

2017 HOOP-A-THON

The HDSA Shoot for A Cure Hoop-A-Thon will take place Saturday, April 8th from 10am - 3pm. The 2017 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

- 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.

Funds raised at this annual event are used locally to provide needed services to families afflicted with HD. These services include access to a social worker who provides links to needed services and who supervises monthly support group meetings for these families.



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National HDSA Convention



The Huntington Disease Society of America will hold its 32nd Annual Convention, June 22-24, in Schaumburg, IL. Registration details, scholarship opportunities, and a tentative agenda may be found at www.hdsa.org/convention.

National Convention Scholarship: This scholarship is open to first time convention attendees who are not Illinois or Wisconsin residents. (Application deadline: April 19, 2017) Go here to apply: <http://hdsa.org/wp-content/uploads/2015/01/2017-National-Convention-Scholarship-Application.pdf>

National Youth Alliance Scholarship: The NYA is offering full and partial scholarships for children and adults from HD families to attend the convention and participate in NYA Day, a special day long program for young members of HD families. (Application deadline: April 12, 2017). Go here to apply: <https://fs22.formsite.com/hdsa/form30/index.html>

Illinois Residents Scholarship: This scholarship is for residents of Illinois. (Application deadline: April 19, 2017) Go here to apply: <http://hdsa.org/wp-content/uploads/2015/01/HDSA-Convention-Scholarship-Illinois.pdf>

Wisconsin Residents Scholarship: This scholarship is for residents of Wisconsin. (Application deadline: April 19, 2017) Go here to apply: <http://hdsa.org/wp-content/uploads/2015/01/HDSA-Convention-Scholarship-Wisconsin-1.pdf>

HIGHLIGHTS OF THIS ISSUE

- *Hoop-A-Thon 2017 announced on page 1.*
- *Memorials for loved ones on page 2.*
- *Cocktails at Cloverbrook page 4*
- *NYA Day Retreats page 4.*
- *Speaker for Annual Meeting announced on page 5.*
- *Advocacy Corner page 5.*

LETTER FROM THE PRESIDENT

Dear Friends of HDSA,

As I am writing this letter to you, we just held our HDSA Night at the Pendleton Art Center on Friday, January 27th. As many of you know, this was our 16th year "sponsoring" a night at the Pendleton Building, which houses some 200 artists in the historic eight floor building.

The HDSA Night at the Pendleton Art Center has become one of our premier events for fundraising **and community awareness**. Over 700 people came through the building on this event and learned about Huntington's Disease. No other event that we participate in brings such awareness to such a large group of people. In addition to the community awareness, we raised close to \$1500 for Huntington's Disease!

Speaking of things to come, we are looking forward to our annual Hoop-A-Thon on Saturday, April 8th, from 10am to 3pm at the Fairfield Mercy HealthPLEX. This will be our 16th year in a row at this incredible facility, and we will be looking to top our record of \$25,000 raised for Huntington's.

Just a few weeks later, on Thursday, May 4th, we are having our fourth annual Cocktails at Clovernook fundraiser at 6:00pm. This is a wonderful "Happy Hour" event that raised over \$7,000 last year. Location of the Clovernook Country Club is 2035 West Galbraith Road. Come on out and have fun!

Last, but not least, we will be holding our Ohio Valley Annual Meeting on Saturday, June 17th, 11:00am at the The Beechwood Home, 2140 Pogue Avenue, Cincinnati, OH 45208. Please make plans to attend.

Thanks as always,
Dan Leugers
HDSA Ohio Valley Chapter President



President Leugers reflects on the Ohio Valley Chapter mission.

MEMORIALS

Lynn Martin

From:
Michelle & Jim Zins

Anne Elsasser

From:
Wayne Schleukter

Carey Lee Jacobs

From:
Ruth Pettit



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

Frank Brinkman

From:
Janice Landrau

Kathy Fitzgerald

From:
Tom Flinn



Lisa Shaffer Ard

From:
Maurice & Kendra Auxier

Maura Stapleton

From:
Maura & Joe Muenchen

Sue Opesky

From:
Steven & Nancy Kari
Mary Williams



From the Social Worker

Mary Beth Bialick, MSW



One of the most rewarding aspects of my position as chapter social worker is facilitating our monthly support group. We have moved locations over the years, but our mission to provide a warm and welcoming setting to learn and share personal experiences of living with HD has remained the same. Our local support group is well attended. Most months we have no preplanned program allowing attendees the opportunity to address and discuss issues that have been ongoing during the previous weeks. As members have different lengths of experience with HD, much support and learning is provided to new members from folks who are familiar with HD and the challenges faced over the course of the disease.

We do have speakers occasionally and our genetic counselors from the HD team join us at least once a year. Our annual meetings held every June also have a speaker discussing relevant topics to the HD community.

