



Huntington's Disease
Society of America



Michigan CHAPTER



BRIDGES OF HOPE

June 2015

WORDS OF HOPE:
"WHEN YOU ARE FACE TO FACE WITH A DIFFICULTY,
YOU ARE UP AGAINST A DISCOVERY"
LORD KELVIN

VOLUME 1 ISSUE 42

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HDSA Michigan Chapter, 2711 Parsons Ct, Midland MI 48642-6916. The Help line Number is 1-800-909-0073, the Chapter's business number is 989-832-4170, and the fax number is 517-827-4950, E-Mail: hdsami@att.net, and the web site address is www.hdsa.org/mi Please note Mailing address.

In my past president's letters to you, I have introduced the board, discussed multiple ways to be involved, provided national convention research updates as well as expressed my gratitude to many individuals. This month, I would like to highlight just some of the many milestones that have taken place over the past five years through your HDSA, Michigan Chapter board.

Through our annual application process, we have sponsored five families by funding them to cover costs associated with attending the HDSA National Convention. This is always joyful for the board so we can share the good news with a family, they are always elated, and they can attend a wonderful convention experience that they wouldn't have otherwise been able to attend. It feels great to give back to our families in the HD community and often these families will volunteer their time upon their return from the event. Each family has shared that they are changed positively after attending. National convention scholarships can now be applied through HDSA National, Lundbeck, and HDSA MI Chapter for those living in Michigan.

It has been exciting to watch our fundraisers and Team Hope Walk locations grow; some have increased financially and some events such as Hoops for Huntington's by the Hathaway Family and Spotlight on a Cure were added. Another event that our Vice President, Dave Stickles is passionate about is our annual HD Circle of Friends Camp which supports many individuals with Huntington's Disease and provides them a welcoming environment and fun activities for a week. We have many ongoing events; please check the newsletters to keep up to date on those in your area!

Our board has held a theme of "education and community" and in order to support this ongoing goal, we have put on four state conferences. Our most recent MI State Conference was held in Lansing and provided strong education to our local HD community thanks to Janet Howes, our warm and caring Social Worker whom we interviewed and hired in 2014. Thank you to the many informative speakers we had including two of our board members Dr. John Kamholz and Kelly Kennelly; they spoke about research progression and genetics counseling. Another board member, Kathleen Samulski gave a solid workshop surrounding advocacy. To keep in line with the educational and community themes, two new support groups have been added as well. We now hold support groups in Traverse City and Jackson; please see the last page of the newsletter for support group meeting details.

Development and growth has been important to our board and we have grown by including more professional members each year. We named the new treasurer in 2015 as Donna Spencer. This board has accomplished goal after goal and we meet in person annually, often at my home, to brainstorm, review the budget, and strategic plan. Throughout the year, we meet monthly via telephone conference to discuss agenda items, hot topics, and vote on pressing matters. It has been one of my objectives to build relationships with HDSA National to ensure we align with their goals as well as developing others for upcoming leadership roles.

Please reach out to me or any board member directly, if you are interested in volunteering your talents for a top performing team. I am looking forward to national convention this month and providing a research update to those who could not attend this great annual event.

Hugs, Krissi Putansu, HDSA MI Chapter President, (586) 822-1730

DAY at the LAKE for HD FAMILIES AND FRIENDS

Saturday, August 1, 2015

2:00 PM to Dusk

Handicap Accessible — All are Welcome !!!!

