



## **2005 ANNUAL REPORT**



## 2005 Annual Report

### *A Message from the President*

2005 was another exciting year for the KDA. There are several major accomplishments to report including:

- The KDA provided \$25,000 in emergency funding for J. Paul Taylor, M.D., Ph.D. and his research team from the University of Pennsylvania who developed the Kennedy's Disease Drosophila (Fruit Fly) Model.
- We distributed Kennedy's Disease information packets to over 10,000 neurologists.
- The KDA was accepted as a member into the National Organization of Rare Disorders (NORD). NORD members share an interest in helping people like ourselves with rare diseases. This membership has allowed us to expand our network and improve our information sharing capabilities as well as giving the KDA a louder voice in the political and research communities.
- A Medical History template was developed for those of us with Kennedy's Disease.
- A new Message Board Forum was implemented to communicate and share information.
- The 2002 Kennedy's Disease Survey results were summarized and published.
- Eighty-one new Associates joined the KDA in 2005, increasing our roster by 10%. At the end of the year, we had a total of 732 Associates.

In last year's annual report, I commented that **"without you, there is no KDA."** That statement truly reflects the case in 2005 and as we move forward in 2006. Without our Associates' support, both financial and with their time, we could never have accomplished what we did this past year. Thank you for your continued support of the Kennedy's Disease Association.

In closing, I want to again leave you with my hope and my prayer. With your support, I believe that one day, in the not to distant future, we will be celebrating the discovery of a treatment and possibly a cure for Kennedy's Disease.

*Working together to make a difference*

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

Bruce A. Gaughran  
President  
Kennedy's Disease Association

March 05, 2006



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## *FY-05 Statement of Activities*

Income	\$ (U.S.)
Donations	\$ 14,495
Others	541
Total Income	\$ 15,036

Charitable Operations	\$ (U.S.)
Research Grants	\$ 25,000
Education	9,831
Total Charitable Expenses	\$ 34,831

Operating Expenses	\$ (U.S.)
Total Expenses	\$ 5,238
Gain/Loss	\$ (25,036)

Net Assets	\$ (U.S.)
Beginning of Period	\$ 74,088
End of Period	\$ 49,053

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 Board of Directors has approved the following goals for 2006:

- Raise \$50,000 in donations
- Fund two Kennedy's Disease research grants
- Sponsor a successful KDA conference and symposium in Atlanta, GA (October 11-13)

We are also planning the following activities:

- Working with the University of Michigan Medical Center and the National Institute of Health, the KDA plans on implementing a KDA Tissue Donation Program that will allow for the collection, storing, and distribution of tissue for Kennedy's Disease research.
- Support the search for a Kennedy's Disease treatment by assisting the National Institute of Health in identifying prospective candidates for a clinical drug trial.
- Provide personalized wallet-sized Medical Information Cards.

### *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 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 research and education ... with a target of earmarking 70% of every dollar donated for Kennedy's Disease research

### *Kennedy's Disease Association Board of Directors*

Bruce A. Gaughran, President  
J. Murray Williams, Secretary  
Terry Waite, Ex. Director & Treasurer

John A. Coakley, Sr., 1<sup>st</sup> Vice President J.  
Ron Wiker, 2nd Vice President  
Paul DeSchamp, 3rd 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](http://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 participate in the chats as featured guests to discuss the latest research, health issues, and quality of life topics. A list of upcoming topics and guests are posted on our web site along with transcripts from previous chats.

### **Other KDA Services**

- Fund Research Grants
- Neurologist Mailers
- Share Research Updates
- Sponsor Educational Conferences
- KDA Forum
- Scientific Review Board
- Tissue Donation Program
- Regional Support Groups
- NORD Membership
- Networking
- Medical History Form
- Wallet Medical Condition Card
- Associates Database
- Clinical Research Trial Support
- Liaison with Research Organizations

*Please direct all correspondence, questions, and donations to:*

**The Kennedy's Disease Association**  
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**Coarsegold, CA 93614**

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