KDA e-XPress

An official publication of the Kennedy's Disease Association

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Kennedy's Disease knows no boundaries

... It is passed from generation to generation in families worldwide

In this issue ...

New Clinical Trial

Article by Bruce Gaughran

Effect of Functional Exercise in Patients with Spinal and Bulbar Muscular Atrophy

A. Summary and Background:

-Spinal and bulbar muscular atrophy (SBMA) is an inherited disorder that affects men. People with SBMA often have weakness throughout the body, including the muscles they use for swallowing, breathing, and speaking. We do not know if exercise helps or harms people with SBMA.

B. Objective:

-To see if a 12-week program of either strength exercise or stretching exercises will improve strength, function, or quality of life in people with SBMA

C. Eligibility:

-Participants will be men 18 years of age or older who have genetic confirmation of SBMA.
-They must be able to walk at least 50 feet with or without an assistive device such as a cane or a walker and stand for 10 minutes without using an assistive device.
-They must have access to a computer with an Internet connection.

D. Design:

-At the first visit to NIH (2 days), participants will have a medical history taken and undergo a physical exam. They will also have blood tests and an EKG, and complete questionnaires about mood, health, and exercise. Tests of muscle strength, balance, and endurance will also be done.
-Participants who qualify for the study will receive instruction about either strengthening or stretching exercises. They will do these exercises at home one to three times a week for 12 weeks.

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-They will wear a small activity monitor while they exercise and record their exercise in a diary.
-At the end of 12 weeks, participants will return to the NIH for 2 days. They will undergo the same tests as they had on the first visit.
-Participants will receive follow-up phone calls and e-mails during the study and for 4 weeks after the last visit.

E. Sponsoring Institute:
-National Institute of Neurological Disorders and Stroke (NINDS)
-Trial: 11-N-0171

For additional information on recruitment, eligibility and who to contact, go to the KDA website and click on the "Promote Research" tab and the "Clinical Trial" page (or follow this link: http://www.kennedysdisease.org/promote-research/research-updates .

KDA Awards $65,000 in Research Grants

October 14, 2011
Thanks to the generosity of its supporters, the Kennedy's Disease Association announced today that it awarded three research grants. The three recipients and a brief explanation of their research are shown below.

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1. **Masahisa Katsuno, M.D. - Ph.D., Department of Neurology, Nagoya University Graduate School of Medicine**
Amount Awarded: $25,000
Proposal: Elucidation of neuronal death signaling pathways and development of disease-modifying therapies for Kennedy's disease
Brief Explanation: Their lab has evidence that the synthesis of two proteins are affected by the defective androgen receptor in KD. They wish to determine if neuronal cell death is caused by the alteration in the levels of these proteins and if cell death can be prevented by the addition of drugs that target the activity of these proteins.

2. **Elise Kikis, Ph. D., Northwestern University**
Amount Awarded: $20,000
Proposal: Modeling SBMA – from understanding proteotoxicity to identifying therapeutics
Brief Explanation: They believe that the specific cell death is due to the accumulation of misfolded proteins (the androgen receptor) and the inability of cells to handle this accumulation. They propose to use a new model organism (a little worm called C. elegans - a very common and important model system in biology) to examine how different cell types handle the misfolded proteins and genetically look for other proteins that may help the cell get rid of the messed up proteins.

3. **Sara Parodi, Ph.D., Department of Neuroscience and Brain Technologies, Genoa, Italy**
Amount Awarded: $20,000
Proposal: Identification of PKA signaling as a new therapeutic approach for SBMA
Brief Explanation: There is evidence that the cell death may involve changes to the androgen receptor (specifically changes in which phosphate is added to the protein, a process called phosphorylation). They hope to determine whether this cell death can be stopped due to the activation of another protein, known as PKA.

