



Huntington's Disease Society of America



Central Ohio CHAPTER

OUR VOICE

FALL 2019

Our Voice, a newsletter of the Huntington's Disease Society of America, Central Ohio Chapter, is published twice a year to provide information and to relay items of interest to individuals with HD and their families, health care professionals, friends, and supporters.

President's Letter

Dear Friends of HDSA,

Please join us in providing *"Help for Today and Hope for Tomorrow"* for those affected by Huntington's disease. The 19th annual Celebration of Hope Event will take place on **Saturday, December 14, 2019 from 7:00 – 11:00 pm** at the **Grandview Café**, Columbus, OH. The Central Ohio HDSA Chapter takes pride in creating memorable, fun, and unique events each year and guarantee that this year will be no exception. All proceeds support the Huntington's Disease Society of America's fight to give hope to families that are facing this fatal disease.

This year's event will honor Dr. Sandra Kostyk for all she has done in support of those affected with HD and their families. Dr. Kostyk leads the Center of Excellence and their vast number of research studies & drug trials, including trials of novel HD treatments. She is a conscientious physician in support of Huntington's disease patients and their families. Dr Kostyk is the medical director of the multi-disciplinary Huntington's disease Center of Excellence at Ohio State.

The Celebration of Hope program is meant to recognize the incredible work done across HDSA's network of forty-three Centers of Excellence. These centers provide an elite multidisciplinary approach to Huntington's disease care and research. The Great Lakes Region is home to eight Centers of Excellence. At these world-class facilities, patients benefit from expert neurologists, psychiatrists, physical therapists, occupational therapists, speech pathologists, counselors and other professionals who have deep experience working with families affected by HD. These professionals work collaboratively to help families plan the best HD care program throughout the course of the disease.

We sincerely hope you'll join us in celebrating our HDSA Centers of Excellence and Dr. Sandra Kostyk.

Sincerely,

Daphne D. Hess

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Join us!

YOU CAN MAKE A DIFFERENCE!

Your Central Ohio Chapter is looking for volunteers for our events and/or have a desire to serve on our board. Please contact President, Daphne Hess, at 614-519-6468.

HDSA CENTER OF EXCELLENCE AT THE OHIO STATE UNIVERSITY

CENTER OF EXCELLENCE

Wexner Medical Center
Martha Morehouse
Tower
2050 Kenny Rd. ,
7th floor
Columbus, Ohio 43221
614-293-4969

Director: Sandra
Kostyk, MD, PhD

Clinic Coordinator
Kate Ambrogi, RN
614-688-6685

Social Worker:
Erica Wright
614-688-9438

The Ohio State University Wexner Medical Center was first named a Huntington's Disease Center of Excellence in 2000 by the Huntington's Disease Society of America and is one of only 43 centers in the country to achieve this distinction. We were chosen because of our state-of-the-art treatment, social and psychological support for patients and their families and contributions to the advancement of education and research in Huntington's disease.

We are central Ohio's only member hospital for the Huntington Study Group, a national consortium of academic centers that offers patients access to clinical trials in search of new and better treatments for the disease.

Visit our website [here](#).

Monthly Support Group

Our HD Support Group meets the second Saturday of the month, 10am—11:30am, at Panera, [875 Bethel Rd., Columbus, OH 43214](#). Join us in the meeting room.

Please note that we do not meet in December but we are back again the second Saturday in January. We hope you can join us!

For more information contact Erica Wright at 614-688-9438 or erica.wright@osumc.edu.

CELEBRATION OF HOPE

Plan on joining us Saturday, Dec. 14th for our 19th annual Celebration of Hope being held from 7:00 – 11:00 pm at the Grandview Café, 1455 W. Third Ave., Columbus.

Be a STAR, purchase tickets at: <https://centralohio.hdsa.org>.

- Company logo placement as “Gold Sponsor” in all marketing and media material
- 20 Tickets for sponsor to attend event
- Recognition from the podium
- Logo placement in HDSA Central Ohio Chapter website and HDSA Great Lakes Region social media
- Logo included on prominent signage onsite

- Company logo/Family name placement as “Silver Sponsor” in all marketing and media material
- 12 Tickets for sponsor to attend event
- Logo placement in HDSA Central Ohio Chapter website and HDSA Great Lakes Region social media
- Logo included on prominent signage onsite

- Company logo/Family name placement as “Bronze Sponsor” in all event marketing and media material
- 10 Tickets for sponsor to attend event
- Logo placement in HDSA Central Ohio Chapter website and HDSA Great Lakes Region social media
- Name listed on signage onsite

- “HD Family Sponsor” Your sponsorship will include 2 tickets to be given to an HD family to attend the event
- 6 Tickets for sponsor to attend event
- Name listing in event marketing materials
- Name listing in HDSA Central Ohio Chapter website and HDSA Great Lakes Region social media
- Name listed on signage onsite

- “Friend/Health Prof” Name placement on HDSA Central Ohio Chapter website and HDSA Great Lakes Region social media
- 4 tickets for sponsor to attend
- Name listed on signage onsite

- “HD Family/Supporter” Name listed on signage onsite
- 2 tickets for sponsor to attend



All contributions are tax deductible to the extent provided by law.
HDSA operates under section 501(c)(3)
of the IRS code, Huntington's Disease Society of America EIN #: 13-3349872
No goods or services were provided in return for this contribution.

