



PRESIDENT'S MESSAGE



Happy Holidays!

Hopefully this newsletter finds you enjoying the holidays and starting a brand new year. I wanted to introduce myself as the new president of HDSA of Northeast Ohio. My name is Carrie Bohenic Dudick, MD. I am currently working as a pediatrician, with Akron Children's Hospital Pediatrics in Brecksville, OH. I grew up in Harrisburg, Penn-

sylvania and attended school in Philadelphia before finding my way to Cleveland in 2002 to complete my medical training at Rainbow Babies and Children's Hospital. Northeast Ohio is now my home. I currently live with my husband Mike and 2 children Natasha (10) and Gregory (8) in Broadview Heights.

My grandfather had Huntington's disease and died when I was eight years old. No one in my family really discussed what he died of, and it wasn't until I was in medical school I really learned anything more about Huntington's disease but hoped it would pass by my mother and my family. However, when my mother was visiting me after the birth of my second child it became apparent she was symptomatic. She tested positive and has been involved with research and drug trials in Baltimore closer to her home. I have not been tested so remain at risk. Although we don't have a cure- I want to do everything I can to help my family as well as other families affected by

Huntington's disease. As a pediatrician I am not a researcher- but hopefully through fundraising, volunteering, educating medical students and the public a cure will be something I see in my lifetime.

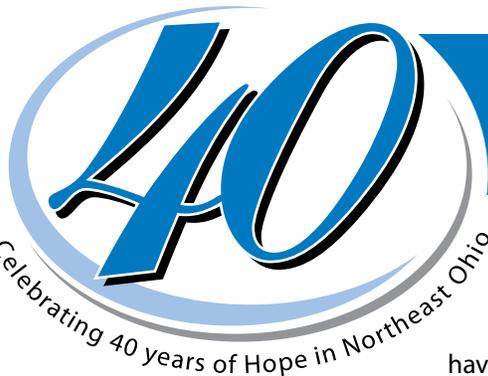
When I moved here, I met Mackenzie Platten at a family party and she introduced me to HDSA of NEOH. In the past 4 years I have helped with Galas, joined the board, attended education days, given talks at local medical schools, attended two National Conventions, and my family and I traveled to Washington to meet with 3 different senators for Ohio and Pennsylvania for the HD Parity act. The more I learn the more I realize how much more needs to be done.

This past year we had a wonderful Education day, a Team Hope Walk at Edgewater Park, expanded our support groups south towards



Youngstown and a very successful Gala. Hopefully, during the next year we will do even better raising more money, reaching out to more families, and educating the public and medical community about Huntington's disease.

Carrie Dudick, President Northeast Ohio Chapter HDSA



The Northeast Ohio Chapter Celebrates 40 Years of Hope!

This is a big year for the NEOH Chapter of the HDSA, as we celebrate our 40th Anniversary!

Over the years we have lost friends, family, and loved ones to this terrible disease, and we have helped each other cope with many factors that come with it.

However, our work and dedication to each other and the cause has also given back to us in many ways. The funds we have raised have lead to incredible leaps in the treatment of HD, we have learned more and more about this debilitating disease, and how we can comfort those stricken. In many ways, our advocacy has created lasting friends, and built enduring relationships.

So in so much as HD has effected us negatively, we should also embrace the positive moments that have come from the 40 years of hard work, dedication, and love that has brought members of the NEOH Chapter closer together, and given us hope that soon, a cure for Huntington's Disease may be found.

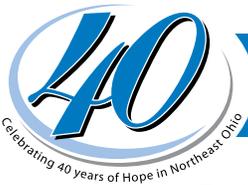
Thank you to everyone who has contributed, donated, worked, advocated, befriended, reached out, or comforted in an effort to help others and to ultimately end Huntington's Disease.

National Convention Update

By Carrie Dudick

In June of 2016 I was fortunate to attend the national convention in Baltimore, Maryland along with our Social Worker Katie Dykman and fellow board member Eric Hutchins. Several local families were also lucky enough to attend. Over 900 people were present at the hotel on Inner Harbor for a weekend of fun, support, and education. There were sessions on financial planning, fundraising, advocacy and new this year special sessions for those affected by Huntington's Disease. My mother who attended with me really enjoyed participating in Music therapy, and several other sessions. As for me- I loved hearing about the start of some human trials for treatments that could actually reverse or stop the progression of the disease. As always the NYA put on a fabulous talent show to raise money for youth to attend next year's convention.

