

2019 HOOP-A-THON

The HDSA Shoot for A Cure Hoop-A-Thon will take place Saturday, April 6th from 10am - 3pm. The 2019 version of this annual event will again be held at the Fairfield Mercy HealthPLEX at 3050 Mack Road, Fairfield, Ohio 45014.

The Ohio Valley Chapter seeks each year to set a new record for money raised in this major fundraising event for the chapter. This goal can be reached if all those concerned with finding a cure for HD step up and "take a shot" at this new record.

Current Corporate Donors

- TEVA
- Encore Technologies
- The Leugers Group/Raymond James
- LuLaRoe Lindsay Morrison

Individuals can support the Hoop-A-Thon by several actions:

- Gather pledges and sign up to shoot
- Sponsor a shooter
- Enlist a corporate donor for this year's event to add to the current corporate sponsors listed above.

The Hoop-A-Thon is a fun-filled, free throw basketball event to benefit HDSA. It brings together people of all ages to have fun and raise money to help find a cure and treatment for Huntington's disease.



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National HDSA Convention



The Huntington Disease Society of America will hold its 34th Annual Convention, June 27-29, in Boston. Registration details, scholarship opportunities, and a tentative agenda may be found at www.hdsa.org/convention **Early bird rate deadline is May 17th.**

National Convention Scholarship: This scholarship is open to first time convention attendees who are not Massachusetts residents. Applicants must be 18 years of age as of January 1, 2019. Open to residents of US only. (Application deadline: April 10, 2019) Go here to apply: <https://fs22.formsite.com/hdsa/dgfkjd3q7n/index.html>

National Youth Alliance Scholarship: The NYA is open to any current or alumni member of the NYA who did NOT receive a scholarship in 2018. You must be a registered member of HDSA's NYA to apply. Membership information is available at www.hdsa.org/nya (Scholarship application deadline: April 10, 2019). Go here to apply: <https://fs22.formsite.com/hdsa/fwxqsk4za/index.html>

Massachusetts Residents Scholarship: This scholarship is for residents of Massachusetts and open to any family member or caregiver who is affected by Huntington's disease. (Application deadline: April 3, 2019) Go here to apply: <https://fs22.formsite.com/hdsa/sekdfprtzs/index.html>

Hotel Reservations: (Not for the individual attending leadership day.) Constituents reservations can be made with the hotel by calling 1-877-901-2079.

HIGHLIGHTS OF THIS ISSUE

- *Hoop-A-Thon 2019 announced on page 1.*
- *Memorials for loved ones on page 2.*
- *Speaker for Annual Meeting announced on page 5.*
- *Advocacy Corner page 5.*
- *Spring Educational Forum page 6.*

LETTER FROM THE PRESIDENT

Dear Friends of HDSA,

The week that I am writing this President's letter, it will be 2 degrees outside with 20 mph winds. When it is this cold, our thoughts naturally drift to warmer weather and sunshine. Speaking of warmer weather, we are looking forward to our annual Hoop-A-Thon on Saturday, April 6th, from 10am to 3pm at the Fairfield Mercy HealthPLEX. This will be our 18th year in a row at this incredible facility and we will be looking to top our record of \$25,000 raised for Huntington's.

When the weather really warms up, we will be having our Ohio Valley Annual Meeting on Saturday, June 15th, 11:00am at the Beechwood Home, 2140 Pogue Avenue, Cincinnati, OH 45208. Our guest speaker will be Jimmy Pollard. Jimmy is the author of "A Caregiver's Handbook for Advanced Stage Huntington's Disease" and "Hurry Up & Wait! A Cognitive Care Companion for Huntington's Disease," which have been translated into eight languages by national HD associations around the world, and spoken at national HD meetings in Australia, England, Italy, Portugal, Ireland, Switzerland, Poland, Scotland, the United States and Canada. Please make plans to attend.

Thanks as always,
Dan Leugers



President Leugers reflects on the Ohio Valley Chapter mission.

