Kennedy's Disease ASSOCIATION

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NINDS Dutasteride Trial and Future Clinical Trial Prospects

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Kennedy's disease (KD) is caused by a mutation in the androgen receptor that makes the receptor protein toxic to motor nerve cells and muscle. The toxicity of the mutant protein is dependent on androgens (the male sex hormones testosterone and dihydrotestosterone) in KD animal models. Importantly, KD mice have progressive weakness and decreased survival that are helped by anti-androgen treatment.

In early 2009, Dr. Gen Sobue's group from Nagoya, Japan, published the results of a clinical trial in KD patients with the anti-androgen drug leuprorelin. In the 48-week placebo-controlled portion of this trial there were signs that the treatment had an effect on the distribution of the mutant protein and slightly improved swallow time, although it was not clear whether the latter effect was noticeable by the patients. In a 96 week non-randomized follow-up period those patients who chose to continue taking the drug did better than those who did not, but it is possible that this was due to selection bias rather than to drug effect. A larger, multi-center trial of leuprorelin is currently underway in Japan.

At the National Institute of Neurological Disorders and Stroke (NINDS) we chose to study another drug, dutasteride, which preserves testosterone and reduces the more potent dihydrotestosterone. Our reasoning was that dutasteride might reduce the toxicity of the mutant androgen receptor in motor nerve cells but maintain the strengthening effect of testosterone (an "anabolic steroid") in muscle. The study was a two year double-blind, placebo-controlled trial. The last subject finished the trial in late 2008, and the results are now being prepared for publication. Physical, neuropsychological, quality of life, and biochemical measures were assessed in 50 KD subjects randomized to receive either dutasteride or a placebo.

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INSIDE THIS ISSUE

A Chat with Dr. Lieberman

A portion of the chat room conversation on August 1, 2009

Welcome: I would like to welcome Andrew Dr. Lieberman, MD, PhD, from the University of Michigan Medical School. He is also a member of the KDA's Scientific Review Board. Thank you for joining us this morning.

Dr. Lieberman: I'm a neuropathologist at Michigan and my lab has been studying Kennedy's disease using a couple of model systems, including cell culture and mice. The mouse model we have was made with support from the KDA. Right now we're working on a couple of projects with our mice. First, we're trying to understand pathways that might alter cell function and lead to cell death because these offer potential drug targets. We've focused a bunch of effort on examining a cell stress pathway called the unfolded protein response. This pathway is a means by which cells deal with misfolded proteins, and we had the idea that it might be triggered by the abnormal androgen receptor of Kennedy disease. It turns out this pathway is really important in helping cells survive the stress of mutant proteins. However, if this survival mechanism fails, the unfolded protein response can cause cells to die. So far, we've found that this pathway is active in our Kennedy disease mice and in muscle from some Kennedy disease patients. We're now genetically inactivating the pathway in our mice. Our initial results are really encouraging that this will impact disease. If so, there are some small molecules we plan to try to see if we can treat mice. One other thing we've been working toward is to try to find new compounds that might be therapeutically active in our model systems. We're collaborating with a chemical biologist at Michigan who has now screened a really large \library\" of chemical compounds (containing tens of thousands of compounds) for small molecules that will help cells digest the mutant AR."

Question: When you say digest the AR, are you referring to the clumping that occurs when the AR cannot enter the nucleus for cleaning (my simple terms)?
Dr. Lieberman: That's right. There are a couple of degradation pathways that cells use to digest things. We're looking for small molecules that help cells take out the trash (sort of like my mom getting me to do it when I was a kid.) Regaining muscle probably will be a really great thing. We also have to do it in a way that helps the muscle cells talk with the motor neurons that control them. Without that connection, it may not be so helpful. Sorry if my lab description was too technical. The screen for small molecules (I didn't want to call them drugs because that might imply more than they are good for) has been interesting, and has yielded a promising "hit" that we're testing in cells. Once that's done, if it's still looking good, we'll go on to testing in mice.