June 23 and 24 of 2017 will see the National Convention outside Chicago. Convention truly gives a sense of community and hope. With it being so close- I really hope more people can attend this year.



A Historical Perspective

By Eva G. Weissman

The Huntington's Disease Society of America (HDSA) Northeast Ohio Chapter was established in 1977 as a Chapter of the Committee to Combat Huntington's Disease (CCHD). CCHD was the National organization formed by Marjorie Guthrie to increase research funding for Huntington's Disease (HD) and to assist people affected by HD, the ailment responsible for the death of her husband, legendary folk singer Woody Guthrie. The Chapter followed Marjorie's lead and committed itself to programs dealing with Awareness, Research, Education and Advocacy (AREA programs).

In 1981, five years after its funding, the Chapter hosted a National CCHD convention in Cleveland. Attendees included representatives from the National Institutes of Health, the National Health Council, the Huntington Society of Canada, the Hereditary Disease Foundation, HD families, professionals and community leaders. The convention, the last one attended by Marjorie Guthrie, was the first to feature workshops and scientific symposia, which are staple elements at current National HDSA conventions.

In 1983, after Marjorie Guthrie's death, CCHD adopted a new name, the Huntington's Disease Foundation of America (HDFA). At that time there were two National HD organizations: HDFA and the National Huntington's Disease Association of America (NHDA). In 1986, HDFA and NHDA merged and became the Huntington's Disease Society of America (HDSA) which is the only current National family oriented HD organization. Locally, community outreach and media attention attracted more and more HD families. The Chapter proudly played an important role in the affairs of the National Organization when, in 1991, the Chapter hosted a memorable meeting of the HDSA Executive Committee in Cleveland.

A glitch in Chapter operations, however, occurred in 1992. After fifteen years of successful activities, there were not enough volunteers who had the time and energy to perform the myriad tasks necessary to keep the Chapter moving ahead. As a result, the Chapter turned in its charter and submitted the \$11,000 it had in its bank account to the HDSA National Office. Chapter members were asked to send their donations directly to the National Office in New York.

Spearheaded by Christine Paternoster, a few volunteers continued the support group meetings and provided information to HD families. These efforts were aided by the local Federation for Community Planning, other agencies and a dedicated medical advisory group. Support for the HD cause was continued by Adora Stout of Stow, Ohio and her children who held highly successful events in their community, events that are still held and increased each year.

An individual honor was bestowed on a National and local HDSA leader in 1995 when the National HDSA Board selected Eva Weissman to receive the Marjorie Guthrie Award, the most prestigious award presented by HDSA for outstanding service to the HD community.

Determined to have a well-functioning Northeast Ohio Chapter again, the original Chapter's charter members, David Waltermire and Eva Weissman, were able to form an energetic Board of Directors and a new charter was received from HDSA in 1996. The Chapter flourished and at subsequent National HDSA conventions, the Chapter received awards for chapter and board development. For her first visit to a local chapter, the then new National Executive Director/CEO, Barbara Boyle, selected Northeast Ohio. During her visit she participated in a radio program and made an audio recording which is available on the Chapter's website at www.lkwd.org/hdsa. That website is maintained by the Lakewood Public Library as a community service.

In 1997, the Chapter was host of an HDSA Regional Conference with participants from near and far. Kim Paternoster, a young Chapter member received an honor plaque in recognition of her courageous efforts to cope with HD. Since then the Chapter staged seminars, symposia, workshops, fund raising and education events in Akron and Cleveland to promote HD Awareness, Research, Education and Advocacy, still know as AREA programs.

Now in 2000, the HDSA Northeast Ohio Chapter is an integral part of the growing National network of HDSA. It is the Chapter's aim to increase the care available for HD families and to help find the cure for Huntington's Disease by increasing financial support for HD research. One of the Chapter's long term goals is to have an HDSA Center of Excellence to help the HD families in Northeast Ohio even more.