Placebo Effect

Article submitted by Ed Meyertholen

One of the difficult things in setting up any clinical trial for KD is determining what factors should be measured to assess the effectiveness of the treatment. This seems like a no-brainer – but to a researcher it is critical to the success of the study. For those of you who were in the Dutasteride clinical trial, you surely remember that different types of measurements were employed to assess the progression of the disease. The researchers were not sure what measurements were best and so hedged their bets by employing a myriad of different functional tests. Most of the tests dealt with objective measurements of muscle function (strength, for example, or how far one could walk in 2 minutes), but they also used some subjective tests, tests that tried to measure the quality of life. These latter tests were essentially questionnaires surveying how the patients felt about their physical condition and how well they felt they coped with the problems of KD.

Dr. Gen Sobue's research group just published a paper in which the compared two groups of patients with Kennedy's Disease. This was not a report from a new clinical trial and it really offers no new insights on how to treat KD. Despite this apparent lack of relevance, I found the paper to be quite compelling. The data reported compared the rate of progression of KD in two groups of

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individuals, a group of men with KD that served as a placebo control in Dr. Sobue's previous study of the effect of leuprorelin on the progression of KD (we will label these PG) and a second group of men with KD who were not part of any clinical trial, we will label them NTG.

So that it is clear, the PG group took a pill that had no therapeutic value for KD – simply, it was a sugar pill. However, they thought it was leuprorelin, a substance they were told would reduce the progression of their symptoms of KD. Since neither of these two groups received any real medicine, we would expect these two groups to show a similar disease progression over the time period of the study, 48 weeks. We will see that this is not exactly what happened.

In Dr. Sobue's paper that served as the catalyst for this article, the progression of the patients' KD symptoms was also measured by both objective and subjective tests. Specifically, they compared how certain clinical 'outcomes' from these two groups changed in a span of 48 weeks. One of the tests they performed was the distance that a patient could walk in 6 minutes – a measurement known as the 6 min walk distance (6MWD). They found that this distance decreased in both groups at about the same rate. This is not surprising as both groups had KD and were essentially untreated groups.

They also measured something known as the ALSFRS-R. This is a self-assessment questionnaire (thus subjective) that attempts to measures how a patient feels they perform normal activities. The patient would be asked, for example, how are they doing at walking (or climbing stairs or swallowing). The patient then scores their answer on a 5 point scale, the higher the number, the better they felt they were doing. The researchers found that the ALSFRS-R scores fell for both groups, but it fell significantly more slowly for the PG than it did for the NTG. So essentially, the PG, who **thought** they were receiving a drug that would lessen their symptoms, reported that they could function better than the NTG, the group that did not take any drug or treatment and had no preconceived expectations. This was despite the fact that both groups received nothing that would actually help them! Remember, there were no differences in an objective measurement (the 6MWD). Apparently, the idea that they **expected** to be helped by a drug was enough to make them **feel** that they were being helped.

Now this result is not groundbreaking research but I do think that it does have an important lesson for those of us with KD as well as those who are trying to cure KD. The results published by Sobue suggest that we need to be cautious when interpreting the results of a subjective test. The biases of the patients and the researchers can come into play in the form of a **placebo effect**. Sobue defined the placebo effect as "the improvement resulting from psychophysiological effects such as a positive expectation for a new treatment by patients and raters or a subconscious desire to meet the attending doctor's expectations." In other words, the patients feel like they are getting better because they **want** to get better and not because they are getting better. It is common, I think, for people to underestimate the power of the placebo effect – it is real!

As patients who have a disease that has no treatments, we need to be aware of the power of the placebo effect when we hear of possible therapies, especially if they are not from a reliable source. Let me give an example. Until recently, a company in Germany (they were able to do this in Germany due to a legal loop hole, no other EU country, not the US or Canada would let them do what amounted to experimental surgery) advertised a safe and effective treatment for KD (as well as a host of many other neurological diseases) using stem cells. At this time, this is no effective standard stem cell therapy for KD or the other diseases they claimed to cure. The website for this company referenced patient surveys to indicate efficacy of their treatment – I had not seen any reference to any objective data and they have not published any clinical trials. To no one's surprise, they claim that something like 50% of the patients reported that they thought that the stem cells made them better.

Now if you think of these results in light of the Sobue paper, we have a group of individuals who desperately want to get better, so much that they spent tens of thousands of dollars to go to Germany and get this 'treatment'. Just as in the PG group described above, this group felt like they were getting better when you asked them. But did they really get better? We cannot know for sure as there were no objective tests employed to verify that the disease progression had really been slowed.