Comment: I read an article recently about the work of Dr. Robert Beal on cystic fibrosis. A different condition, but since he's looking for a drug that would override the gene mutation, it would seem to have applicability. Are you familiar with this?
Dr. Lieberman: I haven't read the article on CF that was mentioned. Sounds like something I should look up. I heard/read mention of a couple of other disorders, such as CF and Parkinson disease. It's great to see that you as a group are keeping up on research that may impact KD. All of these diseases are caused by protein misfolding, so advances in any one may be broadly helpful.

Comment: I've read about research from the Medical College of WI being done. Their focus seems to be Parkinson's with ties to other neurological disorders. Many of the symptoms are similar with these conditions.

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NINDS Dutasteride Trial and Future Clinical Trial Prospects- cont'd from page 1

We found no significant difference in the primary outcome measure, change in strength, as indicated by the quantitative muscle assessment (QMA). Of the secondary outcome measures, physical quality of life as measured by change in the physical component summary of the SF-36v2 questionnaire showed a significant benefit, but this was balanced by a negative effect on the SF-36v2 mental component summary. Subjects taking dutasteride also had significantly fewer falls.

In the placebo group, the QMA showed an average decrease in muscle strength of about 2% per year, indicating that KD patients may need to be studied over a longer period to show a significant effect on disease progression. These observations provide a basis for future therapeutic trials in KD.

At present, neither leuprorelin nor dutasteride has been shown to be effective treatment for KD, although the recent studies show some indications of benefit and further studies are in progress. Meanwhile, we are investigating other approaches to treatment, several of which have shown benefit in KD mice.

Two derivatives of the drug geldanamycin, 17-AAG and 17-DMAG, have been shown to be beneficial in KD mice by Dr. Sobue's group in Japan. These drugs work to stimulate the "heat shock response," a protective cellular mechanism, by inhibiting heat shock protein 90 (HSP90). 17-AAG and 17-DMAG have been developed by the National Cancer Institute and partner companies as potential cancer chemotherapy drugs, and as such they are probably too toxic for KD treatment. They are given intravenously and have serious side effects. Although both have been used in cancer trials, neither has yet been given for more than 6 months. A number of other drugs with similar mechanism of action are currently under development for cancer by pharmaceutical companies, and if any of these turns out to be well tolerated and safe for long term use, then it may be worthwhile to test in KD mice and patients.

Insulin-like growth factor 1 (IGF-1) has been shown by Drs. Maria Pennuto and Isabella Palazzolo to be beneficial in KD cell culture and mouse models. The mouse study, which was just published in the journal Neuron, involved crossing KD mice with mice that overexpress IGF-1. The cross was found to increase strength and survival in the mice. IGF-1 has been tried in amyotrophic lateral sclerosis (ALS) and myotonic muscular dystrophy without benefit, but based on the recent results from Drs. Pennuto and Palazzolo it may be more likely to be effective in KD. Further mouse studies with injected IGF-1 are planned, and if these confirm the benefit, then a clinical trial would likely follow in the coming year.

In 2007, Dr. Chawnshang Chang at the University of Rochester reported benefit of the curcumin-related drug ASC-J9 in KD mice. A biotech company, AndroScience, is developing an oral version of the drug for use in humans, and safety testing and confirmatory mouse efficacy studies are planned for the coming year. If ASC-J9 is confirmed to be safe and effective in mice, then a clinical trial may follow in about two years.

Exercise has been found to be beneficial in ALS mouse models and in small studies of patients. A larger scale clinical trial in ALS patients is planned. A small study published earlier this year from a group in Copenhagen, Denmark had mixed results in KD patients followed for 6 months, but a longer term trial or a trial with a different type of exercise or different outcome measures may show clearer evidence of benefit. A systematic study of endurance and/or resistance exercise, modeled after the ALS clinical trial is currently under consideration at NINDS.