Why do we do it? LOVE



Sitting in a genetic counselor's office at the age of 19 can be daunting to most. Being told that the man you love has a 50/50 chance of inheriting, Huntington's disease, something you never heard of, invokes fear to say the least. Jim Leetch, Hubbard, Ohio, was not only facing his mother's diagnosis and her decline from HD but his wish to marry the girl of his dreams. There was no doubt that his girlfriend; soon to be fiancée loved Jim. No disease was going to stand in their way of their love.

Years passed. Jim's mother passed. Jim became a brilliant, successful manager of engineering at a Fortune 500 company. Carolyn, Jim's wife, stood closely by his side. Carolyn recognized HD symptoms as they presented themselves in Jim. In 2012 when Jim was genetically tested and

officially diagnosed with HD, life changed. Carolyn was no longer just a wife; she was Jim's advocate in every sense of the word.

After watching HDSA webinars, Carolyn filed for Social Security Disability on Jim's behalf. She later appealed his onset date to provide the much needed medical insurance. Carolyn constantly monitored Jim's condition and sought the help of professionals when his medications needed to be adjusted. "Everyone needs an advocate," states Carolyn.

Jim, in his own way, was Carolyn's advocate as well. While sitting at the Cleveland Clinic during a routine office visit. Jim asked if Carolyn's background in Public Relations and Event Planning could be utilized for the local HDSA Chapter. They sure could. The chapter's Celebration of Hope - James Bond Style was chaired by Carolyn in 2016. Jim so enjoyed hearing the day to day details of the event planning, Aston Martins, menu and such; he wanted to attend. Unfortunately, after a sudden turn for the worse, Jim passed away on September 13, 2016 with the James Bond event just 17 days away.

Instead of just mourning the loss of her husband, Carolyn Leetch spent the next 17 days completing a memorable event to raise over \$175,000 for HDSA Northeast Ohio Chapter and to honor those who have succumbed to HD.

"We are the greatest advocates for our loved ones. We shall stand together to find a cure for HD. I vow to continue, along with the Northeast Ohio HDSA Celebration of Hope to raise funds to find a cure for HD." stated Carolyn Leetch.

Save the Dates 2017

April 29th, 2017
Education Day
Embassy Suites Rockside

June 4th, 2017
Team Hope Walk and 5K Run
Cleveland Metroparks Zoo

October 13th, 2017
Celebration of Hope
Passport to Tuscany
Landerhaven



AREA SUPPORT GROUP MEETINGS

Cleveland Area:

Meets on the second Monday of every month
6:30p.m. - 8:00p.m.

Jan 9	May 8	September 11
Feb 13	June 12	October 16
Mar 13	July 10	November 13
April 10	August 14	December 11

Cleveland Clinic Independence Family Health Center
5001 Rockside Road • Independence, OH 44131

Akron Area:

Meets on the first Tuesday of every month
6:30p.m. - 8:00p.m.

January 3	May 2	Sept. 5
February 7	June 6	Oct. 3
March 7	July 4	Nov. 7
April 4	Aug. 1	Dec. 5

Ellet Community Center

2449 Wedgewood Drive • Akron, OH 44319

Painesville Area:

Quarterly pending room availability
7:00p.m. - 8:30p.m.

The Morely Library

184 Phelps Street • Painesville, OH 44077

Youngstown Area:

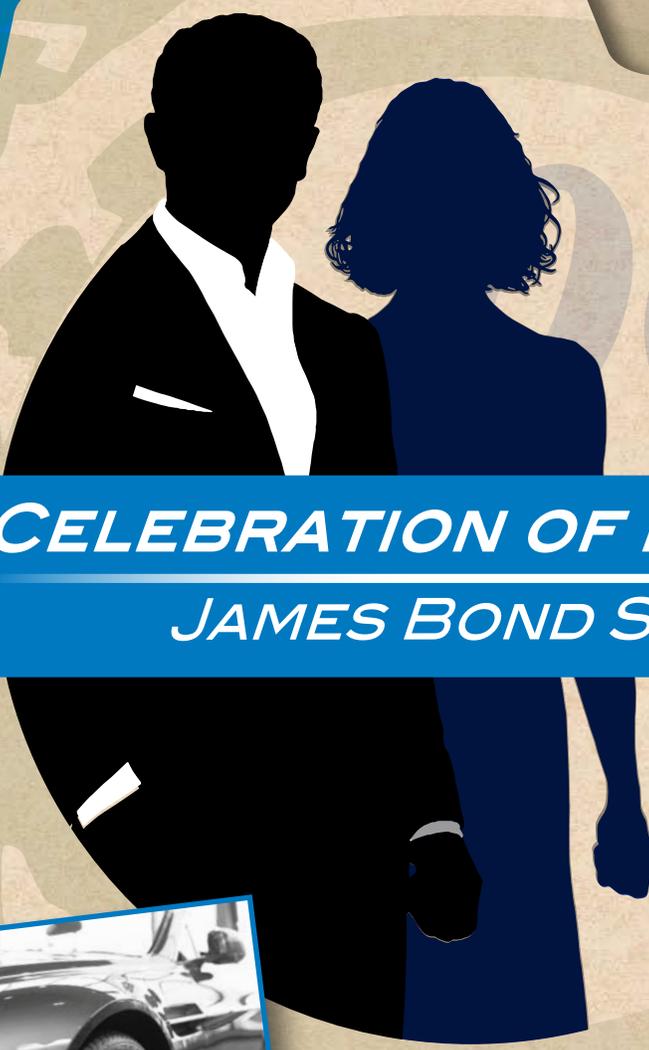
Meets quarterly pending room availability
6:30p.m. - 8:00p.m.

Hospice of the Valley - Hospice House

9803 Sharrott Road • Poland, OH 44514

We invite anyone touched by Huntington's Disease to attend our confidential support group meetings. Meetings provide a supportive environment where participants can share challenges and successes. For more information please contact Katie Dykman, Chapter Social Worker, at kdykman@hdsa.org or (440) 742-1284.
Please consider joining us!





CELEBRATION OF HOPE JAMES BOND STYLE



On Friday, September 30th of last year, the HDSA Northeast Ohio Chapter hosted A Celebration of Hope, James Bond Style, to Benefit Huntington's Disease at Landerhaven.

The evening featured Bond inspired cocktails by Belvedere, Photographs with stylish Aston-Martins, Gourmet Dining Stations, and lively music by the Jason Kendall Band. Fox 8 News' Stefani Schaefer emceed the event.

Thank You to all who attended Celebration of Hope James Bond Style, and to all those who generously gave of their time and talents. We were able to raise over 175,000 for Huntington's Disease!

Thank you to our Celebration of Hope committee: Carolyn Leetch- Chair, Nicole Visconsi Mawby, Carrie Bohenic Dudick, MD, Mackenzie Platten, Jesse M. Lis, Chris Firestone, Melissa Ryant



FOR YOUR EYES ONLY

A huge thank you to all Celebration of Hope sponsors this year:

Thunderball Sponsor

Third Federal Foundation

James Bond Title Sponsor

Dominic A. Visconsi

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Nicole Visconsi Mawby

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Lawrence & Linda Hatch

Mattlin Custom Systems

David Waltermire

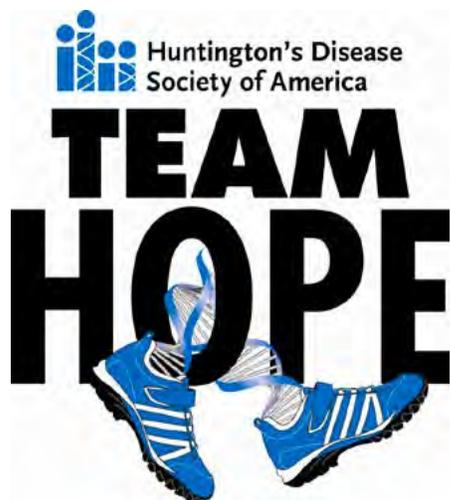
You Only Live Twice Table Hosts

Donald Barr

Geri & Bernie Kosar, Sr.

The Waltermire Family

Visconsi Companies Ltd. Employees



8TH ANNUAL TEAM HOPE WALK & 5K

With beautiful weather and tremendous amount of positive energy, the 2016 Team Hope Walk & 5k Run was a success! Thank you to everyone who joined us for a great day of camaraderie.

Our runners kicked off the event with our 5k race, followed by our mile community walk around beautiful Edgewater Park. It was certainly inspiring to see the turnout, funds raised, and support of our community. Congratulations to Team Jean headed by Mickey LaRosa who won for top fund raising team and Diane Sabo who won for top individual fundraiser!

