



KDA e-Xpress

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"KDA CONFERENCE & SYMPOSIUM EDITION"

November 2004

2004 KDA Conference & Symposium: "Edge of Discovery"

A huge thanks goes to this year's meeting committee: Gail Zittel, Pat Peper, Paul Hagenbuch, Len Janicki, Bill Erickson, and Michael Buttner. I sincerely appreciate their help working with me to put together another successful and valuable Conference.

We also sincerely thank our speakers, doctors and researchers who gave us their time on a volunteer basis and shared their knowledge with us.

Please visit the KDA Web site to see the Speakers', Doctors', Researchers' entire Powerpoint Slide Presentations, more photographs of the Conference, how to order a Video of the Doctors/Researchers Panel and other information at:
www.kennedysdisease.org/2004postconference.htm

~Susanne Waite
KDA President & Executive Director

Keynote Speaker: William R. Kennedy, Ph.D. His Journey of KD Discovery

An amazing journey was shared by Dr. Kennedy with all at the dinner banquet. In 1964, he met George Brunell (aged 57 with a French-Indian ancestry), a patient that presented symptoms similar to Lou Gehrig's and Spinal Muscular Atrophy. Brunell had noticed his weakness beginning in his 30's. Dr. Kennedy noted that Brunell had additional symptoms as well. Dr. Kennedy invited Dr. Milton Alter (who had experience in epidemiology) and Dr. Joo Ho Sung (a neuropathologist) to investigate along with him additional similar patients that may have a "new" form of muscular disease.

They began to investigate various patients' family history and the rest reads like a detective novel. They researched birth records and family



Dr. Kennedy (Minnesota) with Steve and Ann Marie Aoyagi (Illinois)

trees through family interviews, churches (ie., St. Paul and St. Louis Cathedrals), cemeteries, and city hall. They researched in St. Paul down to Grey Cloud Island to Western Minnesota families that they discovered were connected – Brunell's name root of "Brun" is French for "Brown" – There was a prominent family
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Doctors' & Researchers' Discussion Panel



Dr. Patrick Weydt

- Kenneth H. Fischbeck, M.D., NIH/NINDS
- Diane Merry, Ph.D., Thomas Jefferson University
- Lisa Ellerby, Ph.D., Buck Institute
- Andrew Lieberman, M.D., Ph.D., University of Michigan
- Patrick Weydt, M.D., University of Washington
- Lenore Beitel, Ph.D., Lady Davis Institute
- Nicholas Di Prospero, M.D., Ph.D., NIH/NINDS
- Erica Chevelier-Larsen, Thomas Jefferson University
- Jennifer McBride, Thomas Jefferson University
- Shannon Jenkins, Thomas Jefferson University
- Seth Gilbert, Thomas Jefferson University
- P.J. Thomas, University of Washington

The cooperation and culmination of all KD researchers worldwide (present and those who could not attend) has created great synergy this past year and is propelling KD research forward at a fast pace. Its an exciting time for those researching KD and a time for hope for those living with KD.

Only last year was it discovered that Testosterone aggravates KD symptoms in mice... now researchers have narrowed down the type of testosterone – determining it to be Dihydrotestosterone (DHT) type I.

There is a possibility for a clinical drug trial in the USA in Spring 2005 to suppress DHT – Contact the NIH through their Web site: www.ninds.nih.gov/ for further Info.



Dr. Lisa Ellerby

A video of the doctors'/researchers' panel discussion is now available for purchase – please see last page of this newsletter for ordering information. Also visit the KDA Web site for the detailed Powerpoint Slides.

Dinner Banquet – Safari Night!



Dinner was enjoyed by all!