In summary, there are currently several possibilities for KD clinical trials that have a reasonable likelihood of showing benefit. Leuprorelin is now being studied in Japan, and an exercise trial is under consideration at NINDS. Further mouse efficacy studies of IGF-1 are planned, and a clinical trial could follow in the coming year. ASC-J9 is due to undergo pre-clinical safety and efficacy testing in the coming year, with a possible clinical trial to follow. Finally, one or more HSP90 inhibitors currently under development for cancer chemotherapy may be appropriate for testing in KD patients in the future.

Chat with Dr. Lieberman- cont'd from page 1

Dr. Lieberman: *Commenting on exercise:* It's an important question, and one that hasn't been answered by the scientists. Does exercise in patients, or in KD mouse models, help? You would predict it might, but I think we don't have data to know for sure. On the other hand, if it makes you feel better, it seems worth continuing. Exercise alone probably won't halt disease progression. The question is whether it can be used to slow progression.

Comment: The NIH is considering sponsoring a clinical trial on the effects of exercise on patients with KD.
Dr. Lieberman: I didn't know that the NIH is interesting in looking at the effects of exercise. I think it's a great idea that could be one component of a natural history study, looking at the progression of disease.

Comment: I have noticed that this last year or two, more focus has been on the cleaning process of the AR ... trying to get the nucleus to accept the mutant AR or other forms of cleaning. This appears to be a more focused step by researchers.
Dr. Lieberman: I think you're right about the focus being on getting rid of the mutant protein. There is really good data that the mutant AR, like other aggregating proteins, causes problems for cells in a great many different ways, and it may be that there's isn't only one critical pathway leading to toxicity. Therefore, people have begun to think that rather than targeting one pathway, let's find ways to get rid of the toxic protein.
Comment: That's what Beal is looking at -- correcting the mutated protein.

Question: Do you have any of the compounds that look promising enough to put to a mouse trial yet?
Dr. Lieberman: Well, we have one compound that we're thinking very seriously thinking about trying in a mouse. We have a few additional experiments to do in cells first.
Comment: This seems like a better approach than trying to prevent the AR from going into the cell...

Question: Any projected time frame for the experiments and research?
Dr. Lieberman: There a several big challenges in going from cells in a Petri dish to treating a mouse. We have to find a non-toxic dose, we need to make sure it gets to the places we want (spinal cord and muscle) and that it isn't broken down really fast. We're just starting to look into this.

Comment: We were quite pleased this year that when we sent our requests for Letters of Intent of our KD Research Grants that we had eight respondents of which six were from foreign countries. Normally we receive 2-3 responses. To me this shows increased interest in KD research.
Dr. Lieberman: The KDA did have a great response from the research community this year. I think that the number of applications, the diversity of places they're coming from, and the strength of the science is really impressive. You all should feel very pleased with that.
Comment: And thanks to the Scientific Review Board for their continued support of our grant program.

Question: We are also hearing a lot about the potential benefits of IGF-1 (for muscles). Have you had any experience with that?
Dr. Lieberman: There's some really interesting data from Kurt Fischbeck's lab showing that IGF-1 produced in muscle can have a very good effect in KD mice. We've found that there are several growth factors which are normally produced by muscle, that support motor neurons, whose production is decreased in KD mice. This idea makes us think that disease in muscle plays an important part in KD.

Question: And not just the motor neurons?
Dr. Lieberman: IGF-1 is an insulin-like growth factor. It's not insulin, but a cousin. It can be made by muscle, nerve and other cells. We found that IGF-1 and other growth factors normally made by healthy muscle aren't made to the same extent by mouse KD muscle. And now Kurt Fischbeck's lab has some data showing that muscle over-production of IGF-1 can help KD mice.

Dr. Lieberman: We like the idea that diseased muscle isn't supporting motor neurons to the full extent, and in this way contributes to the disease. That's a hypothesis we're working very hard to test.