Using patients from a similar clinic in China, a group of researchers found that despite the reports from patients that they were better, objective criteria showed this was not the case. The stem cell treatment was not effective. This appears to be a classic case of the placebo effect. As an aside, the company in Germany has been closed by the German government after at least one patient died due to the stem cell treatment.

The "take home" message from this is that we have to be alert and be able to differentiate viable treatments from scams and hearsay. Before embarking on any exotic treatment, look for objective evidence that it really works and always make such decisions in concert with your doctor.

Stem Cells

Article submitted by Ed Meyertholen

One does not have to go very far to find articles dealing with stem cells. A 0.1-second Google search for "stem cell" returns over 31 million hits. These hits includes not only articles describing what stem cells are but also the possible use in helping treat a myriad of different maladies, from cancer and liver disease to spinal cord injuries and ALS. Also included are over 3.7 million hits dealing with the ethical issues of using stem cells. No matter what feelings you have about stem cell research, there is no doubt that that many believe that stem cells have the potential to revolutionize medical procedures – especially for those with neurological diseases.

In this essay, I will not venture into the ethical dilemma associated with stem cells but will restrict myself to the world of science. I will try to describe what are stem cells, how might they be employed to treat KD and what is the current state of the clinical use of stem cells for the treatment of neurodisorders. Since this is a fluid field and this is being written for a lay audience, some may find my simplifications too simple as I may have omitted some information. So please beware!

What are stem cells and what good are they?

Stem cells are undifferentiated cells that have the potential to become almost any cell type. What does this mean? I expect that most of you know that the human body is composed of lots of individual structures called cells. It is estimated that there are between 50-100 trillion cells in a typical human. The ancestry of all of these cells in one person can be traced back to one fertilized egg. This egg cell undergoes many cycles of cell division that will ultimately produce all the cells in one's body.

It is important to understand, however, that not all cells are the same. We have liver cells, kidney cells, brain cells and even big toe cells. While each of these different cell types originated from the same fertilized egg, the properties and functions of these cells are quite different from each other. A kidney cell cannot, for example, do the work of a nerve cell; different cell types have different structures and different proteins that are specific for their respective functions. If one was to follow the process by which an egg cell becomes a liver cell, one would discover that there are chemical mechanisms by which a nonspecific cell 'becomes' a liver cell. This is a highly studied area of cell biology and you can imagine a complex one as well. This same argument can be made for any cell type in your body. The process by which a specific cell type is formed from a general cell is known as **differentiation** and the changed cell is said to be **differentiated**. Once a cell becomes differentiated (that is, once it becomes a specific cell type), it is very difficult to go back and become undifferentiated. Essentially, it is tough to teach a differentiated cell a new trick. An undifferentiated cell that has the ability to become a differentiated cell (of any type) is a **stem cell**.

What makes this process more interesting and important is that some types of differentiated cells lose the ability to reproduce. Nerve cells are well known for this. In addition, for most nerve cell types in an adult brain (yes, there a many different types of nerve cells), it is not possible to use new stem cells to make new neurons. This is because neuronal stem cells do not exist in most areas of the brain. Thus, once an adult loses a nerve cell, it is likely that there is no way to replace it and it and its function is gone for good. In KD, for example, the key cause of symptoms is due to the death of motor neurons, a particular type of nerve cells that controls the contraction of muscle cells. There are no known mechanisms that are capable of naturally replacing a dead or missing motor neuron. Thus once it is gone, one loses the ability to use the muscle cells that it controlled and this ultimately is the cause of the symptoms suffered by KD patients.

What this all means is that in order to treat KD, one must be able to either discover a technique to keep the motor neurons from dying or to discover a process to replace those that have died. The more traditional attempts to treat KD have concentrated on the former approach. Researchers have been hunting for a 'pill' that will keep the motor neurons alive and well. This was the goal of the dutasteride and leuprorelin clinical trials. To replace a dead motor neuron requires the development of new techniques by which stem cells are directed to become motor neurons, and then these these new motor neurons are injected into the spinal cord. It is hoped that the new motor neuron can be then be induced to make the same connections to the same muscles as did the old, dead motor neuron. As you may imagine, this is a very difficult set of procedures and it presents researchers with a formidable set of problems that they must overcome before stem cell treatment will be SOP.

