



KDA e-Xpress

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Hurricane Katrina

"We can all learn from what happened"

All it takes is something like Katrina to make us realize the importance of pre-planning. For anyone with a handicap, planning and preparation for an emergency or a natural disaster is even more critical. I do not claim to be an expert on the subject of planning for emergencies, but I do know there are resources available in most communities that can help. Your fire department, police department, local Red Cross chapter, and hospital all should have resources available to help you plan for an emergency. The fire department in most communities will even come out to your house for a walk-through.

Questions worth asking ...

1. Do you have a personal evacuation plan?
 - a. If your house caught on fire, do you have an escape

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KDA Education Update

Mailers Were Sent To Neurologists

In the spring, over 10,000 neurologists received a cover letter and brochures from the KDA that included the following:

- An explanation of Kennedy's Disease
- How Kennedy's Disease is contracted
- A list of symptoms that may be useful in diagnosing Kennedy's Disease
- The possibility of a misdiagnosis of ALS unless a DNA test is given to the patient
- What is the Kennedy's Disease Association?

The actual brochure can be downloaded from our web site.

<http://www.kennedysdisease.org/aboutus.html>

Results of the KDA Questionnaire Published

In 2002, the KDA sent a questionnaire (drafted by Patrick Griffin and Susanne Waite, reviewed by Dr. Merry and Dr. Fischbeck) to all current KDA Associates. Thirty-four Associates responded and volunteers have tallied the results. The names were removed to insure confidentiality.

Susan Wiebusch spent innumerable hours drafting the reports. The KDA thanks everyone who participated in this survey - from the respondents to those who tallied the results.

The actual results can be downloaded from our web site.

http://www.kennedysdisease.org/disc_questionnaire.html

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- plan with more than one exit? Most of us cannot take steps or climb out a window. Some of us are only mobile in a wheelchair. All of these limitations need to be taken into account as you develop several exit options just in case one route is blocked.
- b. Are your important papers in one location? Checkbooks, wallets, and credit cards should all be kept in one location. Insurance policies, savings account information, health information, your wills, etc. should all be easily accessible and, if possible, stored in a fireproof box or safe.
 - c. Do you have more than one route out of the neighborhood and town? Often, in major disasters or emergencies, the main routes are congested or even blocked. What would you do if the only route or all of the routes were blocked?
 - d. Are there any pharmaceutical products that you need to take daily?
 - e. Develop a checklist of needed items and considerations. Not every situation is an emergency and often you will have the time to plan. Having a checklist will help you remember what needs to be done. Examples: Did you turn off the gas? Did you pack your prescriptions? Do you have important telephone numbers (doctors, banks, brokers, hospital, etc.)?
 - f. Most importantly: Conduct a fire or evacuation drill at least once a year. Things change including your needs. You will become more aware of potential holes in your plan by practicing your evacuation.
2. What would you do if your house or neighborhood lost power for more than a day?
 - a. Do you have enough packaged and canned goods stored away that do not require cooking?
 - b. If it is winter, can you keep warm?
 - c. There are several other considerations including what would happen if you could not recharge your wheelchair's batteries.
 3. What if your drinking water became contaminated?
 - a. Boiling water is one option, but what happens if

you do not have electricity?

- b. How many gallons of stored water are needed to sustain the family for several days?
4. Other considerations:
 - a. Do you have a well-stocked first-aid kit?
 - b. Do you have several good flashlights with extra batteries?
 - c. Have you scheduled time each quarter to check the quality of your first-aid kit, food and water supplies, and flashlights?

These questions are not meant to be all-inclusive, but instead are 'starter questions' for you to consider when developing your plans. Again, there are resources available within your community that can help. I encourage you to use them.

KDA Plans to Fund Research Grants in 2006

"We can make a difference"

The KDA, which has supported the research community with two grants in previous years, has Board approval to begin the necessary work leading up to the solicitation for our third grant. While specifics are not available at this time, the initial discussions are leaning to a grant of \$25,000.00 to be awarded during the second quarter of 2006. A second grant may be funded if enough additional donations are received between now and the first quarter of 2006.

As this process moves forward, we will begin to accept applications after the KDA Board has had the opportunity to meet with our Scientific Advisory Board, who will assist and help with the process.