The runners were awarded medals and Dicks sporting goods gift cards! The Chapter is grateful to the Walk Committee and the many volunteers who helped with registrations, donations, raffles, set up, tear down and fund raising.



The 9th Annual Team Hope Walk & 5K is going to be **WILD!** June 4th, 2017

The 2017 Team Hope Cleveland Walk/Run, celebrating 40 Years of Hope in Northeast Ohio will be held at an exciting new location-- the Cleveland Metroparks Zoo!

WE REALLY NEED YOUR HELP!

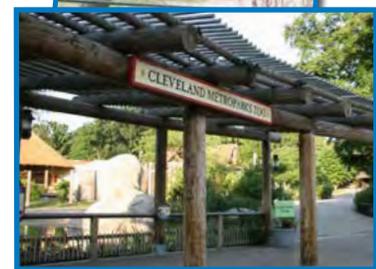
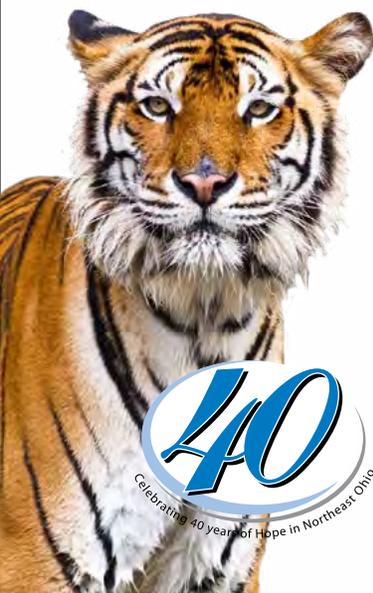
We are actively seeking committee members, sponsors, teams, and support for this year's event.

And of course, we want you, your family, and all of your friends, neighbors, coworkers, etc. to participate. Runners/Walkers who come for the walk, may also stay in the zoo all day.

Please join us **June 4th, 2017** as we run and walk with the animals. Look for detailed information in mail and email soon.

For information or if you would like to be on the planning committee, have a team, want to sponsor, or donate to the HDSA Team Hope event, please contact our Committee Chair, **Jesse Lis** Jesse.Lis@firstmerit.com

This year is going to be WILD!!!



Research News Toxic Protein Identified



Form of the HD Protein Associated with Neurodegeneration is Identified

By Dr. Steven Finkbeiner, Professor of Neurology and Physiology at the University of California, San Francisco, and Gladstone Institute

Dr. Steven Finkbeiner, and colleagues have identified the form of the HD protein associated with neurodegeneration. This is the result of research that began in 2003 with funding from HDSA, that continued over the years with funding from additional sources, and that could only have been completed with the development of a variety of new technologies.

In 1997, large aggregates of the HD protein were found first in the brains of HD mice and then in brain tissue samples from deceased HD patients. At first it was hypothesized that these aggregates, also called inclusion bodies, were the cause of the disease but cumulative research has suggested that they are a coping mechanism. More recent research has pointed to tiny, hard to detect aggregates called oligomers as problematic and suggested that the large inclusion bodies may be protecting the cell by sequestering them.

Dr. Finkbeiner and his colleagues have shown that the toxic species of the protein can be identified through antibodies that are specific to the different conformations (shapes) of the various species of the HD protein. First, they found antibodies for each conformation. Then they determined the survival times associated with each form by tracking thousands of neurons

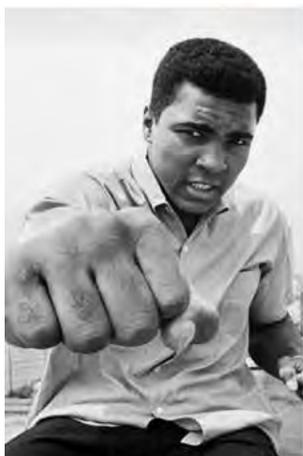
over long periods of time using an automated microscope. This generated an enormous amount of data and a modified form of a statistical technique called Cox analysis was used to determine which species best predicted cell death or survival. Finally, they determined the biochemical and structural characteristics of the toxic species.

