

# **HDSA**

## *Indiana Chapter*



**Huntington's  
Disease Society  
of America**  
*Indiana Chapter*

***Saturday, October 3, 2009***

Indianapolis, Indiana

Benedict Inn  
Retreat & Conference Center  
1402 Southern Avenue  
Beech Grove, IN 46107-1197

**17<sup>th</sup> Annual State Conference**

## Directions to Benedict Inn

**FROM THE EAST:** Via I-70 to 465 South exit Southeastern (#94). Turn left on Raymond. Turn left on Sherman. Turn left on Southern Ave. Enter 3<sup>rd</sup> drive on left (circle drive with flagpole).

**FROM THE WEST:** Via I-70 to I-65 South. Exit Raymond St. (#109) turn left. Turn right on Sherman. Turn left on Southern Ave. Enter the 3rd drive on left (circle drive with flagpole).

Via I-465. Exit Emerson Ave. Beech Grove (#52). Turn left on Emerson. Turn left at Albany. Turn right at 13th St. Cross Southern Avenue and enter the Benedict Inn (circle drive with flagpole).

Via I-465. Exit Emerson Ave/Beech Grove (#52). Turn right on Emerson. Turn left on Albany St. Turn right at 13th Ave. Cross Southern Ave. and enter the Benedict Inn (circle drive with flagpole).

**FROM THE SOUTH:** Via I-65. Exit Keystone Ave (#107) turn right. Turn right on Troy. [Troy changes to Albany.] Turn left on 13th Ave. Cross Southern Ave. and enter the Benedict Inn (circle drive with flagpole).

**FROM THE NORTH:** Via I-65 Exit Raymond St. (#109) and turn left. Turn right at Sherman Dr. Turn left on Southern. Enter the 3rd drive on left (circle drive with flagpole).

## Area Hotels

Holiday Inn Express  
317-791-9100  
5302 Victory Dr  
Indianapolis, IN 46203

Red Roof Inn-Indy South  
317-202-1582  
5221 Victory Dr  
Indianapolis, IN 46203

LaQuinta Inn & Suites  
317-783-7751  
5120 Victory Dr.  
Indianapolis, IN 46203

Holiday Inn Express  
317-788-3100  
3514 S Keystone Ave,  
Indianapolis, IN 46227

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## Keynote Speaker

**Donald S. Higgins Jr., MD** is the Chief of Neurology at the Samuel S Stratton VA Medical Center in Albany, NY and a professor in the Department of Neurology and Center for Neuroscience and Neuropharmacology at The Albany Medical College where he also serves as the director of the Neurology Residency Program. He received his undergraduate education at Illinois Wesleyan University, medical degree from the State University of New York at Stony Brook and neurology training at University of Michigan. Movement disorders' training was obtained at the University of Rochester in The Movement and Inherited Neurologic Disorders Unit. Dr. Higgins is a member of diverse professional organizations, including the Huntington Study Group, and is actively involved in research and authored or co-authored a range of articles related to HD and other movement disorders.

In memory of our loved ones we have lost to HD, "Memory Lane" has been created to honor their lives. Whether you will be attending the conference or not, please send picture(s) and date(s) to:

HDSA Indiana Chapter  
c/o Kathy Karazzia  
13 Westview Estates  
Linton, IN 47441  
Photos will NOT be returned.  
Or e-mail to:  
conference@hdsaindiana.org

Conference Sponsored by:



## Schedule

**8:30-9:00** Registration

**9:00-9:30** Welcome-Patti Day-HDSA Indiana Chapter Board President

**9:30-10:20** Opening Session-Don Higgins, MD

### **"Treatment Advances in the Management of Huntington's Disease"**

**10:30-11:15** Break-out Sessions

1. Maracaibo Memories: Reflections on the HD Venezuela Collaboration Dr. Don Higgins
2. HD 101 Leo Raffail
3. PT/OT/ Speech Therapy RHI Representative
4. Legal Issues Local Lawyer

**11:20-12:15** Lunch

*\*\*\*Make sure to visit the **RESOURCE CENTER** during the lunch break\*\*\**

**12:25-1:25** Importance of Exercise David Zid

**1:30-2:05** Indiana Updates - Activities and Progressing Research at Indiana University and the HDSA Center of Excellence Dr. Quaid, Dr. Wojcieszek, Leo Raffail, Dr. Liz Zaubler, Dr. Joel Ybe, and Dr. Foroud

**2:15-3:00** Break-out Sessions

1. Medical Management of HD Symptoms Dr. Wojcieszek
2. Volunteerism/Fundraising Laura Benedict/Kara Paris
3. Nursing Homes Leo Raffail
4. Genetic Testing Dr. Quaid

**3:15-4:00** Break-out Sessions Encouragement/Support  
Groups

- |                           |                         |
|---------------------------|-------------------------|
| 1. People at Risk         | Jenn Baron/Beth Bechdol |
| 2. People with H.D.       | Dr. Wojcieszek          |
| 3. Care Givers-spouses    | Maria O'Connor          |
| 4. Care Givers-all others | Kathy Karazsia          |
| 5. Teens                  | Leo Rafail              |

### **Other Presenters 2009**

**David Zid** is a graduate of The Ohio State University and has been a professional fitness instructor in Columbus, Ohio since 1997. Certified through ACE and APG as a personal trainer and functional fitness trainer, respectively, he is the owner and president of Columbus Health Works, a personal training company that he started in 1999. Currently, he values the time he spends as the leader and creator of a group exercise class specifically designed for people with Parkinson's disease. Currently he and his partner, Jackie Russell, RN have been well-received as speakers at many Parkinson's support group meetings and symposiums.

