book your hotel room- \$109.00 per night (+taxes) – Call Direct at 800-465-4329 and advise you are with the KDA meeting.

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KDA Grant Recipient Research Updates

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

"I'm really pleased with the progress we've made on our mouse project, but things definitely take time to complete. We're continuing to age mutant males, and to follow them by monitoring weight, survival, and motor function. We've also surgically castrated a group of young mutant males, and treated some females with the mutation with testosterone. All of these analyses are ongoing.

We've also started looking for evidence of genetic modifiers of the disease in mice. Mice come in different in-bred strains, much like dogs, and these different strains have different genetic backgrounds. We're crossing the Kennedy's mutation onto a couple of different backgrounds to see if it behaves similarly in these different settings.

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

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

New Board Member:

- Ronald "Butch" Wiker is has joined the KDA Board of Directors. Following in his daughter, Annette Clipman (past board-member), footsteps, we welcome Ron to the KDA Board and are pleased to have him aboard.

New and Improved Online Forum:

- After surveying our associates via email, we've found that...

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's has been an extremely positive experience for us.

The goal of this Regional Meeting is simple. To provide KD's, and their families, the opportunity to meet with other KD's 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

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

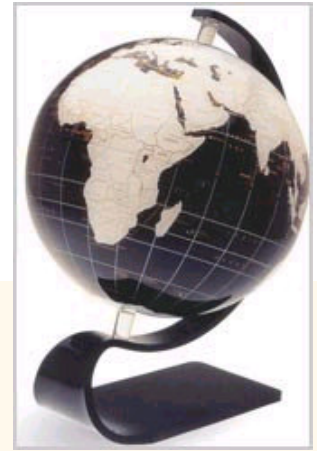
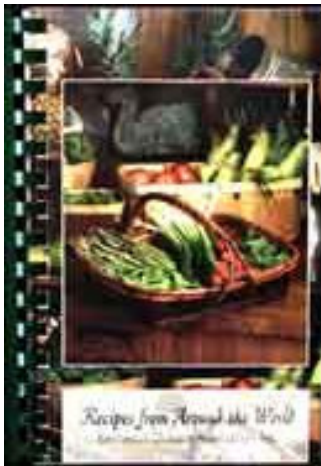
Bright Lights Helping the KDA – Raising Funds to aid Research

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 an 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

KDA Fundraising

The KDA still has quite a few cookbooks "Recipes from around the World" in stock – they are \$12.00 per book shipped in the US. If outside the US the cost due to shipping will be more – please email us with how many books you'd like and what country and we'll advise you the cost. Many KDA Associates contributed some of their family recipes to the book. It contains 300 recipes such as Walnut Maple Cake, Old-Fashioned Meatballs, Pear and other scrumptious recipes...



International KD's at Work:

Claus-Peter Czaya reports that the German group of Kennedy's Disease individuals has gotten together and put together a site in German: www.sbma.info.

Holiday Cards for Sale

It's getting to be that time of year when greetings will be exchanged with family and friends. Please consider purchasing your cards from the KDA this year and help the KDA. They are 10 cards and envelopes for \$8.00 + \$2.00 shipping, 20 cards/envelopes for \$14 + \$2.50 shipping, or 30 cards/envelopes for \$20 + \$3.00 shipping.

For Additional Information

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