The awardees in the past are J. Paul Taylor, MD, PhD, Department of Neurology, University of Pennsylvania and Andrew Lieberman, MD, Department of Pathology, University of Michigan, who received grants of \$25,000 each. Their work has been reported on regularly and is aiding in the attempts to find a cure for Kennedy's Disease.

The KDA thanks ALL researchers who have dedicated themselves to this cause and our Associates who continue to support the funding of these grants.

KDA Board of Directors Changes

The board welcomes a new member, Kathy Purvis. Kathy is a lymphoma survivor and Registered Nurse, and has two brothers diagnosed with KD. She has previous volunteer experience with other organizations, including The Heart Exchange, a heart transplant group in Houston, and the Anderson Network at M.D. Anderson Cancer Center. She also previously assisted the KDA with transcription of the New Orleans conference proceedings. Her experience and nursing background bring an added dimension to the KDA Board.



The 2005-2006 Board of Directors

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

Susanne Waite Steps Down

Susanne Waite has stepped down from the positions of Executive Director and President. Because of her long-standing involvement and dedication to the KDA, Susanne was named 'President Emerita' and given an honorary position for life on the board. She was also given a beautifully engraved lead crystal vase by the other board members as a token of their appreciation. The vase, shown above, bears the Kennedy's Disease logo at the top and read as follows:

"Susanne Waite - President & Executive Director
In appreciation for your vision, dedication, and hard work
August 2005."

New KDA Forum Announced

"New Features – Improved Systems"

After losing all of our forum information because of a computer glitch by our previous free supplier, the KDA has enlisted the services of Groupee.Com to provide 'forum' services in the future.

The benefits of this new service include:

- No advertising/pop-ups
- (Optional) Email notification to messages you post letting you know someone has replied to the message.
- Improved ease of use, message handling and storage

Visit the new forums on our web site.

http://www.kennedysdisease.org/disc_forums.html

KDA Chat Room

"More guests spur increased interest in Chats"

Have you noticed who has visited the KDA Chat Room recently? In the past couple of few, Dr. Kenneth Fischbeck, Dr. Chenju Chen, and Diane Merry, Ph.D. have been our featured guests. If you missed these chats, you can still read the transcripts by visiting our web site.

http://www.kennedysdisease.org/disc_transcripts.html

While there, look at our list of upcoming guests including another visit by Dr. Fischbeck.

Our hats our off to Murray Williams for his work in soliciting more guests and improving the content of the chat rooms.

KDA Fundraising

“Without you, there is not KDA”

COOKBOOKS

The KDA has a wonderful cookbook, “Recipes from around the World.” It contains 300 recipes including many contributed from KDA Associates. The books are \$12.00 when shipped within the US. If the books are to be shipped outside the US, please email the KDA advising how many books you would like and where they will be shipped to and we will advise whether there will be any additional shipping costs.

HOLIDAY CARDS

It is 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. There 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.

KDA COFFEE MUGS

We also have available KDA coffee mugs that are perfect for your beverages. The mugs are \$10.00 + shipping.

Visit the KDA Store:

http://www.kennedysdisease.org/kda_store.html

Other KDA News

TISSUE DONATION PROGRAM

The KDA plans to publish their ‘Tissue Donation Program’ within the next couple of months. With the support of the University of Michigan Medical Center’s Tissue Bank, individuals will be able to donate tissue to the KDA. All donated tissue will only be used for Kennedy’s Disease research.

2004 ANNUAL REPORT

The KDA Annual Report for 2004 has been published. You can download a copy of the report from our web site. <http://www.kennedysdisease.org/2004-Annual-Report.pdf>

PAUL DESCHAMP ATTENDS GORDEN CONFERENCE

This summer Paul made it to the Gordon Conference at Mt. Holyoke College in Massachusetts where he met Diane Merry, Ph.D. of Thomas Jefferson University, and attended the break out sessions for scientists working on SBMA. He was overwhelmed by their professionalism and their dedication to their studies. Paul left the conference thankful that those of us with Kennedy’s Disease had such a great group of scientist trying to find a cure for KD.

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**A publication of the
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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 Kennedy’s 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, with an aggressive target to earmark 70% of every dollar donated to be used for Kennedy’s Disease research