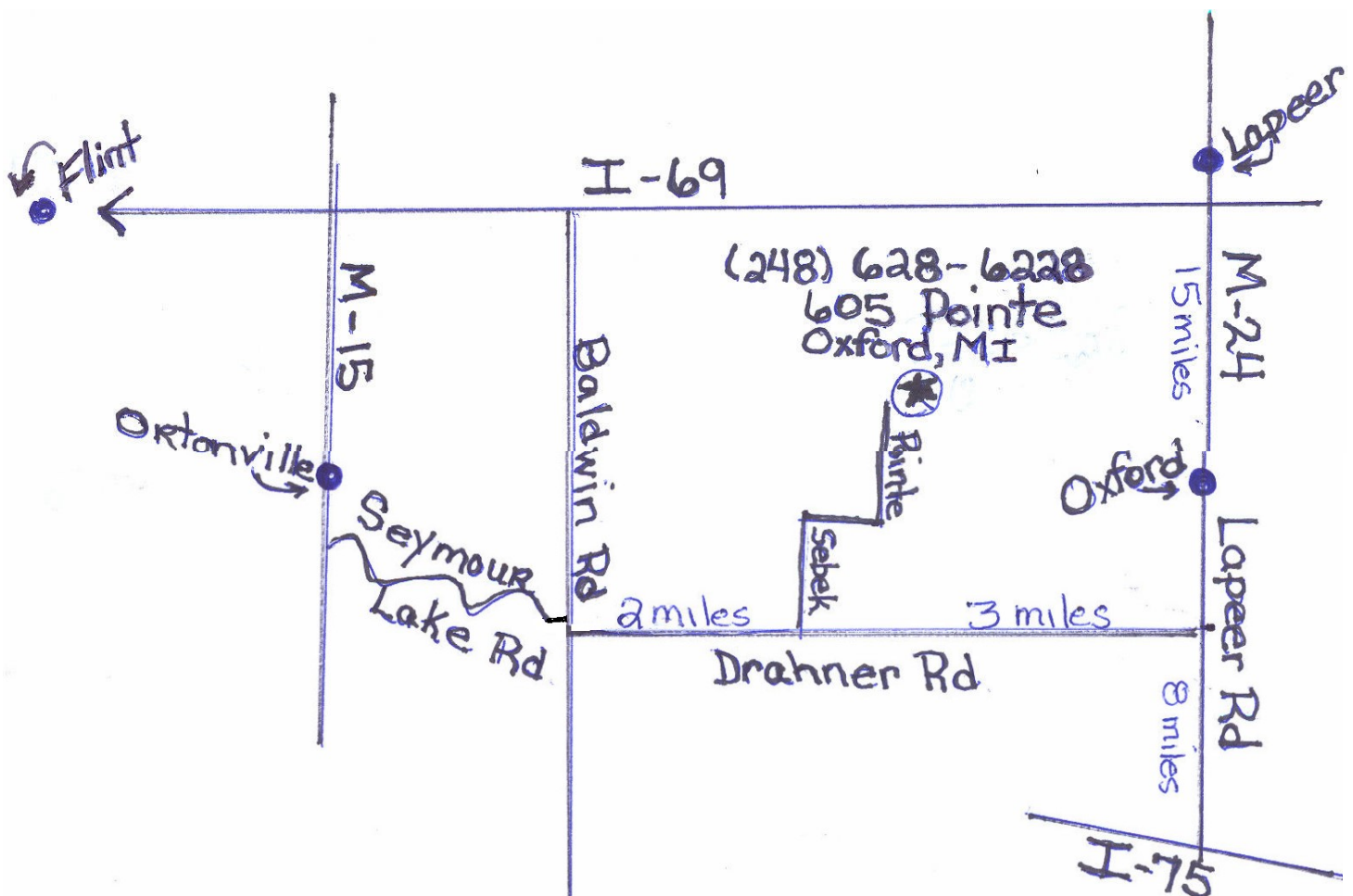
At the home of Dick & Peggy Reddaway

605 Pointe Drive, Oxford, MI 48371 (248) 628-6228

Come early for swimming, boating & fishing Bring your swimsuit, towel, jacket & sunscreen

Stay late for bonfire — Bring your guitar !! B.Y.O. - Cans or Plastic Bottles only !

Dinner at 4:00 PM (meat provided) Please Bring A Dish To Pass, and beverage !!!





12th Annual Royal Oak



Bowl For HD!

Who? For our loved ones with Huntington's disease

What? Royal Oak Bowling Fundraiser

When? Friday August 7, 2015 at 7 pm

Where? Imperial Lanes – Hall Road (M 59) &
Garfield in Clinton Twp.



44650 Garfield Road, Clinton Township, MI 48038

Why? To raise funds to support HDSA's fight to improve the lives of people affected by Huntington's disease.

How much? **\$25*** each will get you 2 games of cosmic bowling, shoes, & pizza/pop And one entry into a raffle of your choice!

After Party: A Rockin' band/ Karaoke will take place in Imperial's bar after

Contact Info: Please pre-register; call Krissi Putansu at (586)822-1730 or email at krissilynn18@hotmail.com

- *Checks should be made payable to HDSA – Michigan Chapter (all profits and donations go directly there).*

For More Information, go to www.hdsa.org or www.hdsa.org/mi.

THANK YOU FOR YOUR SUPPORT IN FINDING A CURE FOR HD!

WALK THIS WAY FOR HDSA!



Walk For HD!



Traverse City Team Hope Walk For Huntington's Disease

Saturday August 15, 2015

www.hdsa.org/thwtraversecity

**Sunset Park
675 E. Front Street
Traverse City, MI 49686
10:00 am Walk**



Walk Check-In: 8 – 10 a.m.

Contact: Jennifer Lewis

Phone: 231-649-1254

Email: jenniferannelewis@hotmail.com



Featuring: Raffles, Kids Corner, Fun with family and friends!