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More on IGF-1 Research

J. Paul Taylor, MD, PhD, member of our Scientific Review Board

J. Paul Taylor, MD, PhD, and a member of our Scientific Review board, further amplified on the merits of this approach in his summation of the recently published paper. "In this paper, it is shown that increasing the levels of a protein called insulin-like growth factor 1 (IGF1) increases strength and function and decreases pathology in a mouse model of KD. This is exciting in two respects. First, it corroborates earlier work from simple cell culture systems suggesting that IGF1 might be helpful in Kennedy's disease. Second, IGF1 was targeted to muscle, a novel strategy for KD therapy. This strategy was used in part because of evidence that muscle may be directly affected in KD and in part because healthier muscle has positive effects on the health of motor neurons (they function as a unit). The success of this approach validates the idea that treating muscle directly in KD patients, which is far easier to access than motor neurons. Not only is it (this research) highly relevant to Kennedy's Disease, but this study was funded in part by a KDA grant to Mara Pennuto."

Here are two web pages discussing this research: Science Daily http://www.sciencedaily.com/releases/2009/08/090812143930.htm and Quest Online http://www.mda.org/publications/Quest/extra/aug09/sbma.html..

New Website Supplier

New Service

As most of you know, the KDA website is the most comprehensive source of information on Kennedys Disease on the worldwide web. A few months ago, the KDA moved its website to GoDaddy.com. The reason for the move was because our website supplier blocked users in several Asian nations from viewing the website. Since moving the website to GoDaddy, Asian interest has picked up significantly. The website averaged 48 visitors a day last month.
Over the last year, the website averaged 1,500 to 3,000 visitors a month. 71% of all visits are still from North America, but the other continents are growing rapidly.

Along with this change, the KDA engaged the services of an email distribution service for our email announcements and newsletters. You will notice a new look in our announcements. They will initially be sent out in HTML format. We realize that some of you still only receive text formatted messages, but we currently do not keep that information in our database. When you receive an announcement (example: the KDA chat room), if you cannot read it, please let us know at info@kennedysdisease.org and we will make a notation on your email file that future messages should be sent in a text only format. Also, if you want to be removed from our distribution list, you will be able to opt-out at any time.

Handicap Accessible Van Rentals

Vacation Idea

If you are considering renting an accessible van on your next trip, the following link provides a list of companies that rent vans in ten countries http://www.kennedysdisease.org/handicap_accessible_van_rentals.htm.

Several companies provide airport delivery. Remember to bring your handicap placard along with you when you travel for use in handicap parking spaces. If you have had a positive experience with other rental companies, please let us know at info@kennedysdiese.org so we can update the list.

Chat with Dr. Lieberman- cont'd from page 2

Right now, the IGF-1 study is a proof of concept. That is, a growth factor delivered by muscle, might have a therapeutic effect.

Comment: It is wonderful that labs are sharing information and models. This is a huge benefit for researchers and for all of us living with KD.
Dr. Lieberman: A lot of us who work on KD in the United States trained together or at least worked in Kurt Fischbeck's lab at one time. I guess it's an extended family, in a way.

Thank You, Sean Blasko!

By Lou Tudor, Fundraising Chair

We associates in the Kennedy's Disease Association are most appreciative for the strength and determination of one rare individual. Sean Blasko who has three uncles diagnosed with Kennedy's Disease, successfully completed his second Ironman Distance Competition with all proceeds going to KD research.

Sean, a 31 year old attorney, started racing in triathlons in 2007. He began by working his way up from sprint distance (-1 hour race) to Olympic distance (-2 hour race) to half ironman (-5hour race). He now has completed the 2008 Ironman Australia and the recent Ironman Coeur d'Alene in June, 2009. The Ironman competition consists of swimming for 2.4 miles, then biking for 112 miles, then running for 26.2 miles. (Whew…I'm exhausted just writing this!)

Even in this year's weak economy, Sean was able to gather donor support in excess of $4,300., with all monies donated to help find a cure for KD. Seeing his family members lose their mobility, made Sean thankful for his own health and he now embraces his good health for the good of others. This is a tough guy, doing a tough race, for all of us facing a tough disease with no treatment or cure available. Who says one person can't make a difference? Sean has taken our hand in this struggle and definitely plans to stay with us until a cure is found.