This year Jimmy Pollard, a well known HD speaker, will be with us on June 17, 2017. His background of over 30 years is in special education and nursing home administration. Jimmy first became involved with HD back in 1986 when he worked with a specialty nursing home care unit in the northeast. He has worked extensively with assisted living and long term care units in Massachusetts. His commitment to the HD community and their special need continued to grow, and he became, and still is, a strong advocate for better understanding and services.

He has presented on HD more times than I can begin to share and has traveled the world participating in HD related conferences.

Jimmy's name will be familiar to anyone who has read HDSA materials as he has contributed to many of the materials. He has been at several HDSA conventions.

Since 2013 he has been a full time consultant for CHDI, Combat Huntington's Disease Initiative. CHDI is a privately funded, not-for-profit biomedical research organization devoted to research and development to slow the progression of HD and to provide meaningful clinical benefits to patients as quickly as possible.

His role is to speak on a variety of HD topics and we are so pleased he will be here in Cincinnati in June. His talk is titled "Hurry Up & Wait" Thinking About Thinking with HD.

It is with great anticipation that we look forward to this special presentation at our annual meeting. I encourage everyone to mark their calendars now and to join us at Beechwood on June. 17, 2017.

Please consider our monthly groups as a part of your HD journey. Take time to look at the photos in this newsletter and recognize we not only address serious topics but we have FUN....note the Christmas party!!!

Thank you...Mary Beth chapter cell 513-918-1440 for any information.

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



Jimmy Pollard



Scenes From 2016

Pendleton Final Friday Art Tour



The Ohio Valley Chapter hosted a Final Friday Art Tour at the Pendleton which was held on Friday, January 29th. The evening achieved the Chapter's goal to provide an entertaining evening for visitors to the Pendleton Final Friday while educating the community about the needs of families living with HD.

The artists and managers of Pendleton Art Center deserve a special thanks for extending to us the invitation to participate in their Final Friday event.

The Ohio Valley Chapter also owes thanks to all the other participants in the evening's tour, entertainment, and festivities. Through their efforts we were able to elevate the community's awareness of HD and to raise \$1500 for the care and cure of HD.

A special "thank you" is extended to the following individuals and groups that were instrumental in the successful evening. This continued support of the Ohio Valley Chapter benefits many HD families.

- **Event Sponsor:** The Leugers Group/Raymond James
- **Refreshments:** Tom Fisher, Dan & Heidi Leugers, Steve & Karen Leugers, Jim Leugers, Mary Jane Cassin & Jim Pashak
- **Musical Entertainment:** Blake & Jonathan of 46 Long & Brittany Gillstrap
- **HDSA Table:** Heidi Leugers, Tom & Brit Fisher, Karin & Kevin O'Donnell, Ben Bessler & Liz, Steve & Karen Leugers, Kate Killian, Mary Jane Cassin, Jim Pashak, Jim Leugers, Al Hartman, Rosemary Reavil, Sue Elsasser, & Georgetta Harris



Musicians with President Dan Leugers



"COCKTAILS AT CLOVERNOOK" FUNDRAISER

PLEASE JOIN US FOR A FUN EVENING OUT AND A GREAT EVENT TO BENEFIT OHIO VALLEY HDSA!!

THURSDAY MAY 4, 2017 AT 6:00 - 9:00PM



CLOVERNOOK COUNTRY CLUB

2035 WEST GALBRAITH RD
CINCINNATI, OH 45239

COCKTAILS & MENU ITEMS WILL BE AVAILABLE
FOR PURCHASE

BASKET RAFFLE AND SPLIT THE POT
ALL PROCEEDS FROM TIPS, BASKET RAFFLE
AND SPLIT THE POT GOES TO HDSA!!

Questions? Email Karen @ decksams77@yahoo.com

NYA DAY RETREATS

The NYA has 4 youth retreats planned for 2017, kicking off the year in Pittsburg, PA on 3/24 - 3/26. We are thrilled to have 21 already registered for the PA event, maxing out our capacity!

Our next event is going to be in Iowa City, IA and applications are open for that event! Just go to www.nya.hdsa.org/nya-day-retreats to apply.



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

2017 is already a busy year for HD Advocacy! With new efforts at healthcare reform coming out of Washington, D.C., we want our Members of Congress to know what we as a community need from any new healthcare reform:

- 1) Protect individuals with pre-existing conditions
- 2) Preserve bans on life-time care caps
- 3) Ensure that plans must offer Essential Health Benefits
- 4) Maintain Medication Choice

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

Please let Jennifer Simpson know that you've made contact by cc'ing jsimpson@hdsa.org on your email or letting her know about your call so that HDSA can follow up.