MEMORIALS

Emery Elizabeth Simon

From:
Yvonne & William Sams

Gladys Elsasser

From:
William Brunner
Donald & Dolores Elsasser
Pamela Leist
Wayne Schleutker

Grace Elsasser

From:
Susan Elsasser

Jackie Berter

From:
Katherine Humbert



*"One of the most meaningful ways
you can honor loved ones is with a
memorial donation to the Ohio
Valley Chapter."*

James Asmann

From:
Dale & Kimberly Tuerpe
Beth Wheeler

Jimmy Asmann

From:
Luetta Louis

Lee Smith

From:
Helen Smith



Marty Martin

From:
Noel & Helen Trout
Michael & Pat Wilkey

Matt Freytag

From:
Sandy Stamper

Michael & Donna Brunner

From:
Gregory Bambach

Tom Brown

From:
Margie Duffy
Kathleen Otten
Maria Sonderman



From the Social Worker

Mary Beth Bialick, MSW



As we head into 2019 I want to take this opportunity to think about what we offer through our chapter and what we already have planned for the upcoming year.

Every month our regular support group meets at the Beechwood Home, 2140 Pogue Ave. Cincinnati. We have good participation usually having 15 to 20 attendees. Some months we split apart into caregivers and people with HD and some months we spend the time together. Topics are addressed as brought up by group participants and the opportunity to learn, share and support is beneficial and empowering.

In April, 4/20/2019, we will be joined by local attorney, Mark Reckman. Mark's practice spans estate planning and medicaid and he will talk with us about financial planning for future long term care needs. We will meet in the Beech Room at 11 AM and look forward to an informative presentation and discussion.

Our annual meeting on June 15th will welcome Jimmy Pollard for his much anticipated return to Cincinnati. He will discuss and share about HD and the challenges of living with HD 24/7. Jimmy has a wealth of experience and I will ask him to bring many of his books to share as they were in much demand following his visit 2 years ago!

The yearly HDSA convention is in Boston, MA June 27 through the 29th. Registration and scholarship information is available at the HDSA.org website. The national convention is a jam packed event with education, research, networking and support available. I encourage everyone to look over the convention information and plan to attend if possible.

Oct. will bring about the Team Hope Walk being held at the Voice of America Park for the 3rd year. In spite of some chilly weather we had a great turn out and enjoyed some fun music and exercise while raising funds for HD.

Our local movement disorder neurologists are generous in their willingness to join support group every year for a day of general Q & A on research, HD care, genetic testing questions and general sharing with us. I will schedule this sometime for later this year. We also will have a support group day devoted to Medical Marijuana and HD and hopefully put some facts and answers out there to the many questions coming in about the possible benefits or lack thereof. Dates will be posted once they are confirmed.

Dec. will bring about another holiday party! Be sure to look over the photos included in this newsletter and see if you can spot your self or someone you know having fun at the 2018 circus!

A designated HD genetics testing clinic will continue to be the first Friday of every month located in Dr. Duker's clinic rooms and staffed by the genetic counselors from CCHMC, Kathleen Collins and Christine Spaeth along with Dr. Duker and his staff and two social workers. For information or scheduling please contact Kathleen at 513-803-2154 or phone me at 513-918-1440 for more specifics.

I look forward to seeing you at future events and working with you as chapter social worker. Reach out to me on our chapter cell at 513-918-1440.

Phone numbers to keep on hand:

Ohio Valley Social Worker:

Mary Beth Bialick
(513) 741-4372 Office
(513)-918-1440 Cell

Genetic Counselor:

Kathleen Collins (513)-802-2154

Local HD Clinical Trial Information:

Erin Neefus (513)-558-6555

Scenes from 2018



Social Worker's cell phone number is for social work contacts: 513-918-1440

The office land line is for business issues only: 513-741-4372

ADVOCACY CORNER

Huntington's Disease Parity Act

With the government back open, advocacy is back on track! We had an incredible meeting with our new advocacy partner, Catherine Finlay of Thorn Run Partners, and Ohio is going to be a major player in getting the Parity Act over the finish line in the 116th Congress! As a quick recap, the HD Parity Act seeks to waive the 2 year Medicare waiting period for folks who are disabled and utilizing Social Security Disability due to their HD. Waiving the 2-year waiting period means that folks will have access to quality healthcare and providers when they need it most.

We'll be needing Ohioans to get in touch and tell their stories directly to your Senators in the coming months. To get involved with advocacy with Senators Portman and Brown, let Jennifer Simpson (jsimpson@hdsa.org) know that you want to get involved! She'll direct you to next steps, whether it's sending a message through HDSA's e-advocate portal, or taking a trip to Senator's offices in Ohio or DC to speak with them directly.