We need more people like Sean to do what we can't. Do you know of any relatives, friends or acquaintances, who would be willing to take on a competition, event or fundraiser of any kind, gather supporters and donate the funds to KDA? If you do, we'll help to get it organized and off the ground. Send me your questions or comments to loutudor@yahoo.com

If you'd like to thank Sean for his efforts on your behalf, leave him a note on our new Twitter account. http://www.twitter.com/kennedysdisease

He's Running for Your Life!

By Lou Tudor, Fundraising Chair

We are blessed to have one of our own associates running a marathon in November. Ed Meyertholen was diagnosed with Kennedy's Disease ten years ago. He realizes now, that his disease progression is slower than most men experience, and is using his gift of ability to raise money for KD research.

Ed is 55 years old and plans to run the San Antonio Rock and Roll Marathon on November 15th, 2009. He only started serious running ten years ago when he was diagnosed. His sister, an experienced marathon runner, convinced him not to give up and to start training.

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Traveling with Wheelchairs

Travel Advice

Many airlines will allow the disabled traveler to use the executive lounges for layovers. These areas often have better seating and restroom accommodations.

Normally you can use your own wheelchair as far as the boarding point of the aircraft, where you will transfer to a special aisle chair. If you are able to walk a short distance, you should request a seat near the entrance doors. Your wheelchair will then be stored conveniently for immediate availability on arrival. The airline will probably want to pre-board you, so be early at the airport. You, however, have the choice not to pre-board.

Wheelchairs fall into three classes:

1) Normal hand-propelled chairs;
2) Electric wheelchairs, including scooters, with wet acid batteries;
3) Electric wheelchairs, including scooters, with dry cell or sealed gel batteries.

Those who have Type 2 wheelchairs should check with the airline, as a leaking battery in-flight can be dangerous. It will be necessary for baggage handlers to remove the battery and place it in a special container. This requires the passenger to be at the airport at least 3 hours before departure. Most modern power-operated wheelchairs have some form of safety battery so that they can be carried without risk of damage to the aircraft. However, it will be necessary for baggage handlers to disconnect the leads from the terminal and to cap them to avoid shorting. This may take some time, so you will have to pre-board. It may be necessary to transfer you to a special aisle wheelchair in the air terminal, and there may be a delay on arrival before your chair is available.

The airlines are responsible for ensuring that your battery is reconnected and that your chair is working on arrival at your destination. Electric scooters can also be transported without problems; their battery requirements are the same as for wheelchairs. As a precaution against loss or damage, always remove all detachable parts before your wheelchair is stored, and label the chair with your name and address and destination airport.

Special note for those taking electric wheelchairs: Make sure you talk to an aircraft loading supervisor prior to letting them have your wheelchair to load on the plane. Have them inspect it for damage and get an inspection tag from them. Also, make sure that if your chair has any special lifting/loading requirements that you have the loading supervisor or crew contact the destination (off-loading) supervisor prior to landing and have them speak with you about the special handling procedures before offloading your wheelchair from the plane. Most loading/off-loading crews do not have much experience in handling electric wheelchairs and can cause serious damage.

In the event of a problem with airport or in-flight personnel, you should require them to contact the Complaints Resolution Officer (CRO). However, to avoid problems, make sure that you let the airline know your needs as early as possible. Also, make sure you have adequate insurance to cover damage to or loss of your wheelchair or scooter.

If you travel in a wheelchair, it might be best to book your flight through a travel agent. If you purchase tickets on a non-stop or direct flight and the airline makes a schedule change to a connecting flight, your travel agent can explore other options, and can even get you a refund on a non-refundable ticket. When you make your reservation, volunteer information on the type of wheelchair (i.e. manual; electric; wet or dry cell). Also, explain exactly how much assistance you will need. If the reservations agent is unfamiliar with special needs clients, (s)he may not ask - which could result in delays or frustration at the airport.

He's Running for Your Life- cont'd from page 3

His first race took him almost five hours and he uttered "never again!" Of course, he kept running. Ed then sought professional training and ran the New York City Marathon in under four hours. He followed that with qualifying for the Boston Marathon.

