



Huntington's Disease
Society of America



Michigan CHAPTER



BRIDGES OF HOPE

February 2016

WORDS OF HOPE:

**"WHEN YOU ARE FACE TO FACE WITH A DIFFICULTY,
YOU ARE UP AGAINST A DISCOVERY"**

LORD KELVIN

VOLUME 1 ISSUE 43

PRESIDENT'S LETTER...

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Social Worker:

Janet Howes

Jhowes@hdsa.org

Helpline:

1-800-909-0073

HDSA Michigan Chapter
2711 Parsons Ct, Midland MI 48642-6916
(ph) 989-832-4170, (fax) 517-827-4950
HELP LINE 1-800-909-0073
E-Mail: hdsami@att.net
www.hdsa.org/mi

Good-bye and Farewell...But Not Really!

December 2015 marks my last month as HDSA, MI Chapter President. I hope it is a good sign about their experience with me, but many people are reaching out to me concerned that they may see my involvement with HDSA decline. I am happy to report that it is not the case! HDSA now requires that new leadership roles be renewed with new individuals every two years and I have served as President including Vice President for the past five years. This is a great way to keep fresh eyes and ideas as well as continued and new visions throughout our growing chapter. The good news is that I am still on the board as the Fundraising Chair and will remain my engagement as the Royal Oak Support Group Leader, Fundraiser of my current (even adding more) events, HDSA Speaker at national universities, and more.

We need "new blood" for continual transformation of the board and developing new leaders. Our board continues to grow; take a look at the current roster:

President Donna Spencer	Vice President Kelly Kennelly	Treasurer Dave Stickles	Secretary Katrina Walker
Family Services Kelly Norris	Education Kelly Kennelly	Fundraising Krissi Putansu	Advocacy/Communications Chelsea Rink
Nomination Peggy Reddaway	Social Worker Janet Howes	NYA Representative Miranda Spencer	Research Dr. John Kamholz/Shawna Feely

This is a strong growing board! Donna Spencer has served on the board for over one year and was in the Treasurer role. She has a great business background as well as Huntington's Disease in her family. I am fortunate that Donna is not only a viable competent candidate, but that she was interested as well due to the time commitment and enthusiasm involved. Kelly Kennelly was on our board for one year and as you may recall, returned last year as she is a Genetic Counselor with a passion for helping Huntington's Disease patients, their families, and I welcome her as Vice President and know she will see successes. We have all spent time together over the holidays to transition into these new positions.

Dave is our longest-standing member and is now treasurer, a role he truly encompasses. I am excited to announce that Chelsea Rink (formerly Chelsea Boers) has returned to the board after a few years! Also, Katrina is a wonderful new addition in our open Secretary role. One of Donna's initial ideas was to add a NYA or National Youth Alliance member to our board and Miranda is currently filling that role for us so she can share what is happening at a national level and take our information to other youth/national.

Thank you all for the support you have provided throughout my presidency; I have enjoyed working with all of you and I am excited for what 2016 holds as I know there is HOPE for the FUTURE! Would love to see all of you at Spotlight on a Cure Saturday March 12th at 7 pm at new locale (see page 4 for details)!!!

Hugs, Krissi Putansu, HDSA MI Chapter, (586) 822-1730 or krissilynn18@hotmail.com

HDSA Michigan Chapter Education Conference

Saturday, April 30, 2016 8:30 AM – 3:30 PM

East Lansing Hannah Community Center

819 Abbot Road, East Lansing, MI 48823

Registration is Free and Required, please register to help with planning – Early Bird Deadline is April 15th

After April 15th, and at the Door a \$5 per person or \$10 per family registration fee will be charged.

Topics are still being finalized but may include:

Research & Clinical Trial Update

Genetic Testing, Invitro (IVF) Procedure

Nutrition and HD

Advocacy and Getting Involved with HDSA,

Social Security - A look inside how it works, Caregiving

Youth Activities NYA & HDYO

Medicaid Waivers and Nursing Home,

Long Term Care and Health Care

Medication,

Physical Therapy Session for those with HD

Topics are subject to change. We will post agenda on the chapter web site as it gets close

The program will include a continental breakfast, lunch, snacks & beverages.

Additional donations will be gratefully accepted with checks made payable to "HDSA Michigan Chapter".

For more information please contact Janet at jhowes@hdsa.org or 1-800-909-0073.

