As 2015 Rolls to a Close....

We only wish that every KDA member could have attended the October conference in Chicago! It was a wonderful opportunity to meet researchers and hear what they are doing in their labs to find a cure for our shared disease. It also gave the doctors and researchers time to put their heads together and discuss how they can quicken the pace to human trials.

It is because of the generosity of so many people, that this association can provide amenities like the yearly conference. We thank everyone who donates not only funding, but their time and talents. In this year-end newsletter, we celebrate the strong participation we have with pictures and snippets of some of the conference presentations and fundraisers.

It was a very good year!

Your Kennedy’s Disease Board of Directors wish you and your families a joyful holiday season!

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Research News at the 2015 KDA Conference

Ed Meyertholen, Ph.D.
KDA Board Member, and Scientific Review Board Member
Assistant Dean, Georgetown College
Georgetown University
Washington, DC

The annual conference of the Kennedy’s Disease Association was held this past October in Chicago. We are lucky in that we have a group of researchers that not only are dedicated to finding a treatment for KD but also able to find time to present their most recent research at the meeting. In addition, our meetings also allow for the interaction between the researchers and the conference attendees. This is by far the most rewarding part of the conference for me personally.

As is typical, researchers who came to the meeting were from most of the labs in the USA and Canada that make major contributions to KD research as well as some from across the pond. The research described at the meeting is generally unpublished work and as a result, is not usually ready for broad distribution. For me, however, one of the more interesting and encouraging developments this year actually was not a part of our conference and did not even deal with KD but its close cousin, Huntington’s Disease (HD). A new clinical trial using something called anti-sense oligonucleotides (ASO) had started this summer. Without going into excruciating details, ASO’s prevent the production of the protein that causes HD and as a result, the symptoms of HD in mice were reduced with the injection of this ASO. The success of these experiments in mice led to the formation of the clinical trial to use ASO’s in humans. Experiments using ASO’s against the androgen receptor (the protein affected in KD) in mice have also shown to be effective in relieving symptoms of KD. Thus, if this treatment works in HD patients, it should work in KD as well.

The KDA Conference is also the site of the notification and presentation of the research grants funded by the KDA. This year, thanks to your donations and fund raisers two grants were awarded at the conference, one to Dr. Miltiadis Paliouras (principal investigator) and Dr. Lenore Beitel (co-applicant) who are Assistant Professors at McGill University; and the other to Dr Constanza Cortes, a post-doctoral researcher in Al La Spada’s lab at UC-San Diego. The competition for the grants was extremely fierce this year as a record number of proposals were submitted – all of them of excellent quality.

Beyond Muscle Weakness- Hormonal Issues in Kennedy’s Disease

Raghav Govindarajan, MD
Assistant Professor
Department of Neurology
University of Missouri
Columbia, Missouri

Kennedy’s disease (KD) is characterized by slowly progressive muscle weakness and wasting with onset in adult males (usually in the fourth or fifth decade). While muscle weakness is a well-known feature of KD herein we will briefly discuss common metabolic and hormonal issues that can co-exist.

1. Androgen insensitivity
Androgen insensitivity characterized by elevated testosterone levels is common in KD. They present with gynecomastia which sometimes predates muscle weakness. In other cases, reduced sexual interest, impotence and decreased facial hair growth can also occur with onset concomitant to or soon after muscle weakness. Complete sterility is uncommon and penis size is normal.

2. Estrogen and other sex hormones
Estrogen (female sex hormone) levels are normal where as there is an exaggerated response of luteinizing hormone (hormone which stimulates the production of testosterone) to brain sex hormones indicating the androgen insensitivity is only partial and thus complete sterility is not a common feature of KD.

3. Glucose intolerance
Non-insulin dependent diabetes mellitus can be seen in KD but more commonly hyperglycemia and insulin resistance rather than frank diabetes are seen.

4. Cholesterol abnormalities
Total cholesterol, bad cholesterol as well as triglycerides are elevated but heart disease is not more common in KD as compared to general population.