**Joanne Wojcieszek, MD** has been a member of the IU Neurology Department since 1995 and is currently Director of the *Movement Disorders Program*. Dr. Wojcieszek is the Co-Director of the HDSA Center of Excellence and the Director of the National Parkinson Foundation Center of Excellence. She works with a multidisciplinary team to treat HD and Parkinson disease (PD). She collaborates closely with IU neurosurgeons, Robert Worth, MD and Thomas Witt, MD, in the *Deep Brain Stimulation Program* that treats refractory tremor, PD and dystonia. She has participated in clinical research trials of tetrabenazine, fish oil, coenzyme Q10, and dimebon.

**Kimberly Quaid, Ph.D.**, is a Professor in the Department of Medical and Molecular Genetics at Indiana University School of Medicine and a Faculty Investigator with the Indiana University Center for Bioethics. She is also Director of the HDSA Center for Excellence and Director of the Predictive Testing Program. Dr. Quaid has been involved in the study of Huntington Disease for over 20 years and is currently Site Investigator at IU for the PHAROS, PREDICT, and COHORT studies.

**4:00** Conclusion of Conference at Resource Center

**Tatiana Foroud, Ph.D.** is the P. Michael Conneally Professor of Medical and Molecular Genetics at Indiana University. She has been active in HD research for nearly two decades, focusing on studies seeking to identify the earliest clinical signs of HD. She has worked with the chapter to help plan the state convention.

**Leo Rafail,BSW** has been working in the Huntington's Disease (HD) community for more than 13 years. Since 2005, when Indiana University Medical Center was designated a Huntington's Disease Center of Excellence, Leo has had the opportunity to provide services at the Center also. In 2008, he was selected as the first social worker for the Huntington's Disease Society of America's National Youth Alliance. Throughout the years, Leo has educated thousands of people about various aspect of HD at conferences and through in-service trainings. He is a 1994 graduate of Marshall University.

**Laura Ciriello-Benedict** co-founded StopHD with her best friend, Karie Moore. StopHD's primary fundraiser is the Nancy L. Irwin Memorial Walk for a Cure, held annually each fall in memory of Karie's mother. Since the inaugural walk in 2005, StopHD has raised over \$200,000 for HDSA. Laura is passionate about increasing awareness for Huntington's disease in our community and raising funds to support research for a cure. She also serves as co-fundraising chair for HDSA, Indiana Chapter

**Kara Paris** is a founding member of Stop HD and serves as co-fundraising chair for HDSA, Indiana Chapter. Since 2005, Stop HD has raised over \$200,000 for HD research through their Nancy L. Irwin Memorial Walk for a Cure, Cool Cars for a Cure and other events. Kara feels very blessed to be involved in the

fight against HD and to be personally involved with helping families affected by this disease.

**Rehabilitation Hospital of Indiana(RHI)** opened its doors in January 1992 as one of the largest freestanding rehabilitation hospitals in the Midwest. It provides inpatient acute services, and outpatient and vocational rehabilitation services for adults with spinal cord injuries, brain injuries, strokes, amputations, orthopedic conditions, neuromuscular diseases, burns and related disabilities. RHI is a community collaboration between Clarian Health and St. Vincent Health. RHI is in the process of developing a movement disorder program in cooperation with the HD Center of Excellence.

**Registration Fees:**

On or before September 19, 2009  
Single \$25      Double \$40

After September 19, 2009  
Single \$30      Double \$50

Checks Payable to:

**HDSA Indiana Chapter**

*For those who have a financial hardship, please call Kathy Karazsia at 812-798-1216 to receive credit for your registration fee, or e-mail conference@hdsaindiana.org  
All inquiries will be handled in strict confidence.*

Please mail registration form and payment to:

**HDSA Indiana Chapter  
C/O Kehla West  
P.O. Box 303  
Indianapolis, IN 46206  
(812)798-1216**

**Total Amount Enclosed:**

\$ \_\_\_\_\_

**Registration Form**

I am purchasing a (circle one) SINGLE      DOUBLE  
Registration for:

Name(s) \_\_\_\_\_

Address \_\_\_\_\_

City, State, Zip \_\_\_\_\_

Telephone \_\_\_\_\_

E-Mail Address \_\_\_\_\_

Please include additional names on a separate sheet of paper.

Special Dietary Needs \_\_\_\_\_

I am not able to attend, but I would like to sponsor a (circle one) SINGLE      DOUBLE scholarship so that a member of the HD community can attend at no charge.