



Kennedy's Disease Association
2014 Annual Conference and Education Symposium
November 12-14, 2014
Alexandria, Virginia

Today's Dream....Tomorrow's Reality

A practical gathering showcasing the combined wisdom and knowledge of leading authorities, doctors, researchers, and folks like you and me with plenty of time to meet and interact with others with KD from around the world

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1. Dates

Wednesday, November 12, 2014

Thursday, November 13, 2014

Friday, November 14, 2014

2. Hotel Information

Location:

Holiday Inn Hotel & Suites

625 First Street

Alexandria, VA 22314

(703) 548-6300

The room rate is \$119.00 (\$129.00 double occupancy) plus tax and includes breakfast for one (two) per day. **Please identify yourself as being with the KDA when making your reservation.** The KDA rate includes breakfast.

3. Transportation

To/From the Airport:

The hotel has a complimentary shuttle (NOT handicap accessible) to and from Reagan National Airport. From the baggage claim, exit through door 5 or 9, and there will be a sign for Hotel Shuttle just outside. Pickups are at 15 and 45 minutes past the hour. The service runs daily from 5:30am to 11pm. **For wheelchair accessible service**, please call Yellow Cab (703-549-2500) at least 24 hours before expected pickup time, and please make sure to specifically mention you have an electric wheelchair or scooter. The hotel has indicated that they will reimburse you for the cab fare.

Metro:

There is a metro station near the hotel – the Braddock Station (stop for the Blue and Yellow lines). It is about a 13 minute walk or the hotel has a free shuttle (not handicap accessible) to the station. Map for the metro lines: http://www.wmata.com/pdfs/pocket_guides/english.pdf. The metro is handicap accessible.



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4. Attractions

The hotel is in the historic district of Old Town Alexandria. It is close to the Potomac River waterfront and just a few minutes from King Street Shopping, shopping, and major attractions including The Torpedo Factory Art Center, National Inventors Hall of Fame & Museum, Lee House at Arlington Cemetery, Mount Vernon, Ft. Belvoir/Woodlawn Plantation. The hotel is also about 40mins from Washington D.C. via the Metro (including a short walk to the metro station near the hotel).

5. Silent Auction

This year, as always, during the dinner on Thursday night the KDA will sponsor a Silent Auction. Thanks to the generosity of the attendees this has been a very successful fundraiser for the KDA. Plus it is a lot of fun! Please bring items for the auction that you feel people would be like to bid on. We are never really sure what people will bid on so we rely on your imagination to bring the items you think will sell.

6. Optional Tuesday Events

Tour of the Newseum (meet in lobby at 11:30am):

The KDA has arranged for an optional outing to the Newseum, a 250,000 square-foot news museum (for more information visit www.newseum.org). The group will be departing the hotel at 11:30am. If you wish to attend, please meet in the lobby before the departing time. The group will return to the hotel at 4pm and lunch is on your own.

Meet and Greet Dinner (meet in lobby at 5:30pm):

From 6:00 – 8:00 there will be an informal dinner (Dutch Style – pay your own) at T.J. Stone's Grill House and Tap Room (608 Montgomery Street). The restaurant is only a few blocks from the hotel. Please meet in the lobby at 5:30pm if you would like to join the group. For more information and menu selection please see www.tjstones.com.



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7. Conference Agenda

Tuesday 11/11/14

- 11:30 - 4:00 Optional outing to the Newseum (meet in lobby 11:30am)
5:30 - 8:00 Optional dinner to T.J. Stones (meet in lobby 5:30pm)

Wednesday 11/12/14

- Breakfast - on your own
7:30 - 8:15 Registration
8:15 - 8:30 Welcome - Co-Chairs Lou Tudor and Andrew Cassar
8:30 - 9:30 Introductions around the room
9:30 - 10:15 Group Q & A – Discussion on activities can still do with KDA
10:15 - 10:45 Break
10:45 - 11:30 Aids to make daily activities easier
11:30 - Noon Mike Goynes – new website and volunteering to help the KDA
Noon - 1:30 Lunch on your own
1:30 - 2:30 Dr. Christopher Grunseich & Angela Kokkinis: NIH Chewing Study
2:30 - 3:00 Break
3:00 - 4:00 Paul W. Nolan, Esq. – Presentation on available disability programs
4:00 - 5:00 Home Renovations – Bring in pictures and layouts of your home for recommendations

Thursday 11/13/14

- Breakfast – On Your Own
8:00 - 8:15 Conference updates and direction for the day
8:15 - 9:15 Dr. Julie Bindeman
9:15 - 10:00 Men and Women's breakout sessions
10:00 - 10:30 Break
10:30 - 11:30 Joe Shrader from NIH - Exercise for KD
11:30 - 1:00 Lunch on your own
1:00 - 2:15 Ed Myertholen – KD-101
2:15 - 2:45 Shelly Arvin – Searching for Kennedy's Disease Information
2:45 - 3:10 Break
3:10 - 3:20 Angela Kokkinis – NIH Clinical Research Nurse
3:20 - 3:30 Alice Schindler – NIH pilot study of SBMA female carriers
3:30 - 4:00 Christopher Grunseich – NIH Update on clinical trials



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Thursday 11/13/14 (continued)

- 4:00 - 4:20** Lenore Beitel – effect of polyglutamine-expanded androgen receptor on proteasomes
- 4:20 - 5:00** Nisha Badders – Targeting androgen receptor AF-2 domain for therapeutic treatment
- 5:00 - 6:00** Setup for silent auction and dinner
- 6:00 - 7:00** Early reception - cocktails and beverages; silent auction (continues through dinner)
- 7:00 - 8:00** Dinner (included with Conference registration)
- 8:00 - 10:00** Live auction and completion of silent auction while mingling with new and old friends

Friday 11/14/14

- Breakfast – On Your Own
- 8:00 - 8:15** Conference updates and direction for the day
- 8:15 - 8:35** Introduction and presentation from Dr. Kennedy
- 8:35 - 8:50** Carlo Rinaldi – miRNA in SBMA
- 8:50 - 9:10** Michael Blonar – Update on research grant award
- 9:10 - 9:40** Helen Cristina Miranda – Stem cell modeling of Kennedy's Disease
- 9:40 - 10:00** Heather Montie – The role of androgen receptor acetyltransferases in SBMA
- 10:00 - 10:30** Break
- 10:30 - 11:00** Naemeh Pourshafie – A miRNA based therapeutic strategy for SBMA
- 11:00 - 11:40** Diane Merry – Research Update
- 11:40 - 12:20** Kenneth Fischbeck – Therapeutics development for Kennedy's Disease
- 12:20 - 12:30** Closing comments – John Coakley, Lou Tudor, Andrew Cassar
- 12:30 - 5:00** Private doctors and researchers breakout session – Lunches for the doctors and researchers provided by the KDA.

Thursday evening's dinner at the hotel will provide an excellent opportunity to interact with many KDA Associates as well as researchers who work towards unraveling the puzzle that is KD. There will be a silent and live auction again this year after the dinner. Please consider contributing a non-breakable item (or two), and bring your checkbook. These auctions have become an anticipated event - we never know what will be up for sale or what the MC will do to get it sold.