Kennedy's Disease ASSOCIATION

KDA e-Xpress

Volume 4, Issue 4 SPRING - 2010

IGF-1 PART I

It Does Look Promising

In early March the KDA chat room's guest was Dr. Maria Pennuto from the Department of Neuroscience at the Italian Institute of Technology in Genova, Italy. Maria is also a 2009 recipient of a KDA research grant. Her current work with insulin-like growth factor 1 (IGF-1) looks very promising for a treatment of Kennedy's Disease. This research is based upon results that Maria discovered when she worked at NIH. She found that a specific modification of the mutant androgen receptors results in decreased toxicity. This modification was due to the activation of an enzyme known as AKT. I felt her work is important enough to include a portion of Maria's chat in today and Thursday's articles. Please understand that since I am not a doctor or researcher, whenever I give an explanation it is only my interpretation of the information provided and I might not explain everything correctly.

"IGF-1 for muscles" shows a great deal of promise in mouse models. The original study was on mice that had the defective gene, but were not showing symptoms yet. In these mice, the IGF-1 reduced the amount of androgen receptor present in the cells and therefore delayed the onset of Kennedy's Disease and slowed the progression once symptoms began to show up. The current study at the National Institute of Health (NIH) is using mouse models that have shown symptoms. Researchers are trying to determine if IGF-1 still works, works to a lesser degree, or does not work at all once Kennedy's Disease symptoms are present. This current research will also help determine the viability of IGF-1 in humans.

A little background information might be useful here. Cells from a person with Kennedy's Disease have a problem cleaning the residual caused by testosterone within the androgen receptor (AR). The cell's nucleus actually rejects the AR when it tries to enter it for cleaning. Because of this, the AR cannot free itself from the residuals (garbage) that are clinging (binding) to it. Eventually, the AR becomes so clogged that it can no longer function and dies.

Article continued on page 2

INSIDE THIS ISSUE

IGF-1 PART II

Transcript of Chat with Dr. Penuto

In IGF-1 Part I, I discussed the research that Dr. Maria Pennuto and others are doing using IGF-1. This is a small portion of the transcript of that chat with some additional explanations and definitions provided by me. For those of us not very scientifically inclined, some of the explanations might be over our head. Do not let that stop you, however, because there is the potential of a major breakthrough for our children and possibly for those just beginning to show the symptoms of Kennedy's Disease.

Q: **Could you bring us up to date on your IGF-1 research?**
DRMP: IGF-1 is a factor that promotes cell survival. IGF-1 works by initiating a signal that modifies factors that are inside the cell.
IGF-1 is outside the cells, but binds a factor on the cell's surface. After this event, a series of changes end up with activation of a factor named AKT.

Q: **What does AKT stand for and mean?**
DRMP: AKT is what we call kinase. It is an enzyme that adds a phosphate group to specific sites in the protein. [Kinases are used extensively to transmit signals and control complex processes in cells] The Androgen Receptor (AR) is a target modified by AKT. So, IGF-1 activates AKT which in turn modifies the AR.

Q: **How does this modification influence SBMA (Kennedy's Disease)?**
DRMP: We have shown that once modified by AKT, the AR is no longer able to bind testosterone. This finding was surprising and very important for the disease because the disease is triggered by testosterone. We have also shown that the AR modified by AKT gets degraded by the cell … it does not accumulate in the cell. So, we decided to use this information to see if in the mouse model that IGF-AKT-AR signal could be used to attenuate (*weaken, reduce severity*) the disease.

Q: **What is the difference between IGF-1 and IGF-1 for muscles?**
DRMP: That is a critical point. In a cell, there are several types of IGF. Some act systemically and are generated by the liver. Muscle IGF is the form of IGF-1 used in our previous study. We know that in principle the muscle-generated IGF works in the mouse model, but to use this approach in humans we need delivery via a virus. Dr. Fischbeck at NIH is using IPLEX, which is another form of IGF already used in humans. If this works, it is to our advantage.

Q: **What is IPLEX?**
DRMP: IPLEX is binary protein complex of human insulin-like growth factor-1 (rhIGF-1) and human insulin-like growth factor-binding protein-3 (rhIGFBP-3), both produced by recombinant DNA technology which means that is acting systemically. [From Wikipedia: **Mecasermin rinfabate** (trade name **IPLEX**) is a drug consisting of recombinant Insulin-like growth factor 1 (IGF-1) and insulin-like growth factor binding protein-3 (IGFBP-3). It is a drug already approved for use by the FDA.]

