# Huntington's Disease Society of America

# **Central Ohio** CHAPTER

## President's Letter

Dear Families,

Greetings from the Central OH chapter of HDSA!

Your Central Ohio HDSA chapter has been hard at work planning our virtual Hoopathon (deadline May 22nd), fall walk on Oct 2nd at Blacklick Metro Park and hoping to be able to host an in person fall Celebration of Hope!

We are always looking for volunteers to help assist us in planning our events! Feel free to reach out to me at 614-519-6468. I'd like to welcome our newest board members, Heidi Crowell and Zach Vaughan and looking forward to welcoming Kellie & John Gedert by our next Board meeting!

We so much appreciate our extraordinary fundraising chairs (Wendy & Zach Vaughan and Paula Lintz, Lenae Hott, & Jaclyn Hindel) who give tirelessly to help families affected by HD and our awesome Ohio State HD Center of Excellence!

We are also extremely appreciative of all of our donors and sponsors who are listed in this edition of our newsletter. Without their generosity we would not be able to help support our families in our fight against HD. Thank you!

Looking forward to seeing you at our online Hoopathon!

With warmest regards,

Daphne Hess President, HDSA Central Ohio Chapter

# OUR VOICE

## SPRING 2021

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.

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## FBI GOLF OUTING



The FBI again this year has designated HDSA as a beneficiary of their golf outing to be held on June 17th in Columbus. HDSA members may support this event by donating door prizes or entering a foursome.

For more information go to <u>https://</u> <u>tonychristymemorial.com/</u> or contact Norm Baldwin at <u>normbaldwin@frontier.com</u>.

# HDSA 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 614-292-9960

## HDSA CENTER OF EXCELLENCE, HERE FOR YOU!

Ohio State's Huntington's Disease Clinic is designated a HDSA Center of Excellence by the Huntington's Disease Society of America, one of only 50 centers in the country to achieve this distinction.

To learn more, click <u>here</u> or go to...

https://wexnermedical.osu.edu/brain-spine-neuro/ movement-disorders/huntingtons



## "Hoop It up for HD"

You are virtually invited to "Hoop It Up!"

May 22, 2021



All in support of HD Research, education & advocacy efforts!

\*For every \$50.00 raised you will be entered into a raffle for some fabulous prizes TBD

**To Register and** 

Create your Fundraising Page, go to

http://centralohio.hdsa.org/events

and click on "Central Ohio Virtual Hoop-A-thon"

### **OFFICERS AND BOARD**

President: Daphne Hess dhess5556@yahoo.com

Treasurer: Jaclyn Hindel jmhindel1213@gmail,com

Administrative Assistant: Debbie Ioia daioia@columbus.gov or cenohiohdsa@gmail.com

Board Members: Norman Baldwin Norm C. Baldwin Heidi Crowl Justin Ford Kellie Gerderts Jeremy Gederts Devon Hatem Marilyn Hixson Lenae Hott Dr. Sandra Kostyk (Medical Advisor) Wendy Vaughan Roger Vaughan Zach Vaughan

WEB Site Manager: Hal Hixson 614-563-4460 halhixson@gmail.com

CENTRAL OHIO HDSA WEBSITE http://centralohio.hdsa.org/

HD Helpline 614-292-9960

## CENTRAL OHIO CHAPTER

HDSA Central Ohio Chapter P.O. Box 2213 Columbus, Ohio 43216

Email: <u>cenohiohdsa@gmail.com</u>

Phone: 614-636-2439 Website: <u>http://</u> <u>centralohio.hdsa.org/</u>

## CENTRAL OHIO TEAM HOPE WALK

## Join us October 2, 2021!

Registration opens at 8am. Walk starts at 9am.