One antibody, 3B5H10, was found to recognize a species of the HD protein that best predicts neuronal death. This species is found in monomers (single polypeptides) and possibly oligomeric forms of the protein but not in the larger aggregated forms, such as the inclusion bodies. The antibody recognizes a compact, structured portion of the polyglutamine that is only minimally present in the normal protein and is either exposed or created in the HD protein.

Interestingly and surprisingly, when pre-formed oligomers were exposed to 3B5H10, they dissolved. They also discovered as those large inclusion bodies form there is a corresponding loss of intraneuronal 3B5H10 binding, suggesting that inclusion body formation is somehow protecting the neurons either by reducing, masking or refolding the toxic protein part.

There are many pathogenic processes in Huntington's disease, a number of therapeutic targets which have been proposed and a number of drugs discovered or developed to address them, leading to a growing pipeline of potential treatments. Prioritizing for clinical trial those drugs which address the most significant, upstream pathogenic processes is critically important in developing effective treatments. The value of a study such as this one is that researchers were able to follow the development of the disease process in numerous cells over time, distinguish between the toxic and nontoxic forms of the protein and identify an important target for drug development.

Now do you recognize us?



Muhammad Ali



Lou Gehrig



Ronald Reagan



Woody Guthrie

PARKINSON'S + ALS + ALZHEIMER'S = HUNTINGTON'S

FACILITIES FOR HUNTINGTON'S DISEASE TESTING AND GENETIC COUNSELING:

Cleveland Clinic Genomic Medicine Institute

Desk NE-50
9500 Euclid Avenue
Cleveland, OH 44195
Amy Shealy, MS, LGC
(216) 445-1251

Center for Human Genetics University Hospitals of Cleveland

11100 Euclid Avenue
Cleveland, OH 44106
Suzanne DeBrosse, MD
Joanna Horn, MS, LGC
(216) 844-7215

Division of Medical Genetics Akron Children's Hospital

One Perkins Square
Akron, OH 44308
Catherine Ward-Melver, MD
Susan Woods, MS, LGC
(330) 543-8792

Genetics Center MetroHealth Medical Center

2500 MetroHealth Drive
Cleveland, OH 44109
(216) 778-4323

HD Care:

HDSA Center of Excellence at Cleveland Clinic

Center for Neurological Restoration, U3

1950 East 89th Street
Cleveland, OH 44195

For an appointment or for more information, please call (216) 444-3596

University Hospitals Neurological Institute Huntington's Disease Clinic

UH University Suburban Health Center

1611 South Green Road, Suite 204
South Euclid, OH 44121

For an appointment or for more information, please call (216) 844-2724

MetroHealth Medical Center

Interdisciplinary team approach for individuals with Huntington's disease

2500 MetroHealth Drive
Cleveland, OH 44109

For an appointment or for more information, please call (216) 778-4323

WANT TO KNOW MORE ABOUT HUNTINGTON'S DISEASE?

The national website at www.hdsa.org is the best resource for the most recent information on HD. From this site, you can link to other sites such as HDYO which is a new organization that provides information and education along with support for young people affected by HD. Another great site is HD BUZZ, which includes Huntington's disease research news in plain language, written by scientists for the global HD community.

Publications are also available for free, or for a nominal fee. They can be downloaded from www.hdsa.org/publications or obtained by contacting *Anita Mark Paul*, HDSA Information and Fulfillment Coordinator, at (800) 345-4372, ext 219, or by email at amarkpaul@hdsa.org.

DOUBLE YOUR DONATION THROUGH THE MATCHING GIFTS PROGRAM

Stretch your donation when your company doubles your contribution! Support HDSA when you and your company participate in the HDSA Matching Gifts Program. Many employers have these programs in which the company matches the tax-deductible contribution you make to HDSA. Your gift doubles (or more) when your company belongs to HDSA's Matching Gift Program.

To make your gift to HDSA grow, simply obtain a matching gift form from your Human Resources Department, enclose it with your gift and mail to the Chapter Office. Anyone can make an online donation at www.hdsa.org/nehdon.

DONATIONS TO HDSA NOW MADE EASIER THROUGH PAYROLL DEDUCTIONS

such as contributions through Community Health Charities.

Contact Mike Ryan at mryan@healthcharities.org or at (614) 891-2566 for more information.



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