This event is mostly funded by the Huntington's Disease Society of America (HDSA)

through an unrestricted educational grant from Teva Pharmaceuticals Industries LTD



Yes I/We will attend The Michigan Chapter Education Conference

Register online at www.hdsa.org/mi Events Page

Or detach this form and mail to: HDSA Michigan Chapter – 2711 Parsons Court. Midland MI 48642-6916

Total Number Attending: _____ Registration Fee _____ Voluntary donation: \$ _____ ☐ \$5/10 Fee enclosed after April 15th

Primary Contact Person's Name: _____ # _____ Adult Track

Address: _____ # _____ Youth Track

City: _____ State: _____ Zip: _____ Phone: _____

Email Address: _____

Names of additional participants: _____

Dietary Restrictions: _____

No HD Circle of Friends Camp in 2016

For business reasons the Michigan Chapter will not be holding the HD Circle of Friends Camp in 2016. We can assist with finding respite care if needed, contact Janet Howes, MI Chapter Social Worker.....Dave Stickles

We're Going Green !!

To help cut cost and become more environmentally friendly we will no longer be mailing paper copies of the newsletter, so this will be the last one mailed. We will also be sending out shorter electronic newsletters either monthly or bimonthly so information on upcoming events will be more timely. Electronic copies can be found on our web site www.hdsa.org/mi. Please send an email to hdsami@att.net with your name and email address to have a notice sent to you when the new newsletter is available. If you sent us your email address in the last year or two you should be on the email list already and receiving notices that way. We will also post on other social media pages when new issues are available. Thank you!!

HDSA's Michigan Chapter National Youth Alliance (NYA)

New this year! HDSA Michigan Chapter's NYA is looking to recruit members to get involved and help advocate for Huntington's Disease! HDSA's National Youth Alliance (NYA) helps youth to get involved with their local HDSA chapters to help with fundraising, advocacy and raising awareness for Huntington's disease. The NYA is a collection of children, teens and young adults from across the country ranging from ages 9-29. Our mission is to be the last generation with Huntington's Disease.

Michigan NYA's hope is to raise more awareness for the NYA and for Huntington's Disease by recruiting more youth who would like to become more active in the Michigan HDSA/NYA Chapter. We also hope that by recruiting more members for MI NYA, we will be able to offer more support to local NYA members by being more involved in group outings that will keep us all together. If you would like to become a member of the NYA sign up at <http://nya.hdsa.org/>. If you would like to meet more members in the state of Michigan and become more active please contact us at michiganNYA@yahoo.com and let us know if you would like to join our new PRIVATE Facebook group: HDSA's Michigan NYA..... Miranda Spencer

***** Announcing the 31st Annual HDSA Convention at the magnificent Hyatt Regency Baltimore, Baltimore Maryland, June 2-4, 2016. Register online at www.hdsa.org. Scholarship applications are open for first time attendees at www.hdsa.org and must be post-marked by Friday April 1, 2016. National Youth Alliance Scholarships are also available at www.hdsa.org for active members of NYA *****

Upcoming Fundraising Events

7th Annual Spotlight on a Cure, a Night of Entertainment

Date: Saturday, March 12, 2016

Time: 7:00 PM, Strolling Dinner, Cash Bar,

New Location: Enchantment Hall, 46915 Hayes Road, Shelby Twp. MI

Register or donate online: hdsa.donordrive.com/event/spotlightmi

Tickets: \$30 in Advanced, \$40 at the Door, \$225 for a Table of 8

Strolling Dinner, Cash Bar, Featuring Simply the Best Performers.