To sponsor the walk or donate a basket to the raffle, please contact Jennifer!

We walk rain or shine!





Royal Oak Walk For HD!

Lundbeck



- Who?** Everyone, For our loved ones with Huntington's disease
- What?** This is the 21st annual Royal Oak Walk for Huntington's Disease, Center Line MI
- When?** Sunday September 20, 2015 at 11:00 AM—1:00 PM
- Where?** Center Line Memorial Park, 25355 Lawrence, Center Line, MI, 48015

*** Please note this is a location with a paved walk-way

Why? To raise funds to support HDSA's fight to improve the lives of people affected by Huntington's disease.

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 at 989-832-4170.

In memory of all of our loved one's who have passed away.

"Let this be the LAST GENERATION of Huntington's Disease"

Start getting donations now - if you bring in a donation you will receive a T-shirt. Together, we can raise funds to bring help for today and hope for tomorrow to everyone affected by HD. We have again seen some big strides in medical treatments so let's keep that momentum going! This is not a pledge walk, but a donation walk. There is no set distance, as people's abilities are varied. Each person may walk however far is comfortable for them. Bring your friends and family! This is a fun event for all! Thank you in advance for spreading the word and promoting these events. We are looking forward to record turnouts!

Checks should be made payable to HDSA – Michigan Chapter (all profits and donations go directly there). Secure online donations can be made at:

www.hdsa.org/thvroyaloak

If paying by cash please fill in your return address on the donation/membership sheet on page 17 and bring it with you to the walk, or checks may be mail in if you can't attend.

For More Information on HD, go to www.hdsa.org or www.hdsa.org/mi.

 **AUTUMN WOODS**
HEALTH CARE FACILITY

**THANK YOU FOR YOUR SUPPORT
IN FINDING A CURE FOR HD!**





HDSA Presents... ***Are you ready for some football?***

The Raffle of Two 2015 Season Football Tickets to the University of Michigan's

BIG HOUSE

(Sec. 21 Row 36 Seats 3-4)

Raffle tickets are \$100 each.

For every two tickets you buy at \$100 each,

.....you will receive a third free!

Only 120 raffle tickets will be sold.

The winning ticket will be drawn on **August 28, 2015**

All Proceeds Go To Support Research, Education & Support For HD Families

Go Blue !

Purchase Raffle Tickets Online Today!

To purchase a raffle ticket online for a chance to win the pair of U of M Season Football Tickets go

to: www.hdsa.org/goblue

We will e-mail you a copy of your ticket for verification

or contact Deb Boyd at dboyd@hdsa.org or 269-629-5452

(Many thanks to the Wagamon family for their 2015 season tickets)



HD Circle of Friends Camp

The Michigan Chapter will once again be sponsoring a circle of friends camp at Camp Fish Tales in Pinconning Michigan. This is a camp that specializes in running summer camp programs for people with various disabilities. It will start the afternoon of August 2, 2015 and finish up at around noon on Friday August 7, 2015.

If you have a loved one who is in the mid-stages of HD and still ambulatory and you think they would enjoy a week of camp experience, please call the chapter helpline at 1-800-909-0073 or email us at hdsami@att.net, and we will send you an application packet when they are ready in June. This week of camp also give the caregiver a week of respite, and time for themselves to catch up on things that are difficult to do while care giving for someone full time.

Dave Stickles

Some of the suggestions I have for living with HD are: *Keep life simple - Rest, Exercise, Nutrition, A daily laugh, *Carry earplugs with you when you are out, (Some people with HD are sensitive to noise), *Carry calendars with you to write down everything you must do for the day and any information you get from other people, *Develop a message center in your home, so other family members have an idea where to look for stuff, *Use an answering machine so you can rewind the tape and recheck those messages (One of the symptoms of HD is transposing numbers), *Use sticky 3M note pads to keep your place in cookbooks - also works in crochet or knitting patterns, *Use one color of paper for phone messages, *Have a check-list on the front door so you can make sure you have keys, etc., *Rewrite recipes so they have a numbering system, (1. Cut vegetables, 2. Spray pan, etc.), *Try to do the same task on the same day of each week (Wash on Tuesday, etc.), *Get a watch with an alarm clock and set the alarm to remind you to catch bus, leave for doctor's appointment, etc., *Listen to relaxing music By Heather Pratt

We're Going Green !!



To help cut the cost and become more environmentally friendly we are updating our mailing database! Please fill out the reverse side of this sheet stating you would like to receive a paper copy at your address. To receive an electronic copy please return the form with your email address. Electronic copies can also be found on our web site. Please mail back the completed form or email the information to hdsami@att.net. Thank you!!