Although Ed is admittedly slowing down, he pushes himself to do what most of us can't even attempt. When he isn't running, Ed teaches Cell and Molecular Biology, Genetics and Physiology at Austin Community College. We are also fortunate to have him as a member of the Scientific Advisory Board of the KDA.

As most of you know, KD is very rare in the big umbrella of neuromuscular diseases. This essentially means that the amount of research dollars going to find a cure for KD is minimal. This Association is the only one dedicated to funding research grants aimed specifically at Kennedy's Disease. None of the board members or any volunteer in the KDA is paid. We all want to give our time and efforts to find a cure for this debilitating disease. Won't you also please come forward and help?

You can help right now by sponsoring Ed for this upcoming Marathon. There is a link on the KDA website where you can donate online. http://www.razoo.com/story/Running-On-Empty-Helping-The-Kennedy-S-Disease-Association. It is safe and all monies donated will go to KD research. If you wish, you may send a check to the KDA directly. Please indicate in the memo field that your donation is to sponsor Ed's race.

You may also ask for a sponsor donation from professionals who know you and your health situation. Some of them are your family doctors, dentists, neurologists, veterinarians, lawyers, etc. We need to raise funds for a cure and nobody cares more than those of us affected. If you would like my assistance in contacting people for donations just let me know. You may contact me directly at loutudor@yahoo.com. I'll be happy to prepare a letter and even send it out for you.

Ed has given new meaning to "Run for Your Life." Let's all support him and help ourselves at the same time. **Together we can make a difference!**

Grant Announcement

2009 Applications

It is the hope for all of us who must deal with Kennedy's Disease that a cure will soon be found. In fact, the first stated mission of the KDA is to "Financially support and promote medical research to find a cure for Kennedy's Disease." Since its inception, the KDA has been using your donations to fund KD research. Despite the fact that we are a small organization with limited funds, the research that we, the KDA, have funded has led to some major discoveries! For example, the KDA funded an initial study that examined the possible effects of ASC-J9 on KD. As some of you may know, this chemical was shown to improve the motor function in mice with KD and the researchers are now hoping to initiate a clinical trial in humans within a few years. While the size of the grants funded by the KDA is small by modern research standards, their effects have been large. They have allowed researchers to expand their studies on KD and to acquire new data that has been instrumental for the acquisition of larger grants from agencies such as the National Institutes of Health (NIH). In addition, several of the grant recipients who were post-docs when they received their KDA grant, are now independent researchers who still study KD. Thus our grants not only have been effective in advancing the knowledge base of KD but also in expanding the number of research labs that investigate KD.

The 2009 KDA grant competition began in June of this year. In the past, we have received between 2 – 4 applications and we have had resources to fund 2 grants – when one considers that NIH only funds about 10% of the proposals that they receive, we have quite a high funding rate. Apparently, the word of this must have spread through the research community as this year we will receive 8 grant proposals!

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Kennedy's Disease Joins the world of Twitter

Follow us @kennedysdisease

The Kennedy's Disease Association will now post periodic updates on Twitter, the popular social media tool. You can easily add yourself to KD's Twitter account by clicking to follow at http://www.twitter.com/kennedysdisease.

We also have a link to Twitter on the KDA website www.kennedysdisease.org.

If you already "tweet" on Twitter, you know how easy and effective the auto updates can be for busy lifestyles. Many of us don't have time to check all our websites of interest on a regular basis. Twitter will give you a brief update and, if needed, direct you to the home site for further information.

The KDA is working hard to give you the updates that give us all hope for the future. If you have something you think should be posted on the Kennedy's Disease Twitter site, please send it to me at loutudor@yahoo.com. Your input is always appreciated.

My Uncle Cy

By Mary Goynes

I'd like to share with you some thoughts on my Uncle S. E. "Cy" Bering who had Kennedy's Disease (KD) back before it was a named disease. Surely, many of us have a hero in the family, someone you wish you had known a lot better, but you have to be satisfied with their memory. Such memories can stir up stories of courage and gratefulness, and positive spirit and attitude, like our early pioneer families.