Article continued on page 2

IGF-1 PART I - cont'd from page 1

To give you a more common example to explain what is taking place, it is like having an engine with a clogged oil filter. The oil becomes so gummed up over time that it can no longer do its job and the engine eventually malfunctions and dies. IGF-1 appears to allow the androgen receptor to clean the garbage caused by testosterone buildup thereby keeping it healthy and able to do its job. Using the same oil filter example, if you keep the oil filter clean so it can do its job, the engine will run better and last a long time.

Something else came out in the chat that was interesting. Many of us with Kennedy's Disease have wondered which came first, the chicken or the egg (*e.g., how did Kennedy's Disease actually start especially in a family lineage*)? According to Maria, the CAG part of our DNA is somewhat fragile and almost any abnormality can change the number of repeats. In other words, a family with no history of Kennedy's Disease could all of a sudden have one or more children with the defective gene. I had always assumed that somewhere in a family's history was a carrier.

The KDA has a saying when it comes to supporting research.

"Working together to find a treatment or cure

… for our generation, and for our children and grandchildren."

Even though it looks like IGF-1 will not be viable for us "more elderly" gentlemen (*aka old codgers*), it does look promising for those not showing any symptoms and possibly those who are in the early stages of Kennedy's Disease. As a parent, I believe that would be a tremendous step in the right direction in minimizing the impact of Kennedy's Disease on future families.

Meanwhile, we patiently wait the results of future testing and hope for a clinical trial. For someone that is not known for having a lot of patience, these waiting periods seem like an eternity.

IGF-1 PART II - cont'd from page 1

Q: **In your research, when IGF-1 is started pre-symptom, the mouse had a later onset of Kennedy's Disease and less severe progression of the disease. Correct?**
DRMP: Yes, in our experiments, if IGF was there before disease onset our mouse models were producing more IGF afterwards. It remains to be established if this can work in the mouse models being tested after disease onset.

Q: **You commented earlier that your original research was on pre-symptom Kennedy's Disease mice. How about those of us that already have the symptoms?**
DRMP: Yes, Dr. Fischbeck is now testing IGF-1 (IPLEX) on mice models already showing symptoms (just after disease onset) because patients are already symptomatic when diagnosed with Kennedy's Disease. Dr. Fischbeck wants to see if IGF-1 will slow the progression after the disease's onset.

Q: **And, what if IPLEX does not work?**
DRMP: We are also generating viruses expressing IGF-1 (muscle-generated) just in case IPLEX does not work. Of course, these viruses have to be tested in mouse models first. We have already discovered a huge effect of IGF on skeletal muscles in SBMA mice compared to the control group of mice. What is also important is that intervention in muscle preserved motor neurons in the spinal cord, suggesting that if we can protect muscle we can also do something for the neurons and it can be easier to plan intervention for muscles than for the spinal cord.

Again, this is just a short portion of the chat. You can find the entire transcription at the KDA web site under Chat Transcripts. The link to the actual transcript is Maria Pennuto.

This is exciting stuff. Other research projects are also making headway in finding that elusive treatment for Kennedy's Disease. I find it encouraging that several of these projects are focusing on finding ways to allow the androgen receptor to do its job.

The KDA Story

Where did we come from?

The concept for the Kennedy's Disease Association began in 1999 after Susanne and Terry Waite and Patrick Griffin attended the Families of Spinal Muscular Atrophy (FSMA) Conference. The conference had about 3,000 people attending including six who were living with Kennedy's Disease (KD). The six were invited to attend a special breakout session focused on Kennedy's Disease. KD is not a disease that the FSMA normally focused on, but they did put a breakout together for those living with KD. At the time, there was no organization supporting Kennedy's Disease.

Before the conference, the Waites and Patrick Griffin both had developed their own web sites and were trying to get the word out about Kennedy's Disease. Both also wanted to start a non-profit organization focused on KD.

At the end of the Families of SMA conference, the six living with KD were able to spend some time with twenty-two doctors and researchers from all over the world including Dr. La Spada and Dr. Merry. The six were so excited because they were able to meet the people who were working to find a treatment and cure for KD. During the meeting, Susanne asked Dr. La Spada if they had more money, could their research move along any faster. He said "yes." Susanne then asked if a non-profit organization was formed for Kennedy's Disease, would they support it. Again, the answer was "yes."