Contact: Krissi Lynn, krissilynn18@hotmail.com, Phone 586-822-1730

Hunting for a Cure, A Michigan Beer and Wine Tasting

Date: Saturday, April 30, 2016

Time: Watch the web site for details

Location: Western Golf and Country Club, Redford MI

Register or donate online: www.hdsa.org/MI

Contact: Donna Spencer, donna_spencer@me.com,

Detroit/Taylor Michigan Team Hope Walk

Date: Saturday, May 14, 2016

Time: Registration begins at 8:00 am, Walk begins at 10 am

Location: Heritage Park, 12111 Pardee Road, Taylor, MI 48180

Register or donate online: www.hdsa.org/thwdetroit

Contact: Katrina Walker, kat86@me.com, 734-778-3960,

Niles Michigan Team Hope Walk

Date: Saturday, May 14, 2016

Time: Registration begins at 9:00 am, Walk begins at 10 am, Walk Rain or Shine

Location: Riverfront Park Amphitheater, Front Street, Niles, MI 49120

Register or donate online: www.hdsa.org/thwniles

Contact: Kristine Cooney, email: Kristine.kmc@gmail.com

West Michigan Team Hope Walk & 5K Run

Date: Saturday, May 21, 2016

Time: Registration begins at 9:00 am, Walk begins at 10 am

Location: KollenPark, 240 Kollen Park Drive, Holland, MI 49423

Register or donate online: www.hdsa.org/thwwestmichigan

Contact: Chelsea Rink, email: crink914@gmail.com, 269-370-3997

HD Painting Pub Fundraiser

Date: Saturday, July 19, 2016

Information will be posted on our web site as it becomes available



Detroit/Taylor Walk For HD!



Upcoming Fundraising Events

Traverse City Team Hope Walk

Date: Saturday, August 13, 2016

Time: Registration begins at 8:00 am, Walk begins at 10 am

Location: Sunset Park, 651 E. Front Street, Traverse City, MI 49686

Register or donate online: www.hdsa.org/thwtraversecity

Contact: Jen, email: jenniferannelewis@hotmail.com. 517-879-7259



Adrian Team Hope Walk

Date: Saturday, August 20, 2016

Time: Registration begins at 10:00 am, Walk begins at 11 am

Location: Trestle Park, 302 Hunt Street, Adrian MI 49221

Register or donate online: www.hdsa.org/thwadrian

Contact: Pam, email: activities.ad.mi@magnum-mgt.com, 517-265-6554



Lansing Team Hope Walk

Date: Saturday, September 10, 2016

Time: Registration begins at 10:30 am, Walk begins at 11:30 AM ends at 12:30 PM

Location: Sharp Park, 1399 Elmwood Rd., Lansing, MI 48917

Register or donate online: www.hdsa.org/thwlansing

Contact: Dawn, email: dawnp3rry@gmail.com, phone: 517-202-8558

22nd Annual Royal Oak Team Hope Walk

Date: Sunday, September 18, 2015

Time: Registration 11:00 AM, Begins at 11:30 am, to 1 PM

Location: Center Line Memorial Park, 25355 Lawrence, Center Line, MI, 48015

Register or donate online: www.hdsa.org/thwroyaloak

Contact: Krissi Lynn, email: krissilynn18@hotmail.com, Phone 586-822-1730

Family Picnic: Bring a dish to pass and your own beverages as we will have a picnic after the walk. Hamburgers and hotdogs will be provided. It is a great place to spend time with family or meet new people. If you have any questions or would like to honor a loved one at the walk, please contact Michigan Chapter office



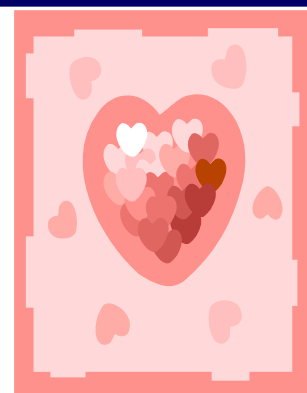
In Loving Memory

*** Louise Bolt *** Nancy A. Dehnke ***

*** Thomas Joseph Flynn *** Alvin Larsen ***

*** Mark Mikula *** David Eugene Renaud ***

*** Christina Nowakowski Wallace ***



FUNDRAISING?

It's true...fundraising is not always easy.

"We're all busy"... "time is hard to find"... "money is tight"... "I'm not very organized"... "I don't like talking to strangers"... "My family and friends get tired of me asking for help"...

These are all the things we think when we hear the word fundraising.

Dispel those myths! Here are some *easy* ways to help raise the funds that so dearly help HD families, research, and education!

- Donate a portion of your profits from your small business!
- Donate money from a garage sale
- Collect pop cans from your neighborhood for a month! (and save those pop tabs too!)
- Have a car wash! Or a Dog wash! Just need a hose, some soap and a sign! And kids can help too!

Remember, you don't always have to think BIG!
Every little bit counts!

Donations can be made securely online by going to www.hdsa.org/mi

Please help to serve all Huntington's disease families better by sending your most generous contribution possible at this time.

YOU MAKE THE DIFFERENCE!