It's been 20 years since Uncle Cy's death in 1989, and the years since have shown so many advances in technology and science and global communication. My hope is his story and others who lived with KD during the last generation can teach us something about what it takes to live with this disease, while waiting for the cure. As I spoke with family members while writing this story, the strongest memory that emerged was his smile and zest for life.

Cy was born in 1915 to Samuel and Teresa Bering, German and Irish immigrant parents who settled in Park Place, a neighborhood south of downtown Houston. He attended night school at the University of Houston, and achieved his BA while working full time. He joined the U.S. Navy and served during World War II. Somewhere in those years he felt the first "weakness" as he called it, as he worked on the ships — the early symptoms of a now-familiar KD. After the war, while working for Humble Oil Company he once again attended night school and earned his MA.

He married Julia Loughmiller in 1949 and they raised four children in Bellaire, Texas. But, it wasn't until the 1960s that he was "diagnosed" - with the best diagnosis they could get back in those days - when the doctors ruled out what it *wasn't*: It wasn't Huntington's Chorea, it wasn't Parkinson's. They thought it was Lou Gehrig's Disease, a form of ALS. That's what I remember to this day: Uncle Cy "has a slow *Lou Gehrig's.*"

His family remembers when they went out on vacation to the mountains or to the east coast, Cy was determined to do all he could to be with the kids and enjoy the time together. If he couldn't climb to the top of the mountain, or finish the most strenuous hike, he would get to his best vantage point, sit, and enjoy the view. He took those vacations, knowing it would be a challenge and he loved challenges.

Article continued on page 6

Grant Proposal - cont'd from page 4

In the past, we usually received proposals from labs in the USA, but this year 5 of the proposals come from labs outside the USA – from Italy, Germany, Canada and Japan. We are very pleased at the increased international participation in the KDA and hope this will help spread the word of our work throughout the world, which in turn will increase the number of associates worldwide.

It must be added that our ability to fund such outstanding research is completely dependent on the donations you give to the KDA. Over 70% of our donations go directly to research in KD – this is a very high percentage and can only be maintained if you continue to support the KDA. So please, do not forget the KDA!

Past KDA Grant Recipients		
2003	Dr. P. Taylor	$25,000.00
2004	Dr. A. Lieberman	$25,000.00
2005	Dr. P. Taylor	$25,000.00
2006	Dr. Chawnshang Chang	$25,000.00
	Dr. Udai Bhan Pandey	$25,000.00
2007	Dr. Maria Pennuto	$25,000.00
	Dr. Udai Bhan Pandey	$25,000.00
2008	Dr. Heather Montie	$50,000.00

Kennedy's Disease Associates

By Country

KDA Associates and Researchers/Doctors

Country	Total Associates	Men with KD	Kennedy's Disease Doctors & Researchers
USA	583	330	53
Canada	77	47	2
United Kingdom	65	45	3
Australia	32	21	2
Italy	14	8	4
France	13	11	0
Spain	8	7	0
Mexico	7	6	0
Netherlands	7	5	0
Germany	6	5	0
Belgium	5	5	0
Greece	5	1	0
China, P.R.	4	3	1
Denmark	4	1	2
West Indies	4	4	0
Japan	1	1	3
Other Countries	33	15	3
Total:	**868**	**515**	**73**
Percent:	**100%**	**59%**	

Notes: a. Doctors and Researchers shown are those that have joined the KDA

b. Updated July 24, 2009

Gas Powered Wheelchair

An interesting video to have a look at next time you are surfing the internet. This one was found on YouTube:
http://www.youtube.com/watch?v=-duZOgoTyW8

My uncle Cy - cont'd from page 5

Back home in Bellaire, after he retired, he would take his riding lawnmower (his version of a 1970 electric scooter that he even equipped with a bicycle horn) out for a spin, to visit the mailbox down the street or a neighbor he wanted to see.

Like his mother he loved to garden, so he bought a little cart he could roll into place, and sit on to dig and plant in the garden - a prototype of a future walker, I guess you could say. Uncle Cy's yard showed his passion for all things horticultural: always green and blooming and full of new bulbs and plants.