If your loved one has been denied Social Security Disability (SSDI or SSI), HDSA May be Able to Help Please contact Jennifer Simpson at jsimpson@hdsa.org if your loved one fits the SSA eligibility criteria for Social Security Disability, but the application was denied by Disability Determination Services.

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 2017 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 17, 2017 at 11am - 1pm at the The Beechwood Home, 2140 Pogue Ave., O'Bryonville. We are looking forward to hearing from speaker James Pollard Jr., full time consultant with CHDI and he will be speaking about "Hurry Up and Wait: Thinking About Thinking About HD."

NEW 2016 OHIO VALLEY TRIBUTES

Individuals

Janice Landrau
Darlene Onyett

Families

Judy Marks
Kevin McHugh
Betty Thompson
Harold & Sue Ward

Benefactors

Beverly Gallimore
Noel & Helen Trout

Century Club

Jim Burg
Kathy Korte
Michael & Lee Smith

Patrons

Beth Wheeler

Golden

Dennis & Janet Martin

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!

Updates From The NYA

The NYA held a successful board meeting in NYC in January 2017, where they voted in a new Research Committee Chair, Miranda Spencer! They also set out their 2017 agenda and finalized their agenda for NYA day at Convention.

The NYA has released the NYA Convention Scholarship Application for 2017, and after a successful fundraising campaign at the end of 2016 have a robust scholarship fund for young people interested in attending HDSA's National Convention! If you're interested in applying, go to www.hdsa.org/nya and apply online for the 2017 NYA Convention Scholarship.

The NYA has 4 youth Retreats planned for 2017, kicking the year off in Pittsburg, PA on 3/24 - 3/26. We are thrilled that 21 young people have registered for the Pittsburg event, maxing out our capacity! As we did last year, the NYA is working together with the Western PA chapter and the HDSA Center of Excellence at UPMC to create a great weekend of fun, learning, friendship and bonding for young people affected by HD. Our next event is going to be in Iowa City, IA and applications are open for that event! Just go to www.nya.hdsa.org/nya-day-retreats to apply.

The NYA is also excited to be part of the new HDNavigator App! In the app, the NYA have created a peer-to-peer connector, for young people to be able to reach out with questions, comments or just to talk to another young person who knows what it's like to be from an HD family. If you haven't yet, download the HDNavigator App today!

For young people looking to get more involved, HDSA now has a new advocacy guide for young people. Available for free at www.hdsa.org, Live Out Loud: A Guide to HD Advocacy, helps break down what it means to be an HD advocate and encourages young people to get involved and speak about their experiences with HD at every level, at home, in school, and even with their Members of Congress! Request your copy today!



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.



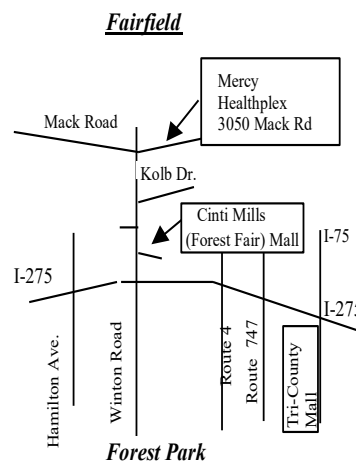
3537 Epley Lane
Cincinnati, Ohio 45247
Phone: 513-741-HDSA

***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. We currently have sponsors at several levels of support including \$250, \$500, \$1000, and \$2000 levels. Again, 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.





Huntington's Disease
Society of America



Ohio Valley CHAPTER

3537 Epley Lane,

Address Service Requested

Phone: 513-741-HDSA

HELPLINE

Greater Cincinnati
513-741-HDSA

MEDICAL ADVISOR

Andrew Duker, M.D.

OFFICERS

Dan Leugers, President
Dennis Martin, Vice President
Sue Elsasser, Secretary
Ben Bessler, Treasurer
Rosemary Reavill, Family Service/
Education
Gary Dickson, Board Member
Al Hartman, Board Member
Jeff Hines, Board Member
Mary Jacobs, Board Member
Becky Kelly, 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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Greater Cincinnati
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513-918-1440 cell
West Virginia
Debbie Armstrong, 1-304-549-3266

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

2017 Hoop-A-Thon
April 8th — 10am - 3pm
Fairfield Mercy HealthPLEX
3050 Mack Road, Fairfield, OH

32nd Annual HDSA Convention
June 22 - 24, 2015, Schaumburg, IL
*Go to www.hdsa.org/convention
for details and to register for the
convention.*

**Ohio Valley Chapter Annual
Meeting**
Saturday, June 17, 2016
11am - 1pm
Beechwood Home
2140 Pogue Avenue
Cincinnati, OH 45208
Further info. Phone (513)741-4372

**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