ENCLOSE
IN
ENVELOPE
AND MAIL
TODAY

TO: HDSA Michigan Chapter
2711 Parsons Ct
Midland, MI 48642-6916

ENCLOSURE: Check or money order made payable to HDSA Michigan Chapter

_____ \$15 Individual

_____ \$25 Family

_____ \$_____ Additional gift amount to help in the fight against HD

Donations can be made securely online by going to : www.hdsa.org/mi

HDSA MICHIGAN SUPPORT GROUP MEETINGS

AREA	WHEN	WHERE	CONTACT
Greater Genesee County Area	1st Monday 7:00 pm (2nd Monday in September due to Labor Day)	Woodhaven Senior Community G-5201 Woodhaven Ct Flint MI 48532	Jean or Barb 810-659-4548
Kalamazoo	Monthly Meetings Through May, Nights Varies, 6:00 pm (Check with Coordinator for Days) March 15th, April 21st, 2016	First Congregational Church (New Address) 345 West Michigan Ave Kalamazoo MI 49007	Sara 269-381-7725
Lansing (New Location)	Varies so please Check the web site for dates 7:00—8:45 PM	Beacon Counseling 2840 E. Grand River Ave. Suite 5 East Lansing MI 48823	800-909-0073 Facilitated by Janet Howes
Living Positive Support Group Grand Rapids -Ada	2nd Thursday 6:30-8:30 PM Day does vary some (For Gene Positive and at Risk Individuals)	Psychotherapy and Consultation Offices 967 Spaulding SE, Suite E Ada MI 49301	Kathy Delp at 616-581-3085 Kath6613@aol.com
Macomb County Caregivers Group	2nd Tuesday 7:30 pm	4571 Reflections Drive Sterling Heights	Deanna (Dee) 586-997-3089
Mt. Pleasant	2nd Tuesday 7:00 pm No Meetings July, August	Coldwell Bankers, 304 East Broadway, Mt. Pleasant MI 48858	Galen 989-245-5725 Dave 989-496-3273
Royal Oak	3rd Saturday Quarterly 1-3PM April 16, 2016 July 16, 2016 November 19, 2016	Wm. Beaumont Hospital Administration Building Conference Room A/B/C 3601 West 13 Mile Rd.	Karen 586-201-2307 Krissi 586-822-1730
Tri-Cities Area Location will change	1st Thursday (may change depending on Attendance) 7:00 pm No March, July or August Meetings	Saginaw Township Fire Dept. Station No. 3 153 N. Center Rd Saginaw MI	Ruth 989-835-9933 Dave 989-496-3273
Traverse City	Last Saturday of the Month 10AM—Noon Feb 27, March 26 2016 Facilitated by: Kathy Martin MA, LPC, CAC-R	Traverse Area District Library 610 Woodmere Ave, Thirlby Room Traverse City, MI 49686	Office 1-800-909-0073 <i>Please call the office if you plan on attending for information.</i>

The Michigan Chapter's Patient and Family Services Committee presents The Caregiver's Corner.

WHO CARES ??? WE DO !!! THEY DO !!! READ ON !!!

Friends, we will post caregiver's stories that will show you that "THEY DO CARE".

Please call us, e-mail us, fax us, or write us with your stories so we can post them on the website. 800-909-0073, hdsami@att.net, fax 517-827-4950. HDSA Michigan Chapter, 2711 Parsons Ct. Midland, MI 48642-6916



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HDSA Michigan Chapter
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CHAPTER HELPLINE:
(800) 909-0073

CHAPTER OFFICE:
(989) 832-4170

FAX: (517) 827-4950

**WEB: www.hdsa.org Click on MI
Chapter or go directly to our
Chapter Web Site by going to:
www.hdsa.org/mi**

CHAPTER OFFICERS

PRESIDENT:
Donna Spencer

VICE PRESIDENT:
Kelly Kennelly

SECRETARY:
Katrina Walker

TREASURER:
David Stickles



"BRIDGES OF HOPE"

Editing and Publishing Team:
Dave Stickles
Krissi Putansu
Donna Spencer

Printing and Mailing:
Tigner Printing,
Coleman, MI

Article inserts & ideas may be sent to
dstick44@chartermi.net or
hdsami@att.net

This newsletter is an official publication of the Michigan Chapter of the Huntington's Disease Society of America, 2711 Parsons Ct, Midland, MI 48642-6916.

This newsletter attempts to report all items of interest relating to individuals with Huntington's Disease, their families, health care professionals and interested friends and supporters. HDSA and the Michigan Chapter do not provide medical advice, nor do they promote, endorse or recommend any product, therapy or institution. Please check all drug treatments, therapies and products with your physician. Statements and opinions expressed in articles are not necessarily those of HDSA or the Michigan Chapter.