Best,
Jennifer

Take a minute today to let your Senators and Representatives know that whatever comes out of Washington has to work for the HD community!

Go to www.hdsa.org/takeaction to send a message today!

Want to make a bigger impact? You don't have to travel to DC, you can start by calling your local Congressional office.

Go to www.hdsa.org/takeaction to find out how you can take your advocacy to the next level!

If you want to find out more about how to advocate with your Representatives and Senators, e-mail Jennifer Simpson, Manager of Advocacy and Education to see how you can get more involved.

Here is healthcare staffer information for the Ohio Senators:

Name	Staff Email	Staff Phone
Senator Sherrod Brown	valarie_molaison@brown.senate.gov	(202) 224-2315
Senator Rob Portman	joe_shonkwiler@portman.senate.gov	(202) 224-3353

WANTED: The Huntington's Disease Society of America, Great Lakes Region Team is looking for volunteers to assist with the planning of exciting events in Ohio to take place in the Fall of 2018 to support Huntington's disease. If you or someone you know is interested in becoming involved to help support our mission to better serve the HD community, fund research and further advocacy & education, please contact Dan Leugers at dan.leugers@raymondjames.com today.

Ohio Valley Chapter Annual Meeting

Plans are already in the works for the Chapter Annual Meeting which is scheduled for Saturday, June 15, 2019 at 11am - 3pm at the The Beechwood Home, 2140 Pogue Ave., O'Bryonville. We are looking forward to hearing from speaker Jimmy Pollard and he will be speaking about HD and the challenges of living with HD 24/7.

NEW 2018 OHIO VALLEY TRIBUTES

Individuals

Darlene Onyett
Ruth Pencil

Families

Mary Ann Hartman
Harold & Sue Ward

Benefactors

Richard Kolmin

Century Club

Richard Stewart
Gregory & Tina Sunderhaus

Patrons

Your Name Here

Golden

Michael & Lee Smith

SIGN-UP FOR THE E-NEWSLETTER

Want to receive this newsletter via email?

Go here <http://eepurl.com/bv8HvX> to sign up for the e-news version today!

Spring Educational Forum 2019

Our friends from the local Parkinson's Support and Wellness group want to invite HD families to their ...

SPRING EDUCATIONAL FORUM 2019

Saturday, April 27, 2019

9:30am–2:30pm

The Manor House

7440 Mason-Montgomery Rd

Mason, OH 45040

\$20 admission includes lunch.

CALL 513-558-0113 TO REGISTER

Our featured speaker will be Elaine Sanchez, author of the book *Letters from Madelyn: Chronicles of a Caregiver* and founder of an online caregiver support program, caregiver.com. Caregivers attending will receive a free copy of Elaine's book *Caregiver Help Survival Guide and Journal*.

In addition to Elaine, Jennifer Heston, PhD, LISW, will lead a program for people with Parkinson's about "Building Community." She is a Research Scholar with Scripps Gerontology Center at Miami University. Her current research projects explore communication and care coordination within caregiving families, efforts to build dementia-inclusive communities, and end-of-life values and decision-making of marginalized individuals and groups. Jennifer is a licensed independent social worker in the state of Ohio. Her 20 years of social work practice include experience in adult protective services, hospice, home and community based services, skilled nursing, rehabilitation discharge planning, and assisted living.

Huntington's Disease Society of America Ohio Valley Chapter Donation

*There is strength in
numbers!*

ANNUAL APPEAL

The strength of our chapter has always been its members. This is no less true today than it was when we first began in 1970. We recognize that it is only through the collective efforts of our family of HD supporters that we can achieve our goals and continue to provide our HD families with the understanding and support they deserve.

Please enroll me in the quest for a cure of HD at the following tribute level.

	Amount
<input type="checkbox"/> Individual Tribute	\$15
<input type="checkbox"/> Family Tribute	\$25
<input type="checkbox"/> Benefactor Tribute	\$50
<input type="checkbox"/> Century Club Tribute	\$100
<input type="checkbox"/> Patron Tribute	\$250
<input type="checkbox"/> Golden Level Tribute	\$500

Method of Payment

- ☐ Check enclosed
Please make payable to the HDSA/Ohio Valley Chapter.
- ☐ Bill Me

Name

Address

Phone

Email

Signature

☐ I would like to volunteer for chapter events.