5. Muscle and liver enzyme elevation
Muscle enzymes are almost universally elevated and can predate weakness. Liver enzymes are also elevated the significance of which is unknown at this time.

Five take home points:

➢ Androgen insensitivity is common in KD and can precede muscle weakness
➢ Diabetes and more commonly glucose intolerance can be seen in KD
➢ Estrogen levels (female sex hormone) are normal
➢ Muscle enzymes are very commonly elevated in KD
➢ Cholesterol and lipid levels are frequently abnormal although heart issues are no different than general population
NIH Updates Presentation – Summary

Angela Kokkinis, R.N.
National Institute of Neurological Disorders and Stroke (NINDS)
National Institutes of Health

The Exercise trial results showed that there was not an overall clinically significant improvement in the primary outcome measure the AMAT. However, it was noted that the functional AMAT score did trend towards improvement in the functional exercise group. It did show that those that had a lower total AMAT score (less than 15) did have a greater improvement overall.

The Saliva biomarker study that was performed at the last KDA conference showed that there was not a correlation between saliva fatigue biomarker in SBMA and the Fatigue Severity Inventory.

Hepatic Function in SBMA study is currently on going. We have had a total of 13 SBMA patients and 13 SBMA carriers that have participated in the study. Of these 13 SBMA patients we have had 3 patients return for the liver biopsies. These 3 liver biopsy results were consistent with fatty liver disease.

BVS857 in SBMA, this study is also currently ongoing. We have two patients enrolled right now that are receiving the infusions here at the NIH. There are a total of 8 sites, 4 in the United States and 4 in Europe.

If anyone has any questions about any studies or SBMA in general please email me at akokkinis@cc.nih.gov.

Exercise Research

Joseph A Shrader, PT, C.Ped
Senior Clinical and Research Physical Therapist
Clinical Research Center, NIH

Recent evidence suggests that functional exercises aimed at improving functional tasks such as sitting up, rolling over, sit-to-stand, and stepping up an 8-inch step were well tolerated by persons with spinal and bulbar muscular atrophy when supervised by rehabilitation and/or nursing professionals. Overall, strength, balance, function, and quality of life did not differ between those who received the exercise versus stretching (control group), however, those with relatively low baseline function improved their functional profile and those with relatively high baseline function improved their general activity level, compared with the control group. More research is needed to help optimize exercise intensity, mode, frequency and duration for individuals with KD. General recommendations for people with KD include attempting to incorporate daily physical activity into your lifestyle, along with good nutrition and sleep habits. If you experience falls, fear of falling, leg weakness, requirement of assistance or assistive devices for standing and walking, it is recommended that you first be examined by your primary doctor, neurologist, or physiatrist to discuss contraindications and exercise goals. It is also recommended that exercises be initially prescribed and monitored for appropriate post-exercise recovery by a physical therapist, until a safe and sustainable self-directed program can be assured.

NIH does not endorse or recommend any commercial products, processes, or services. The views and opinions of NIH authors do not necessarily state or reflect those of the U.S. Government, and they may not be used for advertising or product endorsement purposes.
One of the Options for KD Gene Carriers

Heather L. Montie, PhD

The mutated gene in Kennedy’s Disease (KD) (the androgen receptor gene) is encoded by the X chromosome. A woman can be a KD gene carrier by two different means. All women have two X chromosomes (men only one X, plus a Y). All daughters of KD male patients are obligate carriers. This means, since women have two X chromosomes, they must have received their father’s “KD X chromosome”. Another way a woman can be a KD carrier is if she were to receive the “KD X chromosome” from her mother whom is a carrier (50% chance, because she could also get her mother’s non-KD X chromosome), and this is determined by a genetic test. This also means that if a woman is a KD carrier, her son would have a 50% chance of receiving her “KD X chromosome” and having KD.