We Moved our office:

HDSA Michigan Chapter, 2711 Parsons Ct, Midland MI 48642-6916
Office Phone 989-832-4170, Helpline : 1-800-909-0073, Fax 517-827-4950
Email: hdsami@att.net Web Site: www.hdsa.org/mi

Paper Recycling Fundraiser—PaperGator

Raising Money for

Huntington’s Disease Society of America Michigan Chapter

PaperGator Bin is Located at Four Seasons Yard and Sports Equipment

5426 Alpine Avenue

Comstock Park, MI 49321

What can go in the bins: Newsprint, Catalogs, Magazines, Junk Mail, Phone Books, Office/School Paper

What can’t go in the bins: Plastic, Metal, Trash, Glass, Cardboard

Peace does not mean to be in a place where there is no noise, trouble, or hard work. Peace means to be in the midst of all those things and still be calm in your heart. Unknown

No act of kindness is too small. The gift of kindness may start as a small ripple that over time can turn into a tidal wave affecting the lives of many. Kevin Heath

Caring can be learned by all human beings, can be worked into the design of every life, meeting an individual need as well as a pervasive need in society. Mary Catherine Bateson

We’re Going Green !!

Please send HDSA Michigan Chapter

Publication and information to my:

☐ Email Address

Name: _____

Email: _____

☐ Current Address

Name: _____

Address: _____

☐ Remove my information from the mailing List

HDSA Michigan Chapter

2711 Parsons Ct

Midland, MI 48642-6916

Upcoming Fundraising Events

Kalamazoo — Strike Out HD 2015

Date: Friday, July 17, 2015

Time: 6:00 PM game begins at 7 pm

Location: Kalamazoo Growlers Homer Stryker Field, Bells Bear Cave

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

Contact: Deb Boyd, email: dboyd@hdsa.org

Tickets — Adults -\$50, kids 12 and under—\$30. kids 4 and under.— free, includes dinner.

Royal Oak Bowling

Date: Friday, August 7, 2015

Time: 7:00 PM

Location: Imperial Lanes – Hall Road (M 59) & Garfield in Clinton Twp.

44650 Garfield Road, Clinton Township, MI 48038

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

Traverse City Team Hope Walk

Date: Saturday, August 15, 2015

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/thwtravercity

Contact: Jen, email: jenniferannelewis@hotmail.com

Adrian Team Hope Walk

Date: Saturday, August 21, 2015

Time: Registration begins at 9:00 am, Walk begins at 10 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 19, 2015

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: DawnP@impactsolution.net, phone: 517-202-8558

Royal Oak Team Hope Walk

Date: Sunday, September 20, 2015

Time: 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 386-822-1730

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 print caregiver's stories that will show you that "THEY DO CARE".

You will agree that ""THEY DO INDEED CARE" and are doing fantastic jobs as Caregivers. Our aim in future Newsletters is to bring you stories from people who really care and are doing marvelous jobs as Caregivers for their loved ones.

Please call us, e-mail us, fax us, or write us with your stories so we can publish them in future Newsletters. 800-909-0073, hdsami@att.net, fax 517-827-4950. HDSA Michigan Chapter, P.O. Box 21037, Lansing MI 48909

HD Living Positive Group Invites Participants to Join!

Individuals who test positive through Pre-Symptomatic Testing Programs for Huntington disease and those living-at-risk often feel isolation and uncertainty about their future. Traditional HD Support Groups often are inadequate to address the immediate needs of these individuals who are coping with the challenge of deciding about whether to be tested or how to live in relationships at work and in their personal lives after testing positive. These individuals often are not showing any clinical symptoms. In 2011 an HD Living Positive Group was started in Grand Rapids Michigan to meet this need for those who test positive and/or are living-at-risk. The HDSA Michigan Chapter provides financial support for a monthly group that meets at a private psychotherapy practice location. A brochure was developed to include the topics for discussion. The facilitator is a clinical social worker and a certified genetic counselor. A total of 18 individuals have attended one or more groups. Structure for the meetings includes a talking stick for introductions and for closing. Confidentiality is discussed to provide a trusting environment for everyone to share their personal concerns. Current newsletters and other educational materials are provided. Some of the topics discussed include how to "live positive" following test results, how to prolong the onset of symptoms, the benefits of meditation and exercise, the use of alternative therapies, the challenge of losing the independence of driving, who to tell and how to tell of test results, how to prepare young children and adolescents for HD in their lives, the difference between unawareness and denial, how to navigate the dual roles of being gene positive and a caregiver, how to support one another, and how to deal with the secrecy and stigma of HD. For more Information go to this website and click on Brochure: www.kathleendelp.com or call Kathleen at 616-581-3085



A potential drug targeting the HD gene

The announced clinical trial represents a collaboration between California-based Isis Pharmaceuticals, and the Swiss pharmaceutical giant Roche. The drug, called ASO-HTT-Rx, is a therapy that aims to treat HD by targeting the mutant gene itself.