Huntington's Disease
Society of America



Ohio Valley CHAPTER

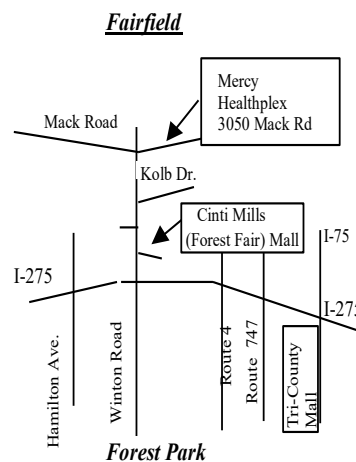
3537 Epley Lane
Cincinnati, Ohio 45247
Phone: 513-741-HDSA

***Thank you!
You make a difference!***

Hoop-A-Thon Participation

Help make our Hoop-A-Thon a record breaking event. You can do this in several different ways.

1. Plan on being one of the shooters on the day of the event. If you need a brochure to begin collecting pledges, contact Dan Leugers at (859) 655-6306 or email Dan at dan.leugers@raymondjames.com. Start now to gather pledges for your shooting.
2. Convince your friends, family, and co-workers to become shooters. Come out together and enjoy the camaraderie that this participation can foster.
3. Send in a donation to be applied to the Hoop-A-Thon fundraiser. If you know a shooter, tell us and we will apply your donation to his or her total.
4. Solicit a corporate sponsor for our event. If you know a business that is interested in supporting a worthwhile charity, the HD Hoop-a-thon is a fantastic opportunity. These corporate sponsorships can make a significant difference in the support of HD families.



3537 Epley Lane,
Cincinnati, Ohio 45247

Address Service Requested

Phone: 513-741-HDSA

HELPLINE

Greater Cincinnati
513-741-HDSA

MEDICAL ADVISOR

Andrew Duker, M.D.

OFFICERS

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Sue Elsasser, Secretary
Ben Bessler, Treasurer
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Education
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Al Hartman, Board Member
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Dennis Martin, Board Member
Roger Martin, Board Member
Lindsay Morrison, Board Member
Karin O'Donnell, Board Member
Kurt Poppe, Board Member
Karen Sams, Board Member

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BUCKEYE BULLETIN

Rhonda Holscher, Editor

DISCLAIMER

The Buckeye Bulletin is the official publication of the Huntington's Disease Society of America, Inc., Ohio Valley Chapter, 3537 Epley Lane, Cincinnati, OH 45247

The Buckeye Bulletin attempts to report items of interest to individuals with HD, their families, health care professionals, and interested friends and supporters.

HDSA and the Ohio Valley Chapter do not provide medical advice, nor do they promote, endorse or recommend any product, therapy, or institution. Please check all drugs, treatments, therapies and products with your physician. Statements and opinions expressed in articles are not necessarily those of HDSA, Inc. and the Ohio Valley Chapter.

HDSA's Mission

*To improve the lives of
people with Huntington's
disease and their families.*

Non-Profit Org.

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Meeting Bulletin Board

2019 Hoop-A-Thon
April 6th — 10am - 3pm
Fairfield Mercy HealthPLEX
3050 Mack Road, Fairfield, OH

34th Annual HDSA Convention
June 27 - 29, 2019, Boston
*Go to www.hdsa.org/annual-convention
for details and to register for the convention.*

Ohio Valley Chapter Annual Meeting
Saturday, June 15, 2019
11am - 1pm

Beechwood Home
2140 Pogue Avenue
Cincinnati, OH 45208

Further info. Phone (513)741-4372
FREE Parking In Rear - Follow Signs
Refreshments Served

Cincinnati Area Caregivers, Patients, & At -Risk Support Groups

We invite all Huntington's Disease patients, their families, caregivers and individual who are at risk to attend out monthly meeting.

Meeting Site

Beechwood Home
2140 Pogue Avenue
Cincinnati, OH 45208

3rd Saturday of month
11:00 - 1:00

Contact Mary Beth Bialick
(513) 918-1440
howardb33@aol.com