



2006 ANNUAL REPORT



2006 Annual Report

A Message from the President

“Working together to make a difference.” 2006 was another exciting year for the KDA and I believe we are making a difference. There are several major accomplishments to report including:

- Thanks to the generous support of so many this last year, the KDA raised over \$60,000 in donations. **83% of the donations went towards funding Kennedy’s Disease research.** With the help of Lenore K. Beitel Ph.D., we were able to establish a ‘tax-deductible’ donation program in Canada through the Jewish General Hospital Foundation where all donations go towards Kennedy’s Disease research.
- The KDA funded two research grants.
 - **A \$25,000 grant was awarded to Chawnshang Chang** Ph.D. from the University of Rochester. His research plans to develop a treatment regimen for Kennedy’s Disease targeting the poly Q-expanded mutant AR. This concept may be a way to cure the disease.
 - **Another \$25,000 grant was awarded to Udai Bhan Pandey** Ph.D. from the University of Pennsylvania. Dr. Pandey proposes to use molecular genetic approaches in *Drosophila* to characterize the mechanism of suppression by HDAC6. His long-term goal is to contribute to the development of therapeutic interventions for Kennedy’s Disease.
- The KDA supported the National Institute of Health’s (NIH) Kennedy’s Disease clinical trial by contacting our associates within the United States and Canada asking if they would be interested in participating in the trial. Seventy-five associates contacted NIH and fifty were selected.
- In February, a Kennedy’s Disease tissue donation program was implemented with the help and support of the University of Michigan and our Scientific Review Board.
- In October, the KDA held a three-day conference and symposium in Atlanta. 47 associates and 15 doctors and researchers attended the event.
- 103 new associates joined the KDA in 2006. At the end of the year we had 738 active associates located in 34 countries. Of the 738, 496 men and 77 women have the defective chromosomes.

“Without you, there is no KDA.” Without our Associates’ support, both financial and with their time, we could never have accomplished what we did this past year. Moreover, without the continued efforts of the doctors and researchers, we would not be so close to finding a treatment for Kennedy’s Disease.

As I have done in the past, I want to leave you with my hope and my prayer. With your continued support, I believe we will be celebrating the discovery of a treatment and possibly a cure for Kennedy’s Disease soon.

Bruce A. Gaughran
President



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FY-06 Statement of Activities

Income	\$ (U.S.)
Donations	\$ 60,428
Conference Registration	7,376
Others	2,199
Total Income	\$ 70,003

Charitable Operations	\$ (U.S.)
Research Grants	\$ 50,000
Education and Conferences	13,078
Total Charitable Expenses	\$ 63,078

Operating Expenses	\$ (U.S.)
Total Expenses	\$ 5,282
Gain/(Loss)	\$ 1,643

Net Assets	\$ (U.S.)
Beginning of Period	\$ 48,561
End of Period	\$ 50,205

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 2007:

- Raise \$100,000 in donations
- Fund two and possibly three Kennedy's Disease research grants
- Sponsor a KDA conference and symposium in Las Vegas, NV on November 6-8

We are also planning the following activities:

- Financially helping Kennedy's Disease researchers attend the 2007 Gordon Research Conference on CAG Triplet Repeat Diseases
- Attend the annual NORD (National Organization for Rare Disorders) Conference in Washington, DC

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 at least 70% of every donated dollar for Kennedy's Disease research

Kennedy's Disease Association Board of Directors

Bruce A. Gaughran, President
J. Murray Williams, Secretary
Terry Waite, Exec. Dir. & Treasurer
Mike Goynes, Member at Large

John A. Coakley, Sr., 1st Vice President
Ron Wiker, 2nd Vice President
Paul DeSchamp, 3rd Vice President
Ed Meyertholen, Member at Large

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 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.

KDA Discussion Forum

The KDA Discussion Forum is a place to ask questions, express opinions, and post information of interest for others with Kennedy's Disease. The web page for the forum is located at http://www.kennedysdisease.org/disc_forums.html.

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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Email: info@kennedysdisease.org
Web Site: www.kennedysdisease.org