The core of the problem in HD lies in a faulty stretch of DNA—an extra long stretch of CAG building blocks within the huntingtin gene. The instructions contained in the mutant gene are first copied into an intermediate ‘messenger’ copy, from which the harmful protein is made. So, the mutant gene is the root of the problem, but it’s only bad because cells use the information in the gene to make a harmful protein.

The strategy behind ASO-HTT-Rx is to “shoot the messenger,” attacking the intermediate step between gene and protein by causing the destruction of the messenger copy.

These types of drugs are called ‘antisense oligonucleotides’, or ASOs. They’re a synthetic DNA-like molecule that can enter cells, stick to the mutant huntingtin RNA message, and cause its degradation. If it works as predicted, this therapy will stop huntingtin protein from being made—a “huntingtin lowering” strategy that, in the long term, has the potential to slow or to halt disease progression.



Great Baseball! Great Food! Great Fun! Great Cause!

proceeds go to benefit the
Huntington's Disease Society's Great Lakes Region



Adult Ticket Prices - \$50
Kids 12 & under - \$30
4 & under - FREE

JOIN US: Friday, July 17, 2015
Time: 6:00 PM (Game starts at 7 PM)
Where: Kalamazoo Growlers Home - Saylor Field - Bell's Bear Cave
Tickets: e-mail sheryl@hdsa.org
Online: www.HDSA.org/growlersonline



Tickets include: Cookout Dinner - awesome view of the game at the **Bell's Bear Cave** with unlimited VIP beverages
We will also have • Silent Auction • Raffle • Fireworks & so much more!

Clarence Hector Caverly	You dropped out of high school	Making purses, hats and wallets
On September twenty-seventh	In nineteen forty-nine,	To store that precious loot.
Of nineteen thirty-one	You joined the U.S. Navy	You worked for Bradley Transportation
God placed you in your mother's arms	And they kept you for a time.	Then later took a test
For you, life had just begun.	Hector, you were called	To land a job with the State of Michigan
You joined sisters Phyllis and Margaret	You served your country well	At the Power plant you did your best.
Brothers Lee and Richard too.	And as any other military man	In 1973 you passed a test
And baby brother Edwin	Oh, the stories you could tell.	Earning your G.E.D.
Who was taken way too soon.	From learning to tie knots	This would land you a job
Born in Mt. Morris to	An Mr. Fixit too,	working on boilers
William and Margaret C.	Why Hec there wasn't any job	To take care of your family.
You were the perfect addition	Too big or small for you.	You purchased with your in-laws
To the Caverly family.	You met a gal named Jean	Property on Grass Lake
Your daddy was a fine man	Who was soon the love of your life.	Later on this became your home
His family held his heart.	In July of nineteen fifty-four	With the additions you would make.
When times got rough	Jean became your wife.	Joining the V.F.W.
he moved you north	Unto this happy union	Was a busy time for you,
To make a brand new start.	The two of you were blessed	Working fish fry's,
He had worked the milk route	With three beautiful daughters	Attending meetings
And later on twas best	Life was at it's best.	Playing Taps when you needed to.
To take a job with C.C.C. Camp	Dawn was born in fifty-five,	Family was important
In your family's best interest.	Sue in fifty-seven,	You taught your daughters well.
He rented a two story home in Vanderbilt	Then in nineteen sixty-one	How to change their oil or change a tire
To give your family shelter.	Carol was sent from heaven.	Drive a car or just sit for a spell.
It was breezy in the winter	You loved wood Grafting and leather,	Camping trips and cooking breakfast
And in the summer you would swelter.	Country music, cowboy boots,	Some of the things you'd do

Everyone loved your pancakes	Camping trips to Two Heart River,	On June the ninth
And spending time with you.	Blueberry picking in the U.P.	Of two thousand and fourteen.
Snowmobiling with the family	Visiting Tahquamenon Falls	Jesus whispered "Come home Hector"
Going through the woods,	Created such good memories.	It was a heavenly dream.
Trips out west with the popup	Sometimes getting stuck in	Jesus was waiting there
Making memories, always good.	The long driveway	With His arms open wide
Walking Carol down the isle	Trying to get back to camp.	And standing there beside Him
Just twenty years ago.	You boys just tired yourself out	Was Jean, your lovely bride.
A precious time in her life,	And ended up cold and damp.	The taps will play another time
An image she'll hold close.	Hector, you lived a full life	And we'll always think of you
You made a harness for Puddles	You taught many people many things.	And how you played so proudly
Dear dog of Tracey and Curt.	You showed them the joy	For those gone before you.
You even put his name on it	Being part of a big family brings.	Love Dawn