As carriers of a known genetic disorder, for which there is no cure or therapy, KD woman carriers have a weight on their shoulders when it comes to family planning. With a risk of having a boy with KD being 50% and a carrier daughter also being 50%, a woman carrier and her mate have to make a decision about planning a family that is best for them. There are many options, and it is usually best to meet with a genetic counselor before you begin your family planning process. There are many choices to consider. Families may choose to have children on their own and take the risk of having a son with KD or a daughter that is a carrier. There is also the possibility of having the baby from such conception tested in utero for the KD gene and then the couple could make a decision about the progress of the pregnancy. Others may choose to not have children, to adopt, and finally others may choose to perform preimplantation genetic diagnosis in vitro fertilization (PGD-IVF). All of these possibilities are for the couple to decide upon themselves, what is best for their family. There should be no judgment made or opinion of others pressured upon the couples’ decision making process. Their choice(s) should be respected.

PGD-IVF offers couples the chance to have a son without KD and/or a daughter that is not a carrier. This process can be quite long (4-6 months or more) and expensive ($20,000 to $30,000 or more), but to some is thought to be priceless. The process begins with genetic counseling and then a probe is made to specifically detect the woman’s “KD X chromosome”. The woman will be working with a fertility clinic that specializes in IVF. Once the probe is made, and having a carrier daughter also being 50%, a woman carrier and her mate have to make a decision about planning a family that is best for them. There are many options, and it is usually best to meet with a genetic counselor before you begin your family planning process. There are many choices to consider. Families may choose to have children on their own and take the risk of having a son with KD or a daughter that is a carrier. There is also the possibility of having the baby from such conception tested in utero for the KD gene and then the couple could make a decision about the progress of the pregnancy. Others may choose to not have children, to adopt, and finally others may choose to perform preimplantation genetic diagnosis in vitro fertilization (PGD-IVF). All of these possibilities are for the couple to decide upon themselves, what is best for their family. There should be no judgment made or opinion of others pressured upon the couples’ decision making process. Their choice(s) should be respected.

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Further reading and more details about PGD-IVF can be found below (the last link is a company that can make “KD X chromosome” probes).


Genesis Genetics: http://genesisgenetics.org/pgd/

- Heather L. Montie, PhD
  (please inquire with the KDA if you would like to speak with me in further detail about this process)

Clinical KD Research in Germany and Europe

Dr. med. Patrick Weydt
FA Neurologie, fachgebundene genetische Beratung
Abteilung für Neurologie
Oberer Eselsberg 45
Uniklinikum Ulm
89081 Ulm
Deutschland

Patrick Weydt, a neurologist from Ulm University in Germany, reported on the current developments in clinical KD research in Germany and Europe. Ulm is one of the largest clinical centers for KD. One encouraging piece of news was an update on the Novartis trial. There are currently two centers in Europe, Ulm in Germany and Copenhagen in Denmark, are recruiting patients for this therapeutic trial. The existence of this trial has invigorated the Kennedy’s disease patients community in Europe and some have moved to form a patient interest network. In parallel the European SBMA researchers have gathered for a workshop sponsored by the ENMC (European Neuro Muscular Center) in Naarden, the Netherlands, to discuss how research efforts can be coordinated. So both, researchers and patients in Europe, are taking important steps to advance cooperation and coordination in the quest for a treatment of SBMA.

Working together to find a cure ... For our generation ... and for our children and our grandchildren

The KDA’s mission is to inform, support, communicate, educate, research, and find a cure for Kennedy’s Disease
**Report on the Role of Functional Domains of the Androgen Receptor in the Disease Process in SBMA**

Diane Merry, PhD  
Associate Professor of Biochemistry and Molecular Biology  
Thomas Jefferson University  
Philadelphia, PA