Are all stem cells created equal?

To begin stem cell therapy, obviously, one needs stem cells. Where do they come from? How does a researcher get them? There are, it turns out, several different sources for stem cells.

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1. **Embryonic Stem (ES) Cells**: ES cells are the type that are the most controversial. ES cells are harvested from an early embryonic stage. They are capable of forming almost every possible cell type as these cells are the 'authentic' stem cells. In practice, these cells are acquired from embryos formed by *in vitro* fertilization (IVF). This is the same process by which infertile couples attempt to get pregnant using IVF.
   The value of ES cells is that they truly can be differentiated into any cell type. In the case of KD, for example, they could be differentiated into motor neurons. These motor neurons could then be injected and hopefully, they will find the right area of the spinal cord, begin to mature and grow and make the correct neural connections to the muscle cells. In this way, they would replace the missing cells which should relieve the symptoms of KD.
2. **Neural Progenitor Cells (NPC)**: These are a subtype of stem cells that essentially are partially differentiated into stem cells that can only become neural cells. These are found in more mature fetuses and in certain parts of adult brains. They can also be formed from ES. It is possible that these cells could be obtained from post-mortem brains or even collected from the brains of individuals undergoing neurosurgery. It is believed that these cells can be induced to differentiate into almost any neuronal cell subtype, including motor neurons. Like ES, the NPC's can be maintained and differentiated in a petri dish and then injected into patients.
3. **Mesenchymal Stem Cells (MSC)**: These are stem cells isolated from bone marrow. These cells are primarily precursor cells for creating different types of bone and cartilage cells. There is evidence that it might be possible to 're-educate' them to form nerve cells.
4. **Induced Pluripotent Stem (iPS) Cells**: These are cells that are generated from adult tissues (often a cell known as a fibroblast) and are reprogramed to become stem cells. Ideally, this would be a great way to obtain stem cells, however, there are technical and safety issues that need to be worked out before this becomes a viable source of stem cells.

Stem cell technology has great potential especially in regard to the treatment of diseases such as KD. We are, alas, many years from the realization of this potential. There are still several major technical barriers that must be overcome before it will be a viable therapy. For example, if one forms motor neurons from either ES or NPC, these will not have been derived from the patient's own cells, thus there is a good potential for tissue rejection. On the other hand, if the cells a derived from the patient's own cells (as would be the case for MSC or iPC), the cells that are injected would contain the same genetic defect of the cell that has died.

Another issue is how do the injected cells know where to go? In KD, there is a loss of motor neurons in the lower parts of the brain and all along the spinal cord. One would need to inject cells into all these areas. It is not possible to simply inject the cells into the blood – they would not make it into the brain. A more complicated surgical procedure would have to be used to place the cells in the correct areas.

Even if this problem is solved, the transplanted neuron must now grow and make the physical connections to the muscle cells, not just any muscle cells, but the cells that lost their connections. Assuming that this could be done, it is estimated that the growth of the new connections would likely take a year to complete. Of course, there is also a problem of how the rest of your brain communicates with the new, transplanted cells. Each of us has conscience control over our motor neurons and this control is mediated by neural connections from our brain. These connections must be recreated in all the transplanted cells. What I am trying to say is that while the use of stem cells, no matter what their origin, has unparalleled potential to treat diseases such as KD, the actual use of stem cells to treat neurodegenerative diseases in clinical practice is years away.

Let me add one more point. One can search the internet and find many sites that advertise stem cell therapy for many different disorders. Some are legitimate and, sorry to say, many are not. At the present time, there are no proven clinical procedures using stem cells that will successfully treat KD. If you see a web page claiming otherwise, you should be very suspicious. Please, talk it over with your physician before you risk your money or your life on such treatments.

2011 Kennedy's Disease Association Conference and Education Symposium

The Kennedy's Disease Association Conference and Education Symposium will be held this year in Bowie Maryland, at the Comfort Inn and Conference Center. The conference dates are November 9-11, 2011.