OFFICERS AND BOARD

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Norm L. Baldwin
Justin Ford
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Devon Hatem
Marilyn Hixson
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(Medical Advisor)
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Wendy Vaughan
Roger Vaughan

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Central Ohio Chapter of the
Huntington's Disease Society of America
Proudly invites you to attend

The 19th Annual CELEBRATION OF HOPE



Saturday, December 14, 2019
7:00pm-11:00pm
Grandview Café
1455 W. Third Avenue
Columbus, OH



Please join us for a night of music and celebration as we support HDSA's Central Ohio Chapter & HDSA Center of Excellence at the Ohio State University Wexner Medical Center.

2019 Honoree: Dr. Sandra Kostyk, Medical Director at The Ohio State University HDSA Center of Excellence

Tickets: \$75 (Tax Deductible Amount: \$50)

Purchase or Donate online at:
<https://centralohio.hdsa.org>

For questions, contact Daphne Hess at
614-519-6468 or dhess5556@yahoo.com

Sponsorship Opportunities Available



See you there!

AMARYLLIS SALE IS GOING ON!

Our Amaryllis Sale has started. You can order amaryllis bulb kits online at: <https://hdsa.org/shop/flowers-for-hdsa/>.

As you place your order online, please select on the LOCATION dropdown "CENTRAL OHIO CHAPTER".

You can order individual bulb kits on line, as well as full cases (16 kits). There are a variety of colors to choose from! These make for thoughtful gifts at the holidays and support a great cause!



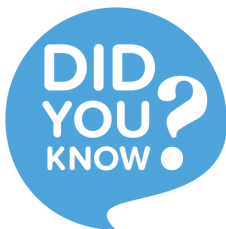
OUR SYMPATHIES to the family of Dr. George W. Paulson



Dr. George W. Paulson passed away Thursday, July 25th. He was very involved in the HD community and attended many of the early Central Ohio Celebration of Hope events.

Dr. Paulson organized the International Centennial Symposium on HD here in Columbus in 1972. (George Huntington's paper on Chorea and HD was published in 1872). One of the presenters was from Venezuela and it was at this meeting that Nancy Wexler and colleagues began organizing their efforts to characterize the population there, leading to the identification of the locus causing HD on chromosome 4.

To read Dr. Paulson's obituary, please click [here](#).



Did you know that you can always the latest news about our Central Ohio Chapter on our website at: <http://centralohio.hdsa.org/>

CENTRAL OHIO CHAPTER

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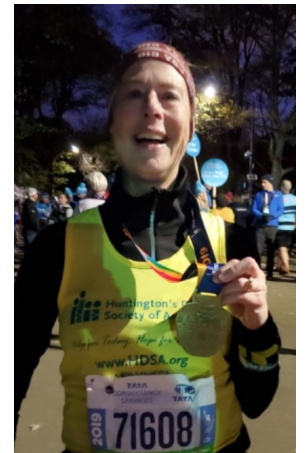
OUR VERY OWN CENTRAL OHIO CHAPTER AMAZING RUNNERS!

The Central Ohio Chapter had two runners in the NYC marathon, Paula Lintz and Amber Rutledge. Each one raised \$3,750 for HDSA. And as a team of 25 runners



from various states raised over \$130,000 for Huntington's Disease.

The Central Ohio Team Hope event will begin planning and scheduling next year's event. If anyone is interested in supporting, please contact Paula Lintz or Lenae Hott.



National Youth Alliance was on the run, too!

Melissa Ryant and Raegan Heitzenrater ran the Chicago marathon on October 13th on Team Run for HD! They were each required to raise at least \$2,100, and as a team they raised over \$56,000!

This was Melissa's first marathon and Raegan's second. Reagan's first marathon was on the HDSA team for the NYC marathon in 2018. Anna Lunsford is also a local member and was signed up to run in the Chicago marathon but unfortunately



had to drop out because of an injury. She is still raising the money though! Anna ran the Chicago marathon for the team in 2018 as well.

CONNECT TO THESE PROGRAMS! IT COSTS YOU NOTHING AND YOU'RE MAKING A DIFFERENCE!

Two ways you can donate to HDSA and it costs you nothing are through the "Kroger Community Rewards" and "Amazon-smile".

Kroger allocates money each year and gives it to charities as their customers designate. To make HDSA as your charity designation, go to <https://www.kroger.com/communityrewards> and follow the prompts.



You MUST register after May the 1st, EVERY YEAR with the Kroger Community Rewards program. If you do not register each year, your designation will be dropped.



Amazon sets aside .5% of each sale for donation to charities. To designate HD as your charity go to <https://smile.amazon.com/> and follow the prompts.

Other business places have similar programs, watch for them and name HDSA as your choice.

WHY WE RAISE FUNDS AND AWARENESS

Huntington's disease is a fatal, degenerative brain disorder that devastates families for generations upon generations -- emotionally, socially and economically. HD slowly diminishes one's ability to think, eat, talk, walk and reason, they become entirely dependent upon others for care. Symptoms typically appear in the prime of one's life between 30 to 50 years old, however symptoms of Juvenile HD have been seen in children as young as two years old.

*Help for Today,
Hope for Tomorrow.*

More than 30,000 people in the United States are currently diagnosed with HD and over 250,000 people are at risk. Each of their siblings and children has a 50 percent risk of developing the disease.