The work of my laboratory presented at the KDA meeting in October 2015 were focused on our analysis of the role of functional domains of the androgen receptor in the disease process in SBMA. It is well known that the androgen receptor undergoes an interdomain interaction between the amino (N)- and carboxyl (C)-ends of the protein. Through the study of both cell models and new transgenic mouse lines to test the role of this domain, we found that prevention of this N/C interaction substantially prevents cell death of motor neurons and substantially delays dysfunction and neuropathology in the mice. In addition, we found that blocking the N/C interaction causes a substantial increase in the phosphorylation of serine 16. The phosphorylation of this amino acid is required for the neuroprotection that occurs when we block the N/C interaction. We wondered if the effect of blocking the N/C interaction is due to its decreased transcriptional activity. To test this idea, we created cell models and transgenic mice in which we prevented AR transcriptional activity by mutating an amino acid that is required for AR DNA binding to specific DNA sequences. The DNA-binding-deficient AR protein with a long polyglutamine tract caused as much DHT-dependent toxicity to motor neurons as did an AR that is capable of binding DNA. Moreover, transgenic mice expressing the mutant DNA-binding-deficient AR developed severe disease. We conclude that the mutant polyglutamine-expanded AR causes disease by a mechanism that is independent of its ability to function as a transcription factor. These results further support the idea that allowing the mutant AR to carry out its normal “day job,” while preventing its “moonlighting” as an aggregation-prone protein, has merit for therapeutic development.

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**Conference Photo’s**

Thank you to our Photographers  
David Yelton, Paula Goynes, Mary Ann Tavares and Maria Montie

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2015 KDA Conference Chair  
Andrew Cassar

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KDA President  
Lou Tudor  
Lou asked all attendees to sign a card for John Coakley Sr. (Thank you Mary Ann Tavares for bringing the card!)

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David Yelton  
Working hard to keep the conference online for members to view and listen!
Gerry & Maria Montie

Angela Kokkinis, NIH Nurse

Mike & Paula Goynes always having a good time!

Lou Tudor and grant recipient researcher Lenore Beitel

Dr. Raghav Govindarajan answers questions from Andrew Cassar.

“Cousin Billy Bob” checking in with his nurse!

Bill Tudor, Auctioneer!

Jack Durning & Mary Ann Tavares
In December of 2014, Matthew and Nathan Cassar gave their father a most thoughtful and generous Christmas gift. They had saved their allowance and gift monies for the KDA. These young teenagers are the sons of board member Andrew Cassar. They donated $300.

Member Bob Tudor completed another hand cycle marathon in December of 2014. He exceeded his goal and donated over $10,000 to the KDA!

In April, the family of John Coakley, Sr. held a 5K called the Queen Anne’s Race. Under the direction of Sara Coakley Kawa, the race raised $12,892!

The University of Sioux Falls sponsored a fundraiser to raise funds for the KDA. Students sold Chapstick during the semester and raised over $1,000! The coordinator wishes to remain anonymous.

Coordinator, Jason Coopper put together an August golf tournament fundraiser for the second year in central New York. He exceeded his goal and raised $9,000!

Texas Golf Tournament organizer Ed Noack and his team raised $29,000 in September! Ed has also been gracious enough to share his “how to” success with anyone who asks.

All of these KDA families are an inspiration. They go above and beyond to help pay for research. Please consider what you can do for the KDA in the new year. The possibilities are endless…
Ed Montie Race to Cure Kennedy’s Disease
Heather Montie, PhD

On September 20, 2015, the Montie family sponsored the first “Ed Montie Race to Cure Kennedy’s Disease”. This event was organized as a memorial for “Coach” Ed Montie, who was a not only a wonderful husband, father, brother, grandfather and friend, but who was also a volunteer track coach and the biggest cheerleader for Lincoln Park High School track. Our hearts were all broken when we lost him in April 2011, due to complications of KD. Sept. 20th would have been his 70th birthday.

It was a beautiful day, filled with love and reflections of the wonderful person we all knew and dearly miss. Friends and family ran, walked, and cheered; and those that couldn’t make it to the event kindly sent donations. There was a raffle prize, consisting of very special donations from the KD community. They included beautifully hand-made jewelry bags from Dr. Cindy Jordan (KD researcher from Michigan State), a gorgeous handsewn purse provided by Mary Ann Tavares, and a sign, graciously hand-carved by her significant other and KD patient, Jack Durning, that said “Never Give Up”, a quote by which Ed Montie courageously lived his life. We plan for this to be an annual event, so that we continue to celebrate the beautiful life of Ed Montie, so we all remember his motto “Never Give Up”, and most importantly, to raise awareness about KD and money to find a cure for this devastating disease. So look out for an even larger event near the third week of Sept., 2016!