The goal of the conference is to provide the men with KD, Carriers, and care givers the opportunity to meet and talk with other folks who are living with Kennedy's Disease; to exchange information, ideas, and to offer emotional support to each other. There will be interactive discussions amongst all the different groups which will offer each attendee the opportunity to ask questions and discuss issues that they are concerned about.

Ed Meyertholen, a researcher and KDA Director, will present the scientific facts about Kennedy's Disease. The beauty of Ed's presentation is it's presented in **non-technical language** that we all can understand.

Each attendee will also be given the opportunity to meet with the Doctors and Researchers who are working daily in search of a cure for Kennedy's Disease.

There are scheduled presentations offering practical tips for living with KD. The Conference has ample time built into the schedule so you will not feel rushed or overwhelmed.

At this time we have attendees from Canada, Brazil, Taiwan and nine states as well as a number of Board of Directors of the Kennedy's Disease Association.

For information and to register please go the KDA website at:
www.kennedysdisease.org/share-information/kda-conference-events

If you have any questions please e-mail me at: pdeschamp1@roadrunner.com.

We look forward to seeing you there.

Paul DeSchamp - Conference Chair

Veterans with Kennedy's Disease

Article submitted by Bruce Gaughran

Last year I published an article in my "Living with Kennedy's Disease" blog on a Canadian veteran who was turned down for VA benefits. If he had ALS he could receive benefits, but not if he had Kennedy's Disease.

Recently I received an email from a U.S. veteran with a similar story. He is being treated at the ALS Clinic and V.A. Spine Center, but when he applied for disability benefits from the Veterans Administration he was turned down. This man is working with the Paralyzed Veterans of America and hopes to appeal the decision.

In the previous article, I wrote:
"… since ALS is the primary misdiagnosis for those of us living with Kennedy's Disease, the link (between the two), in my opinion, between the two is very strong. I can easily say that 50-70% of us are originally misdiagnosed with ALS. I have always called Kennedy's Disease the "poor man's ALS" because our progression is slower and life expectancy is close to normal.

ALS affects the upper motor neurons, while Kennedy's Disease affects the lower motor neurons. However, many of the symptoms are closely related and that is why it is often misdiagnosed. (Note: It wasn't until the late 1990s that a conclusive test was made available for Kennedy's Disease)

I believe this might be an opportunity, however, … something that he needs to investigate with the Veterans Administration. There might even be a veterans association that can provide some advice and counsel. They might also be able to recommend an attorney that has experience with these type issues. This could open the door for several men living with Kennedy's Disease to receive veterans' benefits should it be approved."

Often appeals like this are difficult to win, but that doesn't mean we shouldn't try. I would be willing to write a letter from the KDA to the Veterans Administration expressing the similarities in symptoms and the often subsequent misdiagnosis of ALS.

If you are a veteran, or know a veteran, with Kennedy's Disease and are interested in determining if V.A. benefits could be made available for men with Kennedy's Disease, please let us know. There is strength in numbers (*the greater the number the better the opportunity*).

Just do it!

Many of us with Kennedy's Disease will suffer with depression and anxiety at some point as the disease progresses. I had always told myself that I could handle any feelings in my head that come along without help; I was wrong and almost DEAD wrong. Over the past 6 months, I started on a downhill slide in my progression that seemed to have no end. About 5 months ago something very strange started happening to me. Most mornings, just as I awoke, I would be overtaken by anxiety and a deep emotional overflow that would have me in tears and I could not control it. Along with this was the feeling that I wish I had died in my sleep. This would happen most mornings and seemed to get somewhat better as the day went on. However, at anytime during the day no matter where I was I would sometimes just breakdown into tears. I did some research online and found some interesting information.

One of the worst times for those with Anxiety and/or Depression is waking up in the mornings. When you come out of your sleep that is when your problems start. In the morning all the things that you have been suppressing come to the top of your awareness. Morning anxiety is caused by debating with yourself (can I handle this? How am I going to get things done? Is this ever going to change? How many more days like this before something changes for the better?) I found out that in the morning you become back in touch with your subconscious mind upon awakening.