When the Waites returned home, they collected all the email addresses in their web site's guest book. There were over 100 names of those with KD or their family members. The Waites talked with Patrick Griffin and they agreed to join forces. Patrick sent all of his contacts and the Waites combined the two into one mailing list. The Waites emailed everyone on the combined list telling them what they were trying to do and asking for their support. They also asked if anyone knew an attorney who would volunteer to help them incorporate and apply for their non-profit 501(c)3 certification. Paul Liu provided a name of a very large and internationally respected law firm. The firm agreed to help pro-bono. The Waites did have to come up with $700.00 to pay for the processing fees and other costs associated with the incorporation.

Audrey Lewis, one of the founders of FSMA, once again supported the start-up of the KDA. She helped mentor the Waites through the beginning stages of the association. The KDA was incorporated in August 2000 and received their 501(c)3 status in November of that year.

Today, the KDA has grown to over 900 associates of which 542 men and 103 women have the defective gene. Over the past 5 years, the KDA awarded $230,000 in research grants through the generous donations of our associates and other supporters.

2010 KDA Conference and Educational Symposium

Mark Your Calendars

The 2010 Kennedy's Disease Association Conference and Educational Symposium is scheduled for Wednesday, November 10 through Friday noon, November 12. The conference will start promptly at 8:45 AM. Attendees are encouraged to arrive on Tuesday afternoon, November 9, and attend an informal get-together at an area restaurant that evening. This year's conference will be held at the Holiday Inn - Bayside, in San Diego, CA (http://www.holinnbayside.com/).

Hotel room rates would be $129 per night (double occupancy) for 11/09 and 10, and $159 per night for 11/11. Rates shown do not include applicable taxes. Additional information will be made available after contracts are signed and meeting topics/schedules formalized. Registration fees have not been established yet, but will be similar to the last conference (approximately $225).

Additional details and registration information will be announced this summer.

The 2010 Conference Committee:

Susanne Waite, Chair
Ann Borden
Len Janicki
Jeanne Janicki
Maria Pennuto, Ph.D.
Kathy Thompson
Dan Wolfe

Helping at the conference:

Andrew Cassar
John A. Coakley
Jack Durnig
Bill Erickson
Paula Goynes
Parsa Kazemi-Esfarjani
Rosie Kropf
Ed Meyertholen
Lori Jessop Welchoff

eBay

Another Way to Raise Needed Funds

Here is a great way to help raise the funds we desperately need! Sell your unwanted items on eBay and help the KDA.

We are looking for items you wish to donate to the KDA that we can sell on eBay. Some of our Board members have eBay seller accounts and can set these up so that 100% of the selling price goes to the KDA less any shipping costs.

Contact me Lou Tudor - loutudor@yahoo.com if you have something to donate. You will be asked to take a picture of the item and give a written description. When the item sells, you will be notified of the buyers name and address. You will be asked to ship the item promptly and the KDA will reimburse you for the shipping costs.

How simple is that!

Hobbies

Stan Highe
For People with Kennedy's Disease

It's been a long time since I wrote any type of article. So, here I decide to write an article on hobbies. Not to mention I need to gear this for people with Kennedy's Disease (KD). I don't think I could have picked a tougher subject to begin writing again. In preparation, I decided to do a little internet research to see what is out there and what might apply.

During my research I found a whole myriad of information on hobbies. I found information on the number and types of hobbies, how to decide on a hobby, benefits of hobbies, hobbies for profit, as well as hobbies for people with disabilities.

First, I found out this article is late. January was National Hobby Month. I also found a site that listed over 200 different hobbies. That is a lot of choices! (When I was growing up, I think hobbies were just starting because there weren't that many.)

Dictionary.com defines a hobby as "an activity or interest pursued for pleasure or relaxation and not as a main occupation." We need an outlet to relieve stress, have fun or whatever. Some people may eat, sleep or just watch TV. A hobby offers another more productive alternative to languishing on the couch.

I don't think anyone disputes the value of a hobby. Besides being a source of pleasure or relaxation, some of the benefits of a hobby are self-improvement, keeping the mind active and sharp or acquiring new skills. A hobby can be a source of physical and psychological benefit too. It may get you out of the house for some exercise and fresh air, or just provide piece-of-mind. In addition, as one gains experience and knowledge, a hobby can become profitable or lead to a new career. However, there are considerations that must be taken into account before starting a hobby.

Everyone is different. I have no way of knowing what other people like, what type of room they have, what their interests are or how much time and money they have to devote to a hobby. I have no idea what the person's motivation is or their expectations. I also have no idea of the physical capabilities or limitations of the individual.

Article continued on page 4

KDA e-Xpress

A publication of the Kennedy's Disease Association.