Len & Jeanne Janicki (Nevada)



Duane & Lori Benson (South Dakota)

Speakers Highlights:

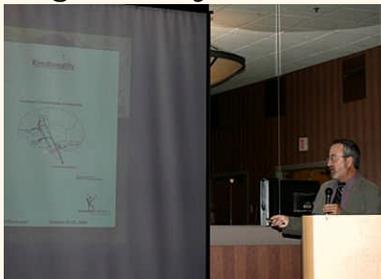
Kevin Philips ATS, CRTS – The Ability Center – Mobility: Key to an Active Lifestyle



Philips gave excellent tips in regards to mobility: “the ability to go where you want to go when you want to go there”. He pointed out that your car is a mobility aid, so is a wheelchair, scooter, cane or walker. So why do some view those aids as any different a tool than a car? He walked us through various types of aids including wheelchairs, converted vans and lifts.

He recommends finding a Certified individual (ie., RESNA, NRRTS, or best: CRTS Certified Rehab Technology Supplier) that cares more about fitting you for the right aids, than a quick sale! This would be done through a thorough needs assessment – thinking about what you will need in a few years, not just your present needs.

Dr. Richard Smith – Center for Neurologic Study: Emotionality



Dr. Smith has been studying emotionality in ALS and MS. He has discovered sudden, uncontrollable onsets of crying and/or anger come from the bulbar part of the brain and has found treatment with Neurodex (currently in Drug Trials for FDA Approval) is effective. Could emotionality be affecting those with KD? Further studies would be needed to determine if this is the case.

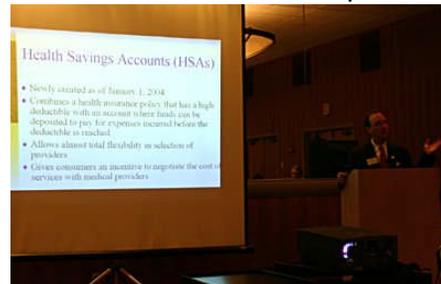
Keynote Speaker: Dr. William R. Kennedy (continued)

with the last name of Brown located in Western Minnesota, that they found was related to the Brunell family in St. Paul and Grey Cloud Island. Through extensive familial research they discovered that Kennedy’s Disease is a genetically inherited disease, X-linked (passed on from the mother’s side).

Dr. Kennedy co-authored an article about Spinal & Bulbar Muscular Atrophy with Drs. Alter and Sung, its signs/symptoms and its genetic inheritance. They presented the findings to the AAN in 1966 and their article was published in “Neurology” in 1968.

Dr. Paul Delwaide, from Belgium, speaking in the 1980’s about SBMA dubbed it “Kennedy’s Disease”. From there, it caught on and kept its namesake after Dr. Kennedy, one of the early SBMA research pioneers of this disease.

John Greene – National Association of Health Underwriters: Health Insurance Options



Greene walked us through the various types of Health Insurance available: PPO’s, HMO’s, HSA’s, High Risk Pools, Medicare and where one can access these different types of insurance.

Adrian Moravcsik, CFA – Stein Roe Investment: Investing



Moravcsik advised on Wealth Counseling, Financial Independence Projections, Economic/Market Overview, Asset Allocation, and Investment Vehicles and their providers.

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Silent Auction

This year's silent auction raised over \$2,000 – Thank you to all who brought and bought an item!

John Coakley, Sr. was our "MC with the mostest" for the evening, announcing the winners of the auction and entertaining us with his witty sense of humor.

Some of this year's highlights were hand-carved gourds that Kent Zittel made, a singing mouse and lion, Duane Kropf's original oil painting, various safari themed items such as stuffed animals, candle holders, mugs, pins, as well as a beautiful silver and mother-of-pearl apertif liqueur server.



Back to front: Lori Benson, Susanne Waite, Boyd Benson, Bill Erickson, & Judy Erickson

Video for Sale:

Doctors'/Researchers' Discussion Panel and Dr. Kennedy's Keynote Speech

If you would like to purchase a video, please send \$40.00 + (\$5.00 shipping if you are in the USA. If you are outside the USA, please email us at tswaite@sti.net to obtain the total cost including shipping to your country) advising us you would like the 2004 Conference Video to the Kennedy's Disease Association – (address is below).



Above From left to right: Dr. Kennedy, Dr. Fischbeck, Dr. Di Prospero, Dr. Lieberman, Dr. Merry, & Dr. Smith – Below: Dr. Beitel



For Additional Information:

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