Some people with anxiety oversleep to avoid life because it is horrible. At some stage when you are asleep you become detached from all your problems and your soul merges with pure consciousness and deep silence. You take a deep rest and feel at peace. At that stage, your problems have disappeared completely. When you are asleep, you have no problems. As you are waking up, you are aware that you are coming out of peace and your worries or concerns return.

This had gotten to the point that I was avoiding going places and even trying to do things because I had already set myself up for failure before I even started. My wife Susanne suggested that I should speak with my doctor and perhaps try a medication to help uplift my mood for a while because I was no longer able to control these thoughts. I drove to the doctor's office and spoke with him for about an hour and a half about what was going on and he suggested I try Cymbalta to see if would help. I went home and took my first dose and the next day I started to feel improvement. Each day forward, I felt better. Within 3-4 days, I was waking up without the anxiety and depressive attacks. It also changed my outlook on trying to get out and do things and quit being ruled by the "what ifs" and the "I can't's". I had a 50th Birthday coming up and Susanne had been trying for the past few months to get me to pick something special to do. I looked up tandem hang gliding on the Internet because I had always wanted to do that, but I found that all of them had a requirement that I be able to run 20 steps at a fast pace. That shot down that idea but I was determined to keep looking. A friend of Susanne and mine has suggested that I do a Tandem Skydive. I had always said I would like to do it, but I started to get those "what ifs" and I can't's" again but this time my mind was more balanced and I was ready for it, and I said, "YES! I will do it!" I pushed those bad thoughts aside and was not going to let them ruin my life. A couple other friends decided to join in – three were sky diving with me, while Susanne, her mother and another friend were our 'ground crew pit party'. We caravanned 3 hours to the Lodi Parachute Center in Central California. I was perfectly calm (more than the other first time jumpers) people said afterwards that they could see it in my face even seconds before the jump (see photo) and I was to be the first one out of the plane. It was awesome and the landing was perfect even with my bad legs. My Tandem professional jumper held my legs up and used his to plant the soft landing. The jump facility was fantastic! I explained to them about Kennedy's Disease and they thought that it was great that I came out to do this. They assigned extra help to assist me getting up into the plane (5 guys lifted me up), ordered a larger chute for a slower/softer landing and then my tandem instructor hooked me up to his rigging while en route to our jump spot. My instructor told me that the week prior, he had a man with no legs jump with him and he had a great time as well.

I am sharing a very personal story of mine because I know that many of you that will read this can relate. Some of you may be a little too close and if this story helps just one of you, I will be happy. If you feel the way I felt, see your doctor if you have not about the possibility of some extra help (even if just temporary) with perhaps some medication.

My next adventure is to find a place where I <u>can</u> do a tandem hang glide where there is enough updraft that I do not need to run to launch. I know they are out there because I have seen videos of it.

Therefore, for those of you who have stopped enjoying life because you are stopping your dreams before you even give them a try, JUST DO IT….or at least try. We can still do many things!

Terry Waite

An Open Letter to the Women

"Isolated…" "Lonely…" "No one to talk to…" "No one understands what I'm going through."

These are the words I read from women who are reaching out to the KDA for support. They are dealing with a disease most of them didn't even know existed until their husband or loved one received the diagnosis.

There's another word, too – "fear."

Most of them don't say it, but it permeates their correspondence.

Of course they are worried about their man, but many of them are also having private thoughts they are afraid or even ashamed to admit out loud to their friends and family.

"How can I handle the physical aspects of my man's disease – the ramifications for me, personally? Am I strong enough physically and emotionally to deal with what lies ahead? What will happen to ME?"

Unless a woman has a friend who has already started down the path of being a "Significant Other" for a man who has KD, she often feels as if she is truly alone and isolated.

As wives, mothers, sisters and daughters of men with Kennedy's Disease, we are in a unique position to offer support and comfort to each other, especially to the women who are just beginning to face the same issues and emotions we have already been dealing with.