Editor: Bruce Gaughran

Comments, suggestions, and questions should be sent to:
kennedysdiseaseinfo@gmail.com

For Additional Information

The Kennedy's Disease Association
P.O. Box 1105
Coarsegold, CA 93614

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

Arm Wrestling for Food

Stan Highe

I knew I had Kennedy's for some time, as did my family, but it didn't matter. I decided a long time ago that I would do what I could when I could while I still could, any way I could. This is just one of many stories, but sticks with me the most.

When you are parent with school-aged kids, there is always something to do after school. It might be dance, a play, sports, Scouts or any number of other activities. Often we would not get home until nine or ten o'clock. Even though it was late, and we were tired, we always seemed to be hungry, for anything.

This was one of those nights just like the others before. We just got home from a Scout meeting, and as always, the first stop was the refrigerator. It was a race between my son and I who would get there first to grab the choice "snack" or leftover. Wouldn't you know it, we both had our eye on the last piece of Apple pie, and so the contest began. To decide who would get it, we'd arm-wrestle for it. This was one of those moments of father-son bonding that I had to take advantage of while I can.

My son was only twelve and a little smaller than me, but already out-weighed me. That is really no surprise since I have only weighed about 125-130 all my life. (I am one of those people that have trouble keeping weight on.) Still, I had the strength, or so I thought.

Like so many times before, my son and I lay down on the living room floor and assumed the position. Of course, my wife and daughter knew what was going to happen and were already laughing. My son had that same smile on his face he always got. He knew I'd eventually give in after a few minutes and let him have the tasty treat anyway. So we started, hands and arms locked, but something felt different this time.

In past competitions I would get his arm over where it would almost touch the floor, and then let up enough so he could win. This time as we lay there, I found I could not push his arm over past mid-point. I could keep him from moving my arm over, but that was it. It seemed like we were there for fifteen or twenty minutes; stalemated. Of course, he's giggling the whole time, unaware of what is really happening. Then I started to weaken. The pressure was causing my arm to move over more and more, but I could only hold against it. I couldn't push his arm back the other way. A few more minutes passed and my arm went over onto the floor.

We were done but instead of the usual smile, my son had a puzzled look on his face. Finally he says: "You didn't let me win this time, Dad, did you?" I smiled and said: "No, this time you really earned it." I don't know if he realized it- maybe he did and didn't let on- but I knew what it meant. I was getting weaker. As he went into the kitchen to claim his prize, I sat in my easy chair and rubbed my arm. We would have other moments as father and son in the coming years, but we never arm-wrestled for food again.

Hobbies – cont'd from page 3

It really doesn't matter if you are healthy or someone with KD. It is necessary to answer the questions of expected benefits, interest, funds, space and time as those are tools used to decide on a hobby, or at least narrow the field. Taking all these things into consideration will help in your search and lead to finding a hobby that will hopefully stay with you for years, and provide a more rewarding experience. It is important to address each of these items to find the right hobby for you.

So, what are some hobbies for a person with KD? Looking at a couple lists of hobbies I found on the internet for people with disabilities, there are the usual hobbies listed like collecting baseball cards, coins and stamps. You can play cards, paint, sew, knit or do macramé. You can build models, do ceramics or pottery or you can make crafts. You can also read or write. If you notice, these are hobbies undertaken by healthy people too. Some I have done. I don't believe you should be that limited in your decision.

I decided to look back at the big list for some more ideas. Ever consider amateur astronomy, electronics, fishing, making fish lures, model railroading, ATV trail riding, photography, radio controlled vehicles, or woodworking? I chose these because I have done some of them too. Maybe you want to try home brewing. Now there's something that will whet your whistle. Then I thought of, Game Show Contestant. Imagine spreading the word about KD when Alex Trebec asks for a little biographical information. These are just some I came up with. There are many more.

You should be able to see that there is no way for me to put together a list of hobbies and say this one is for those with KD. There are just too many choices and too many variables. I also would not want to limit potential opportunities by missing some. The whole idea of a hobby is to have an outlet to take your mind off your cares, find something you like or want to do and stay active. Be open-minded in your research.

Also, KD should not be the major determining or limiting factor in choosing a hobby. It really should be left open for the individual to decide based on the other criteria first. Healthy people must consider their physical abilities when choosing a hobby. One thing to remember though is that as your strength wanes, your hobby may have to change or you may need to adapt. By the way, there is no rule that says you can only have one hobby. You could have one for rainy days, and one for nice days.