Auspex Pharmaceuticals Plans Phase III Clinical Trial for Chorea in HD Patients

Auspex Pharmaceuticals is a small biotechnology company based in La Jolla, CA. Auspex's unique approach to developing therapeutics is to incorporate deuterium (a non-radioactive, non-toxic, naturally occurring form of hydrogen) into the molecular structure of existing FDA approved drugs.

The rationale and hope for this is that the substitution of deuterium for hydrogen at specific locations on a drug will reduce the drug's rate of metabolism, or breakdown, by enzymes in the liver. Decreased metabolism could increase the length of time a dosage has an effect without changing the drug's mechanism of action. As a result, lower doses and less frequent dosing, possibly leading to improved safety and convenience than the original drug formula.

Auspex's lead compound, SD-809, is a deuterium-substituted analogue of tetrabenazine (Xenazine), the only drug currently approved in the United States for the treatment of Huntington's chorea. Both tetrabenazine and SD-809 work by inhibiting the vesicular monoamine transporter 2 (VMAT2). VMAT2 is responsible for priming small synaptic vesicles with the neurotransmitters, dopamine and serotonin so that they can be released into the synapse as needed by the body. Treatment with a VMAT2 inhibitor will prevent these neurotransmitters from being packaged and result in decreased synaptic dopamine levels. Lowering the levels of synaptic dopamine is thought to improve the chorea commonly associated with HD.

SD-809 is expected to enter Phase III clinical testing in April 2013 to determine whether is effective in the treatment of chorea. Auspex hope plans to recruit 90 participants in all, across 30 different research sites across the US and Canada. 45 people are expected to receive SD-809 and 45 are to serve as placebo controls.

For more information on this trial visit Clinical Trials.gov website at: <http://clinicaltrials.gov/ct2/show/record/NCT01795859> and check back on the HDSA website research section for news and listings of trial sites as they come online. To receive email notices for this upcoming trial, or any HD clinical study or trial, please register at HDTrials.org.

A Legacy Lives On

Celebrating the Life of Ryan J. Currie

By Kathleen J. Delp, LMSW, CGC



Born 1-29-63

Died 4-18-15

It's a Long Way to the Top - AC/DC

It's a long way to the top if you wanna rock 'n' roll
It's a long way to the top if you wanna rock 'n' roll
If you think it's easy doin' one night stands
Try playin' in a rock 'n' roll band.
It's a long way to the top if you wanna rock 'n' roll

Ryan's favorite band was the Australian rock group AC/DC. He loved jammin' to their music for many years, even up to the time of his death at age 52.

Ryan lived with Huntington Disease for the past 20 years experiencing a slow but steady decline in his physical and cognitive function. He was a resident at the Cherry Hill Haven Assisted Living Facility in Traverse City for the past 3 years.

Ryan competed in track at Alma High School with his buddies, and they ran the 440-meter relay, setting the record for the high school which still stands today. His teammates visited Ryan at his home and one time they gave him the baton from the relay with a special note inside for Ryan, but he was told to wait to open it. What that note said, no one knows, but Ryan and his fellow teammates.

Ryan was the youngest of three siblings: Jan, a sister who died of HD at the age of 50 from a choking accident; Greg, who was fortunate to be gene negative; and Ryan, the youngest, who showed very early signs as young as 32. Ryan worked as a salesman for the family business, Currie Furniture, in Traverse City, until his handwriting became difficult to read and his cognitive decline interfered with his ability to remain in sales. His job description changed to furniture assembler in the store, and then to maintenance at the store and warehouse. Unaware of any changes in his abilities or limitations, he could climb 14' ladders to change light bulbs while his brain switched to his non-dominant hand to complete this task. Never really feeling affected by HD, Ryan would say, "I am going to get sick when I get old."

Greg and Karlene, Ryan's brother and sister-in-law provided an apartment for Ryan within their home on Silver Lake. Ryan was a neat-nick and loved orderliness. His routine consisted of doing laundry every Saturday and detailing his car on Wednesdays, his day off. It might take him all day, but he took such pride in his pristine vehicle.