I would like to personally thank all of those that helped organize this event and all of those that came out to support it or made donations from afar. This fundraiser was truly a team effort all around and we are honored to have such a wonderful community of family and friends that loved Ed Montie and support KD research.

- Heather L. Montie, PhD, Ed’s forever proud daughter and KD researcher

Magnolia Texas, 5th Annual Golf Scramble
Louise Noack Goforth, KDA Board Member

The 5th annual Kennedy’s Disease Golf Scramble held in Magnolia, Texas on September 26th is all but a memory now, but there are stories to share and people to thank! Anyone who has been involved with a fundraiser knows there is a lot of work leading up to the event. Special thanks to the many volunteers who dedicate so much to this annual event. Some of the volunteers are personally affected, or have family members personally affected by Kennedy’s Disease: Murray Williams (retired BoD of KDA) whose tireless efforts and wonderful auction donations by 2nd Millennium Arms always ensure a success; Ed and Nancy Noack who contribute with so much heart and hard work; Beth Noack, Lori (Noack) and Chllie May; Verna (Noack) and Mike Hoke; William (Billy) and Beverly Noack, and Charley and Louise (Noack) Goforth. Then there are those volunteers who give so much just because their hearts are so big and good: Jamie and Billy Zbranek; Gayle and Fred Hafner, Cathy and Mark Phillips; Faylin Reimer; and Gale and Nancy Burr. All of these folks, and many others, worked toward a 2015 goal of donating more than $100k to the Kennedy’s Disease Association. They succeeded in a big Texas way....this year we were able to donate another $29k to KDA, bringing our 5-year total donations to $119k!

Golfers began their day by registering and enjoying breakfast sponsored by Brookside while browsing magnificent auction and raffle items. Some of the top auction items were a brand-new, custom made Remington shotgun, a beautiful fall wreath with $165 lottery tickets, a Home Automation package (can you say, “Alexa, what’s the weather like? Alexa, explain Kennedy’s Disease to me”), a Ruger 10-22 rifle, DPS (state police) Texas Ranger memorabilia....and many, many more fantastic items. The top raffle items were a cruise for 2 aboard the magnificent Carnival cruise lines, a Gulf Coast fishing experience for 4, and (drum roll please!)...no Texas raffle would be complete without tickets to a Houston Texans’ home game (vs NY Jets)!!

For the second year in a row, the Goynes’ Gang showed up in full force! Mike Goynes (retired BoD of KDA) and his wife Paula drove from the Tampa Bay area in Florida. They were joined by his brother and sister-in-law Lee and Susan (New Braunfels, Texas), and their son Scott (Austin, Texas). Sister Mary and her husband Greg from San Antonio, Texas were also there! The Goynes’ Gang support reaches much further than those that were able to be physically present. Mike Goynes, once again, sponsored a microsite soliciting donations to support this worthy cause. Unbelievably, the Goynes’ Gang, and their supporters, were able to raise and donate more than $3000 from this endeavor. In recognition of this tremendous contribution, a Goynes’ Gang banner was placed on the golf court and waved proudly in the wind at golfers as they passed by as if to say “We support this cause – and it’s important to us – thank you for supporting it too.” What a wonderful tribute to this family from those who supported them this way!!! Few people know how hard this family has been hit by Kennedy’s Disease. In Mike’s immediate family of 5 siblings, 3 brothers have the disease and 1 sister is a carrier. This just underscores the importance and urgency we all feel in finding a cure for this disease!

Raul Ternate, a local Houston, Texas man who has the disease read about the tournament in the KDA Newsletter and immediately let his brother Felix know. Felix, who also has Kennedy’s Disease, wasted no time in sponsoring a Platinum team and drove to Texas from Sacramento, California to join in this worthy cause! While Felix golfed the 18 holes in the tournament, Raul participated by helping volunteers who were busy behind-the-scenes decorating the hall for the barbecue, auction and raffle following the golfing, staging the raffle items, and greeting newcomers. As the tournament was winding down, Felix, with tears in his eyes, on behalf of he and his brother took to the microphone and thanked all those present for giving so much and working so hard to make this event so successful. Felix announced, as long as he’s able, he’ll be back every year. There wasn’t a dry eye in the room! This is why we do what we do!