So what is my hobby you ask? Stuff. I am involved with acquiring, breaking, building, buying, creating, designing, fixing, moving, selling and storing stuff. If you need further clarification, go to YouTube.com and look up George Carlin's routine on "Stuff."

"The opportunities of man are limited only by his imagination…"
Charles F. Kettering

Sources:
http://hobbies.suite101.com/article.cfm/january_is_national_hobby_month
http://www.notsoboringlife.com/list-of-hobbies/
http://en.wikipedia.org/wiki/Hobby
http://www.about.com/hobbies/
http://www.disabled-world.com/artman/publish/elderly-hobbies.shtml

2009 KDA Annual Report is now Available

The KDA's 2009 Annual Report can be found on our website by clicking on this link: KDA News. Or, click on this link to download a PDF file directly to your computer: 2009 Annual Report.

Santa Ynez Valley Woman to run first Half Marathon and Running for a Cure

Susanne Waite, KDA Founder, President Emerita

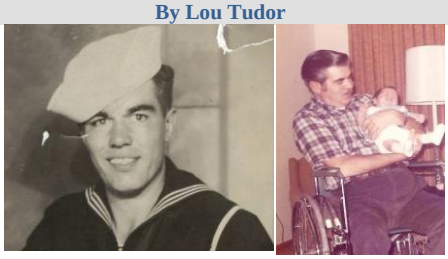
Beth DuVall, of the Santa Ynez Valley, is going to run her first ever half marathon coming up in May - in the Santa Ynez Valley Wine Country Half Marathon. This is a feat in itself, as Beth only recently started running... but she is a very determined person! She sets her mind to something, she doesn't quit.

She is also going to be raising money through this run for a rare neuromuscular disease called Spinal Bulbar Muscular Atrophy, aka Kennedy's Disease (KD). KD causes adult men (affected with the gene) to lose their muscle strength, their balance, speech and swallowing abilities, as well as a myriad of other issues. The disease is commonly misdiagnosed as Lou Gehrig's Disease/ALS as the symptoms are very much the same, but slower progressing in KD.

For more info on Beth's training and run, please visit:
http://www.razoo.com/story/Running-For-A-Cure-1

A Tribute to my Dad
William James Coons
1921 - 1981

By Lou Tudor



When I sat down to write this story, memories made me realize that I've been praying, donating and volunteering to find a cure for Kennedy's Disease most of my life. Although my Dad was wrongly diagnosed with both ALS (Lou Gehrig's Disease) and then Spinal Muscular Atrophy (SMA), we now know through research and proven DNA blood tests, his true diagnosis.

Daddy lived his entire life against all odds. His mother died of Tuberculosis when he was twelve, leaving him and his three sisters in a difficult situation. Because it was the depression years, no relatives were able to care for them properly. Their alcoholic father placed the children in the county orphanage. My father was never adopted or put with a good foster family, but spent several years abused and running from place to place. He finally was able to join the Navy, finish his high school education and spent several years serving honorably in submarine duty during WWII.

When he returned from active duty, he found and reunited with his three sisters. He also married and eventually had four daughters. It would seem that his life had turned in a positive direction. Unfortunately; he found it necessary to keep changing jobs and sport interests due to physical limitations. He couldn't run fast enough to keep his job as an umpire, his hand tremors interfered when he tried drafting classes, and he became a company liability as a welder in the sheet metal industry... I can still remember the sad look of rejection on his face when he came home from his last day at work.

As a family, we spent a few difficult years. Hard as it was to accept, we temporarily lived on welfare. Our mother found a job and Daddy became "Mr. Mom". Our mother had told us our dad was going to die. Thankfully, he lived and the Muscular Dystrophy Association provided mobility aids through the years, as needed.

The physical, mental and emotional impact of this disease was a constant toll on the entire family. But, at no time, did our father ever give up. He pushed himself to try new things and his sense of humor sustained him. He took on household repair projects and vegetable gardening with vigor. He helped us with our math homework, taught us how to ride a bike and throw a ball. He drove us to school, sporting events and parties. He became active in our church. He was a wonderful father and showed us how to handle life's disappointments. I distinctly remember losing my first job as a telephone solicitor, selling aluminum siding at the age of fifteen. My dad encouraged me… "Now you have work experience!" Daddy taught us unconditional and selfless love. He also taught us to laugh at stupid mistakes we'd make and just learn from them.

I must say that my father would be devastated, to learn that having Kennedy's Disease, resulted in all four of his daughters being carriers. Even with careful pre-marital genetic counseling, my sisters and I were given the wrong information. Through DNA testing, both my son and my cousin have been diagnosed with KD. Thankfully, we now have the Kennedy's Disease Association which gives us reliable and up to date information and hope for a cure.