Ryan maintained his independence as long as he could and often cared for their dogs, and even taught their dogs, Cody & Lilah, tricks like rolling over. When his health declined he was able to stay in his apartment for three more years with the assistance of the Comfort Keepers, who made home visits to prepare his food, assist with bathing, dressing and grooming, like shaving. In preparation for an eventual transfer to an assisted living, Ryan with Greg and Karlene, visited several facilities to determine the best fit for Ryan three years prior to his transition from his apartment to a residential setting.

Ryan was frugal and saved and invested as much of his income as he could. His savings provided care for him at Cherry Hill Assisted Living in Traverse City. As Ryan was the youngest resident there at age 48, Greg and Karlene requested his room be close to the commons area so he could kid around with the nursing staff and have immediate exposure to the daily activities within the nursing home where he lived the last three years of his life. The close proximity to their home and business allowed Greg and Karlene to visit Ryan often. Their walks outside with Ryan in his wheelchair allowed him enjoy the warmth of the sun and the fresh breeze on his face in the presence of Mother Nature.

Greg described Ryan as a "really nice guy," and Greg expressed a brother's love and devotion for Ryan his whole life. And Ryan loved when Greg would give him a haircut, like their dad used to do. But a testimony to Ryan's life would be totally inadequate without paying tribute to Greg's wife and Ryan's sister-in-law, Karlene, as she gave of herself tirelessly as caregivers often do, to make sure Ryan always had his correct medications, managed his medical appointments, and made sure he had clothes he liked that met his needs and desires.

It was Karlene who was there when Ryan took his last breath as Greg was out of town on business when Ryan took a turn for the worse. Ryan's health took a downhill course the last six months of his life with rapid weight loss in the two months prior to his death. Hospice was called in just the day before he died. Father Ken was called by cousin, Pete, to provide that Last Rites. While his death was not unexpected, he took his last breath before Greg could return from his business trip.

It was Ryan's desire to divide his remaining assets to his niece, Corey, and to National HDSA, and specifically to the HDSA-Michigan Chapter for the development of an HD Living Positive Support Group in Traverse City. For many years, the Curries sponsored annual golf outings in Traverse City to benefit HDSA of Michigan. Ryan inherited his generosity and giving nature from his family, as well.

Just as Ryan accepted the life he was given, the joys along with the suffering, he accepted his death with grace and humility and without struggle. Greg got to talk with him one last time on the phone to say goodbye and to tell him he loved him. Ryan took his last breath peacefully with those loving dogs, Cody & Lilah, by his side. And now Ryan is experiencing what it feels like to "be on the top if you want to rock and roll." Rock and roll all you want Ryan. Your legacy lives on.

In Loving Memory

Christopher Bohnett

Debra Wasylewski-Burge

Dennis Burge

Geraldine Burton

Gail A. Clazie

Ryan J. Currie

Leon Fickel

Howard W. Roe

*To Those I Love and Those Who Love Me
(Author Unknown)*

When I am gone, release me, let me go,
I have so many things to see and do,
You mustn't tie yourself to me with tears.
Be happy that we had so many years.

I gave you my love, You can only guess,
How much you gave to me in happiness.
I thank you for the love you each have shown,
But now it is time I travel alone.

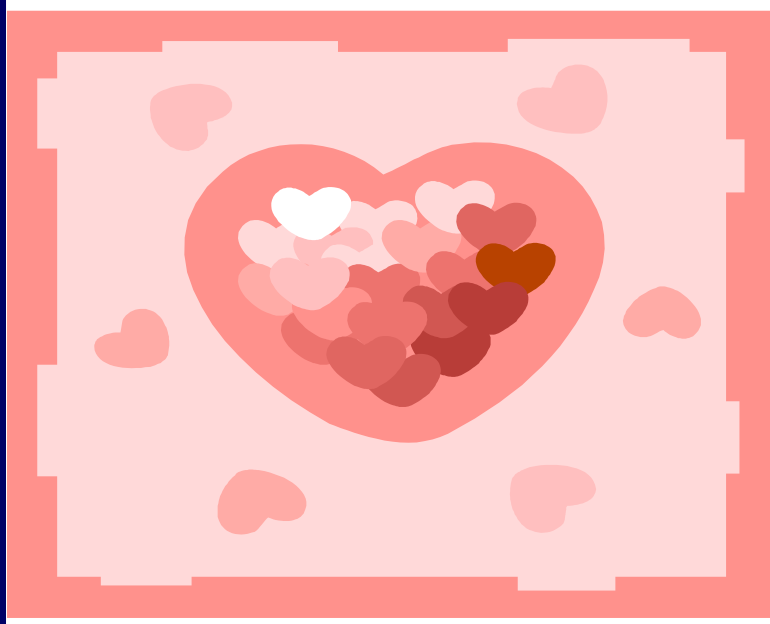
So grieve a while for if grieve you must,
then let your grief be, comforted by trust.
It's only for awhile that we must part,
so bless the memories within your heart.