Cont’d next page...
There are many, many folks who deserve recognition for this success, not the least of which are those loyal golfers who return year after year to support the KDA; without them we would not have a tournament. The Texas golf tournament committee is humbled by the support that is received in many different ways: on-line raffle purchases, friends, family and colleagues who support us by sign sponsorship or donations (many who are out of state, and some who are out of country); KDA members who unfailingly continue to provide support monetarily by making donations for auction or raffle, or sponsoring a sign in memory or support of a loved one affected by this dreadful disease; businesses who make monetary donations or donations for auction/raffle; folks willing to do microsites, spreading the word by social media, and of course, our Title Sponsor MPO. Each and every supporter is integral to our success – and we are grateful beyond words.

This year our goal was to raise over $100k donated to KDA since the beginning of this small little golf tournament – and we did! For 2016 our goal is to enjoy even more success by getting folks like yourself to leverage their contacts to help in this effort. If just 15% of all KDA members participated, we see a day in the not too distant future, where we could increase our annual donation to $50K a year.

...stay tuned for golf tournament details in 2016!
Avoid the Run-Around: Find an ATP!
Jameson Parker, KDA Board Member

A few years ago, I recognized that I need mobility help when going to places like the store or a museum. I have an electric scooter but no way to get it in and out of my car on my own, so I decided I would go for a manual wheelchair. It needed to be light so I could lift it and it had to be the right size for me otherwise the effort to use it would be too much. I did a little bit of research and figured out that I needed a chair that is classified as “ultralight”. This is a chair that is in the weight range of around 20 pounds.

Next, was how do I pay for it? A quick internet search reveals that ultralight wheelchairs start around $1000 and go up from there. It was important to me to get something that I could use under my own power and easily transport, so I looked at my insurance plan. My coverage included “durable medical equipment” such as wheelchairs. So I called the general line for my insurance company and let them know what I needed. I was referred to the durable goods department. So I called that department and again repeated my medical needs. They said they couldn’t help me and that I should use the special equipment hot-line since I wanted a special kind of chair. I called the special equipment line and left a message.

After playing phone tag for a week or so, I talked to someone from the special equipment hot-line, and was instructed to talk to the insurance company’s onsite doctor to evaluate my needs. After a week of back and forth he let me know that I need to fill out form LM-38B in triplicate with the pink copy filled out only in blue pen...

I think you get the idea of what this was like and I am sure you have your own stories to tell after spending hours listening to music that is interrupted every thirty seconds with the recorded message, “we value your call, please hold and a representative will be with you shortly”. My insurance company is one of the big ones that employs thousands of employees and after a few weeks of navigating their system, I had talked to most of them trying to get this wheelchair.

An ATP (Assistive Technology Professional) is a person trained to connect the right technology with your needs. Specifically, men with KD want someone with an SMS certification (Seating and Mobility). It just so happens that an ATP attends my church and I connected with him after my fruitless attempts to go through the insurance company. He came into my home to measure my strength. He measured several body parts (heel to knee, knee to hip, etc) to make sure that the wheelchair he had built for me would fit me perfectly. Not only did he design the right wheelchair for me, he also expertly navigated the insurance process. I never had to call my insurance company, he took care of the whole thing!

I didn’t know that there were people out there with the kind of training that an ATP has. Needless to say, that will be my starting point from now on! To find an ATP, go to RESNA and search in your State. Under “Areas of AT Practice”; select “Seating, Positioning & Mobility” from the list.

MAKE TRAVEL PLANS NOW!!

The 2016 KDA Conference will be held in San Diego, California
November 9-10-11
hotel is not yet confirmed
Plenty to enjoy at this popular destination, so extend your trip before or after the conference!