At Blacklick Woods Park Buttonbush Shelter 6975 E. Livingston Ave. Reynoldsburg, Ohio 43068

Contact: Paula Lintz Phone: 614-207-9708 Email: Paula Lintz@hsc.honda.com

Register, Give, or check for updates at the Central Ohio HDSA website: <u>http://centralohio.hdsa.org/about/central-ohio-team-hope-walk</u>



## 36th ANNUAL HDSA CONVENTION



## JUNE 10—13, 2021 36th Virtual Annual HDSA Convention

Join the countless others, across the world! Watch on June 10— 13 at <u>https://hdsa.org/about-hdsa/annual-convention/</u>.

You can also find excellence videos and reports from past conventions the link above.

"The Huntington's Disease Society of America (HDSA) is the premier nonprofit organization dedicated to improving the lives of everyone affected by Huntington's disease. From community services and education to advocacy and research, HDSA is the world's leader in providing help for today, hope for tomorrow for people with Huntington's disease and their families. In the battle against Huntington's disease no one fights alone. *At HDSA — family is everything!*"

https://hdsa.org/

## NATIONAL HDSA

http://hdsa.org/

NATIONAL YOUTH ALLIANCE:

Melissa Ryant mryant@hdsanya.org

"Dedicated to making ours the last generation with Huntington's disease."



## MEMORIALS AND HONOREES March 2019—March 2021

## In Memory of...

#### 2019

John Karnemaat Susan J. Pfeiffer

Jeff Hindel Fred & F. Kay Graham Athern M. Sheets Sons of American Legion Joann & Chris Boetcher

Courtney Hinger Pam Hostetter Cindy & Dan Henry Dave O'Brien Luanne Dunham

Bonnie Baldwin Russell & Elaine Meyer Lawrence & Verna Meyer Michael L. & Christie C. Meyer

### 2020

Jack Jones Edwina J. Jones

Thomas Williams Neighbors of Westbury Woods -NOWW

#### 2020

Nora Miller Preston & Pamela Cunningham Jo A. & John D. Fincato Vockell Family

> Jeanette Lee Jennifer S. Hunter Joseph & Ronnica Lee

Carol Ann Martino Molly S. & David B. Kenny

#### 2021

Steven Lieb Bonnie J. Baldwin Rev Trust -Norm Baldwin Kathleen Lieb Michele L. & Brett Meyer Thomas H. & Angela S. LaVigne

### Loren Plassman

Marion Retcher Doris Mekus Bonnie J. Baldwin Trust - Norm Baldwin

#### **2019 HOOP-A-THON**

#### **Bonnie Baldwin**

Curtis W. Martel Martin E. & Laura M. Kochevar Henry E. & Cindy A. Zorn Bruce & Stephanie E. Laybourne Susan E. Kochler Barbara J. Hill Julie Buehler Christine J. Thompson John D. Kinn Sidney C. John Edward Sterling Margaret A. Simmons Gary L. & Debra Smith Les & Joanne Lipski (Gold Sponsorship)



## In Memory of...

#### **2019 FBI GOLF OUTING**

Special Agent John & Sheryl Karnemaat Tony Christy Memorial Golf Tournament Committee

### **2020 FBI GOLF OUTING**

Special Agent Anthony L. Christy Special Agent John & Sheryl Karnemaat Tony Christy Memorial Golf Tournament Committee In Honor of...

### 2019

Norm Baldwin Dave & Betty Meyer Mark & Kathy Meyer Michael L. & Christie C. Meyer

#### 2020

Michelle Jones Goodrich's Birthday In support of her brothers: Keith & Greg Jones Edwina J. Jones

Kylie & David Hess Donald R. & Mary E. Hummer

## Celebration of Hope...

#### 2019

In Memory of John Karnemaat S. Pfeiffer

Family Donation Ioia Family Roberta Moro

Friend Donation Hess Family J. Chester

Family Sponsorship Baldwin Family Bonnie J. Baldwin Trust

Hess Family Artisan Engineering - Harry Shamansky

Friend Sponsorship Hess Family B. Duncan

## CONNECT TO THESE PROGRAMS It costs you nothing and you're helping fight HD!

Two ways you can donate to HDSA and it costs you nothing is 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 <u>https://www.kroger.com/communityrewards</u> 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 <u>https://smile.amazon.com/</u> and follow the prompts.

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