I am currently sharing emails with a couple of KD wives from other countries. These are ladies who are very much in need of support and friendship from other women who are dealing with KD and, although the Significant Others Chat is intended to help with this need, it is inconvenient or impossible for many women to attend the chats because of time differences or conflicting responsibilities during the chat times. I thought about Facebook or some kind of blog, but those wouldn't work because the needs of these women are personal and in many cases, private – not something to be out on the Internet for everyone to see.

My experience in corresponding with the women who have contacted the KDA has been emotionally gratifying and has resulted in new friendships that I believe will last a lifetime.

So I am proposing an email version of a pen pal club. If you would be willing to correspond directly and personally with other women who have reached out to us through the KDA, please let me know.

Your friendship and support could mean the world to another woman!

Thanks.

Paula

813-642-8660 (H)

813-476-3258 (C)

pggoynes@verizon.net

"Never doubt that a small group of thoughtful, committed people can change the world. Indeed, it is the only thing that ever has." -- Margaret Mead

Approximately $12,000. was raised for KDA research!!

The First Annual Kennedy's Disease Association Golf Scramble Benefit Tournament was a HUGE success! Saturday, October 1st in Houston, TX turned out sunny with a cool breeze for sixty seven happy golfers!

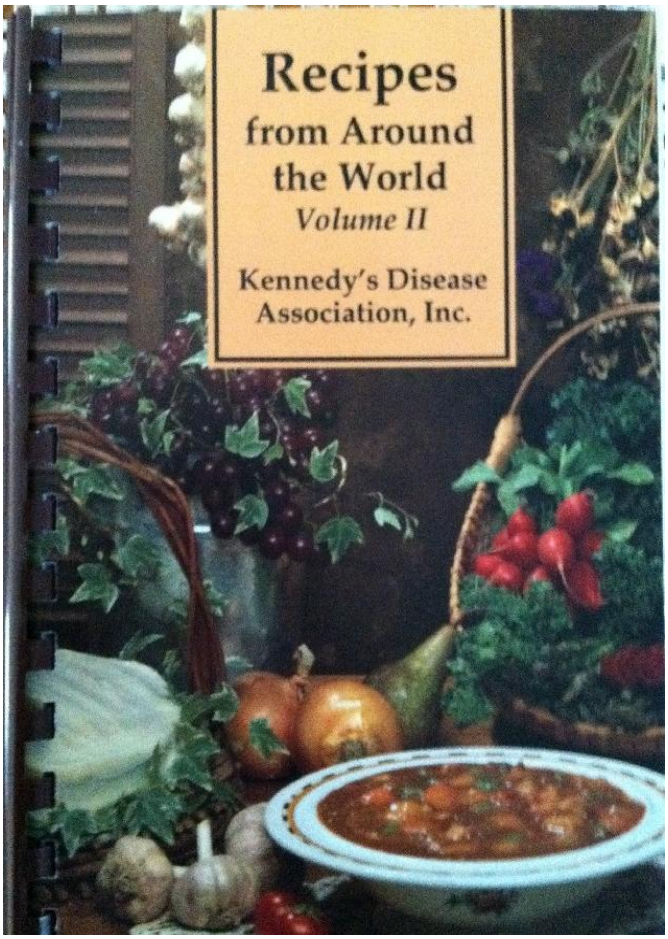
The morning started at 6:45am with registration, goodie gift bags and breakfast snacks of coffee, juice, bottles of water, fresh fruit and *Chick-Fil-A* sandwiches. The shotgun start at 8:00am was heartwarming to see, with all those golf carts lined up ready to support our cause. Committee Chair, Ed Noack, gave simple starting instructions and the day on the course proceeded smoothly. When the golf games ended, an afternoon BBQ lunch was served, followed by an awards ceremony and an auction of impressive items. Included were beautiful gift baskets for wine lovers, spa enthusiasts and margarita fiesta lovers, a Keurig coffee maker and assortment of coffee, a grand John Connally art collection of limited edition signed prints, a gold $50 buffalo coin, a $1,500. professional landscaping package, an autographed Texan football jersey…to just name a few. The auction was fast and exciting with professional auctioneer Ed Noack running the show!