My sisters and I are all now successful adults. I credit our father's lifelong example of tolerance and fortitude. We live life to the fullest and laugh at those things that really don't matter…but never give up for the things that do. Thank you Daddy.

The Pepsi Refresh Project

WE NEED YOUR HELP

The Pepsi-Cola Company is providing funding for great ideas. The KDA is registered for April's challenge. If we are one of the top ten charities to receive votes during the month of April, we will win $50,000.

Goals

- To provide mobility assistance to associates who have a proven financial need

Overview:

The Kennedy's Disease Association is a free support system to those families affected by Spinal Bulbar Muscular Atrophy. Many associates throughout the country are experiencing limited or no funding available for mobility assistance. This program will allow us to fill a gap and give those with proven needs a way to help themselves.

Deliverables:

- Build wheelchair ramps at patient homes
- Repair or replace broken wheelchairs and power chairs
- Provide canes and walker

PLEASE VOTE EVERYDAY... UNTIL THE END OF APRIL. IF WE ARE ONE OF THE TOP TEN, $50,000 WILL BE AWARDED TO HELP KDA ASSOCIATES IN NEED

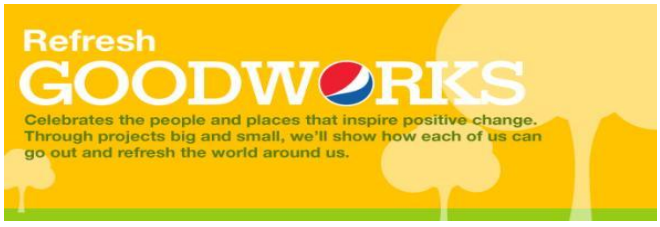
Instructions:

- Just click on the blue link "Help Americans with Spinal Bulbar Muscular Atrophy needing mobility" and register to vote in this contest. We can't win without your help! Get this message to all your relatives and friends too! Note: The first time you vote, you will be asked to register and provide your email address and a password.

Background:

- Because of a lack of funding from other sources, many of our members are unable to have the mobility help they desperately need. This is an opportunity for you to help! (Pepsi has limited funding to the United States at this time).

- This project has been approved by Kennedy's Disease Association Board of Directors. If you have questions or problems voting, please contact me directly at loutudor@yahoo.com



Kennedy's Disease Association
Polo Shirts

We now have some beautiful KDA polo shirts for sale. They were donated by one of our associates so 100% of the money paid (less shipping) will go to the KDA. These are top quality shirts with the KDA logo embroidered on the front of the shirt and SBMA under it - to indicate the medical term for our particular Neuromuscular Disease (Spinal Bulbar Muscular Atrophy).

The price for the shirt is $35, which includes shipping within the United States and Canada (*). They are available in men's sizes only at this time. Small (34-36), Medium (38-40), Large (42-44), X-Large (46-48), and XX-Large (50-52). When ordering, please indicate the number of shirts requested for each size. There are limited quantities of these shirts, so get your orders in early!

Check or Money Order: Send a check or money order made out to the Kennedy's Disease Association along with this form or a letter stating:

- Number of shirts ordered by size: Small [ ] Medium [ ] Large [ ] X-Large [ ] XX-Large [ ]

- Mailing address of where the shirts should be sent:

_____

_____

_____

_____

Send the check or money order to:
The Kennedy's Disease Association
P.O. Box 1105
Coarsegold, CA 93614

Credit Card Order:

Go to the "Secure" KDA web page in Razoo: http://www.razoo.com/story/Kennedys-Disease-Association Enter the amount ($35 per shirt ordered) under "Make a Donation" in the right hand column. Click on the green "Donate" button right below the amount. This will take you to another page with a "Donate to Kennedy's Disease Association" header. In the middle of the window is a check box titled "Add a Designation." Click the box and a text field will open up. In this text field type: "For XX polo shirts" (where XX should be the number of shirts you want to order). Continue going through the "check-out" process. If you are a "first time" user of Razoo, you will be asked for your credit card and other billing information. After you have successfully made the payment through Razoo, send the KDA an email (info@kennedysdisease.org) stating that you made the payment on Razoo and include the following information:

- Number of shirts ordered
- Sizes needed
- Mailing address of where the shirts should be sent

Note: If the shirt does not fit, return it to the KDA with a letter requesting a different size. Should you have any questions or issues, please let us know.