He just went on day by day, hoping for a treatment or a cure, getting excited and trying them all when they would come available - but never letting himself get down and out.

He developed the first version of trekking sticks, for hiking in steep terrain, when he picked up two canes, one for each hand. It allowed him to stabilize himself and avoid falls. His attitude helped him find solutions when there weren't any on the market.

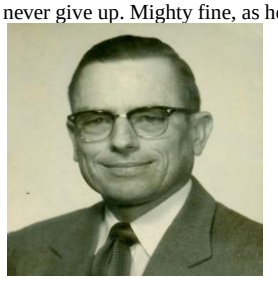
He had what the family remember as the "so what" attitude. He seemed to say, "I've got this disease, so there are things I can't do - "so what?" He'd find a way, and do everything he could, and somehow let go of the things he couldn't. He stayed positive. He didn't quit - never gave up.

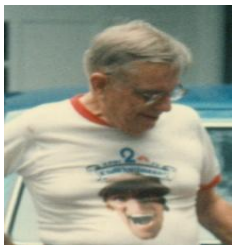
At his funeral in 1989, the parish priest of Holy Ghost Parish, a family friend for many years, told the story of watching Cy after one of the dozens of parish bazaars Cy had participated in. Cy was helping pick up a piece of lumber - a 2x4 - with one hand while holding himself up with a cane with the other hand. The priest thought, "Cy shouldn't be doing that." But, that's the way he approached any job to be done. "I've got one hand free, and I can help you."

Cy was a family man, a man of God, and a businessman respected in the community. He was a loveable, spirited individual who stands out in our family and in the community where he lived, worked, and played.

Cy did have KD but it never defined or limited who he became: it only made him more a man of grace. That's the way I see it.

He was a pioneer, in the early days of KD, and I only wish he were still here to encourage us all to keep going, do everything possible for a cure, and never give up. Mighty fine, as he used to say a lot, and thanks, Cy.





Delicious Easy Dessert Everyone Must Try!

Peanut Butter Cake

Submitted by Tiffany Beck-Ortner

Peanut Butter Cake

Boil together:

½ c. peanut butter	**1 c. water**
1 stick margarine	**½ c. oil**

Remove from heat and add the following:

2 c. sugar	**1 tsp. baking soda**
2 c. flour	**1 tsp. vanilla**
½ c. milk	**2 eggs, beaten**

Mix together until blended. Batter will be thin. Pour into prepared pan. Bake at 375° F. For 9 x 13 inch pan bake 20 to 25 minutes. For 10 x 15 inch pan bake 15 minutes or until tested done.

FROSTING:

Boil:

½ c. peanut butter	**⅓ c. milk**
1 stick margarine	

Remove from heat and add:

1 lb. confectioners' 10X powdered sugar	**1 tsp. vanilla**

Beat until smooth and spread on cake.

Anna Lea Rannells
(United States)

This recipe is from the Kennedy's Disease Cookbook "Recipes From Around the World". Each cookbook costs $12 which includes shipping and contains a $5.00 US tax-deductible receipt. If you are interested in purchasing a cookbook please **mail your payment to Kennedy's Disease Association, P.O. Box 1105, Coarsegold, CA 93614-1105. Please include the information listed below.**

1. **Name**
2. **Mailing address including city, state, zip code and country**
3. **Phone number**
4. **Number of cookbooks you would like to purchase**
5. **Your check or money order made out to the Kennedy's Disease Association for the correct amount of cookbooks you are ordering.**

There is a limited supply of cookbooks! Order yours today before they are all gone!

We need your feedback!

KDA is wondering if you would be interested in making a second cookbook. We would need people to contribute new recipes and need volunteers to help sell the cookbooks to their families and friends. If you are interested or have any other fundraising ideas please contact Lou Tudor at loutudor@yahoo.com.

KDA e-Xpress

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Editor: Bruce Gaughran

Comments, suggestions, and questions should be sent to:
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