The day ended with the presentation of a check for the Kennedy's Disease Association. WOW!! So much work went into creating this day…and we appreciate the Houston committee that spent uncounted hours of labor and money from their own pockets to make their vision a reality. The core committee consisted of Murray Williams, Ed and Nancy Noack, Louise and Charley Goforth, Verna and Mike Hoke and Krissy McLaren. All families affected by Kennedy's Disease, thank you!

Would you and your family and friends be interested in doing a fundraiser in your area? All of the groundwork has been laid…contact me loutudor@yahoo.com and I'll put you in touch with this committee. They are willing to share information to make the job easier and help make you successful! The same organizational detail can apply to lots of different fundraisers…casino night…bowling tournament…dinner and auction…the possibilities are endless.

Here are some memorable pictures of the day and more will be posted on the KDA website and KDA Facebook page.

Lou Tudor



The new KDA Cookbooks Vol. II are in!

"Recipes from Around the World"

Hot off the press and ready for the gift giving season …order now! Each book is a $20 donation which includes shipping to USA addresses. Proceeds benefit the Kennedy's Disease Association for research grants. We gratefully thank Mike and Paula Goynes for their generous donation which paid for the book publication.

You can use your credit card at this site: http://www.razoo.com/organization/Kennedys-Disease-Association. Please remember to indicate you want cookbooks and the number you are ordering.

You can also write a check and send it with your cookbook order to:

Kennedy's Disease Association

P.O. Box 1105

Coarsegold, CA 93614

For shipping cost outside the USA:

Please send your request to loutudor@yahoo.com

KDA Muscle Car T-shirts

We completely sold out all the previous t-shirts in stock. This new design was created by our members, Carla and Stan Highe. They introduced and sold these shirts at a custom car and hot rod show in Michigan! Order yours now while all sizes S-M-L-XL-XXL are still available. The shirts are white with blue lettering. A donation of $25 includes shipping in the USA. Your generosity helps the Kennedy's Disease Association fund research grants to find a cure for this neuromuscular disease.

You can use your credit card at this site: http://www.razoo.com/organization/Kennedys-Disease-Association. Please remember to indicate you want t-shirts and the number and sizes you are ordering.

You can also write a check and send it with your order to:

Kennedy's Disease Association

P.O. Box 1105

Coarsegold, CA 93614

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Kennedy's Disease Tissue Donation Program

Spinal Bulbar Muscular Atrophy, aka Kennedy's Disease, is considered a rare disorder. Approximately 1-in-40,000 people have the defective gene. Most research is performed on fruit flies and mice models; however there has always been a need to perform some testing on human cells with the defective gene. Until recently, human tissue was not available to research labs. Today, tissue donated from an individual with Kennedy's Disease is being used in several labs. This human tissue is very helpful in studying the biology as well as the effects of the disease. Researchers feel that the availability of additional human tissue will further benefit their research and might help them discover a treatment for Kennedy's Disease.

Last month, the Tissue Donation Program guide was updated. The revised guide can be found on the KDA website under the "Share Information" Tab and then on the "KDA Information Guides" page (or by following this link: http://www.kennedysdisease.org/share-information/info-guides .

Article submitted by Bruce Gaughran

Are scheduled Chat Room times too early or late?

We have heard from several associates in Australia and the United Kingdom that the current chat room schedule just does not work for them. The good news is that the KDA chat room is open 24 hours a day – seven days a week. Any Kennedy's Disease related support group can use the chat room during non-KDA scheduled chat times.

The 'always-open' chat room can be an excellent opportunity for people in other countries to schedule their own chats to develop a regional support group. The KDA would be willing to contact other associates within a country to determine if there is an interest in participating. Before doing this, however, we would need one or two associates to take the lead on organizing the group and initially hosting the chats. If the group desired, we could also post their chats on the KDA website for others to read.

If interested, contact the KDA and we will work with you to help establish a support group in your area.

Article submitted by Bruce Gaughran

"Working together to find a cure"

Kennedy's Disease Association

P.O. Box 1105
Coarsegold, CA 93614-1105

Phone: 559-658-5950
Email: info@kennedysdisease.org
Web Site: http://www.kennedysdisease.org