



2004 ANNUAL REPORT



2004 Annual Report

A Message from the President

The KDA was formed five years ago. It has been an amazing period of learning, sharing, and growth for all of us. Susanne Waite said it very well in an email message to our associates, “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.**”

2004 was an exciting year for the Kennedy’s Disease Association:

- The KDA Conference and Research Symposium “Edge of Discovery” was held on October 20-22 in San Diego. Everyone who attended felt the conference was a huge success. Our thanks go out to all those who attended and contributed to the success of the conference including the planning committee, the twelve doctors and researchers, the board of directors, and participants.
- The first KDA regional meeting took place in Gettysburg, PA. The KDA thanks Paul DeSchamp for leading this activity.
- In regards to the two research grants funded in late 2003 and early 2004, we continue to receive positive updates from Andrew Lieberman, M.D., Ph.D. from the University of Michigan regarding the Knock-In Mouse Model, and from J. Paul Taylor, M.D., Ph.D. from the University of Pennsylvania regarding the Drosophila (Fruit Fly) Model.
- Fifty new Associates joined our ranks in 2004, increasing our roster by 8%. The total number of Associates stood at 664 by the end of the year. We look forward to continued growth in 2005.

In closing, I want to thank all of you who have worked so hard to make this association a success. With your continued support, I believe that one day, in the not to distant future, we will be celebrating the discovery of a cure, or at least a treatment, for Kennedy’s Disease.

A handwritten signature in blue ink that reads 'Bruce A. Gaughran'.

Bruce A. Gaughran
President
Kennedy’s Disease Association

August 21, 2005



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FY-04 Statement of Activities

Income		\$ (U.S.)
Donations	\$	50,359
Others		2,886
Total Income		\$ 53,246

Charitable Operations		\$ (U.S.)
Research Grants	\$	25,000
Education		7,984
Total Charitable Expenses		\$ 32,984

Operating Expenses		\$ (U.S.)
Total Expenses		\$ 5,371
Gain/Loss		\$ 14,891

Net Assets		\$ (U.S.)
Beginning of Period	\$	59,328
End of Period	\$	74,219

Note: Complete financial statements are available upon request from the KDA.

The Kennedy' s Disease Association is a non-profit corporation, incorporated in California on August 21, 2000. We are recognized under United States Internal Revenue Code 501 C3 as a publicly supported organization as described in sections 509 (a) (1) and 170 (b) (1) (A) (vi). Donations are considered tax deductible by the I.R.S. in the United States.



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Looking Towards the Future

The KDA's plans for 2005:

- Sending out Kennedy's Disease information packets to over 10,000 neurologists.
 - Developing and implementing a KDA Tissue Donation Program. We will be working with the University of Michigan Medical Center and the National Institute of Health to collect, store, and distribute tissue for Kennedy's Disease research.
 - Joining the National Organization of Rare Diseases (NORD), whose members share an interest in helping people with rare diseases. This will benefit the KDA greatly by expanding our networking and information sharing capabilities and giving a louder voice to our efforts.
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The Goals 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 the 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 for Kennedy's Disease, with an aggressive target of earmarking 70% of every dollar donated for Kennedy's Disease research
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Kennedy's Disease Association Board of Directors

Bruce A. Gaughran, President	Ron Wiker, 2nd Vice President
J. Murray Williams, Secretary	Paul DeSchamp, 3rd Vice President
Terry Waite, Exec. Director & Treasurer	Kathy Purvis, 4 th Vice President
John A Coakley, Sr. 1st Vice President	

Honorary Board Member – Susanne Waite, President Emerita



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KDA Web Site

The KDA has a comprehensive web site to help share information in a cost-efficient and effective way. The web site is located at www.kennedysdisease.org. We constantly update related information as it becomes available. Please visit the site regularly to see 'What's New'.

KDA Chat Room

The KDA hosts a chat room on the first and third Saturdays of each month at 10:30 AM Eastern Time (7:30 AM Pacific). Doctors, researchers, and specialists are invited to the chat room to discuss the latest research, health issues, and quality of life topics. A list of chat room topics and guests are posted on our web site.

Please direct all correspondence, questions, and donations to:

The Kennedy's Disease Association
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