I won't be far away, for life goes on.
So if you need me, call and I will come.

Though you can't see or touch me, I'll be near.
And if you listen with your heart, you'll hear,
All of my love around you, soft and clear.

And then, when you must come this way alone,
I'll greet you with a smile, and say,.....

"Welcome Home"



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/mich/midon.html

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/mich/midon.html

HDSA MICHIGAN SUPPORT GROUP MEETINGS

AREA	WHEN	WHERE	CONTACT
Battle Creek (New)	Second Tuesday 6:30-8:00 PM	St. Philip's Catholic High School, 20 Cherry St., Battle Creek, MI 49017	Office 1-800-909-0073
Grand Rapids & Western MI By Appointment	Fourth Wednesday Quarterly 6:30-8:00 PM January, April, July, October	St. Mary's Neuroscience Center , Hauenstein Quiet Room 220 Cherry Street SE Grand Rapids MI 49503	Dave 800-909-0073 Please call if you would like to attend
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)	First Congregational Church 129 S. Park Street Kalamazoo MI 49007	Sara 269-381-7725
Lansing (New Location)	Varies so please Check the web site for dates 7:00—8:45 PM Next meeting 7/23/15	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 (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
Jackson Area	Thursday March 5th, 7 PM	Ashton Ridge Apartments Clubhouse, 2907 Ashton Ridge Drive Jackson, Michigan 48201	For Information Call Elton Higgs 517-612-2404
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 2015, July 18, 2015 November 21, 2015	Wm. Beaumont Hospital Administration Building Conference Room A/B/C 3601 West 13 Mile Rd.	Karen 586-201-2307 Krissi 586-822-1730
Taylor or Downriver	Currently Inactive - if you are interested in attending please contact us so we can determine interest	TBD	Chapter Office 989-832-4170
Tri-Cities Area Location will change	1st Thursday (may change depending on Attendance) 7:00 pm No 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	Starting up a new one hopefully in September, we will post information on the chapter web site hdsa.org/mi	Still working out final details	Office 1-800-909-0073 Please call the office if you plan on attending for information.

HDSA MICHIGAN SUPPORT GROUP MEETINGS

Grand Rapids & Western Michigan—Fourth Wednesday Quarterly, July, October, January, By appointment only, Please call 1-800-909-0073 if you would like to attend a meeting.

Greater Genesee County—1st Monday of the month, except 2nd Monday in September due to Labor Day, No Meetings, July, August, January

Jackson Area - New Support Group, First meeting March 5th at 7:00 PM, Then 1st Thursday Monthly at 7:00 PM. Ashton Ridge Apartments Clubhouse, 2907 Ashton Ridge Drive Jackson, Michigan 48201, contact Elton Higgs 517-612-2404

Kalamazoo— Monthly Meetings through May, nights varies each month, check with Sara. No Meeting in July or August.

Lansing—Varies each Month, please Check web site or call, next meeting 7/23/2015.

Living Positive Support Group, Grand Rapids/Ada— 2nd Thursday from 6:30 –8:30

Mt. Pleasant - 2nd Tuesday of the Month, No July or August meetings,

Royal Oak- 3rd Saturday quarterly, 1-3 PM, April 18, July 18, 2015 & November 21, 2015

Traverse City— New Support Group Starting in September Time & Location TBD, check web site www.hdsa.org/mi or call helpline 1-800-909-0073 near the end of August for info.

Tri-City -1st Thursday of the Month, No January, February, March, July or, August meetings.

FOR YOUR INFORMATION:

What you need to bring with you for your Social Security Disability Interview

- An original or certified copy of your birth certificate
- Proof of U.S. citizenship or legal residency if born in a different country
- Original or certified copy of your discharge papers for all periods of active duty in the military
- W-2 form from last year
- If you were self-employed, your federal tax return (IRS 1040, Schedules C & SE)
- Workers compensation information, including date of injury, claim number and payment amount
- Social Security Numbers of your spouse and children
- Name, address and phone number of a person who can get in touch with you if necessary
- Names, addresses and phone numbers of all doctors & other treating sources
- Dates seen by each treating source
- List of medications you are taking
- Medical records in your possession
- Kind of jobs and dates you worked in the 15 years before becoming disabled
- Doctors or Neurologists HD diagnosis, the more thorough and better this is the more likely the disability will go through the first time.

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

***ADDRESS SERVICE REQUESTED ***

**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**

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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