



BRIDGES OF HOPE

*Words of Hope:*  
 "When you are face to face with a difficulty,  
 you are up against a discovery"  
*Lord Kelvin*

Volume 1 Issue 28

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HDSA Michigan Chapter has moved, the new address is: HDSA Michigan Chapter 1174 James Savage Road, Midland MI 48640. The Helpline Number remains the same (800) 909-0073. The Chapter's new business number is 989-832-4170 and the new fax number is 989-832-4171. So please make note of those changes.

The HDSA Michigan Chapter held its Annual State Meeting in September. Guest speakers were Dr. James Garbern of Wayne State University who gave a talk on The Neurology of HD, and Dr. Gary Dunbar of Central Michigan University who gave an Update on HD Research. Both talks were excellent and well received, my thanks to both presenters.

Officers for HDSA Michigan Chapter for 2007-2008 are President Dave Stickles, Vice-President Kurt Davis, Treasurer Cheryl Heinzman, and Secretary Christine Salewsky. There were no new nomination to the board.

In December the Michigan Chapter contracted a new Social Worker/Patient and Family Services Coordinator, Danny Berry. Danny is a graduate of Saginaw Valley State University and has his State of Michigan Social Worker licensed. Danny will be working out of the Midland Office. Danny has been hard at work learning about HD, reading literature, viewing HD video's, visiting HD web sites, viewing In-Service Powerpoint presentations, and setting in on answering the Chapter Help-line for the last month and a half. Danny has most recently started to answer the Help-line voicemails and e-mails. Danny has been involved with one office consultation and one court hearing for a person with HD, and he has attended two Tri-Cities Area Support Group Meetings. Danny has also been updating information in his HD Resource Guide; List of Nursing home in the State of Michigan, list of Genetic Councilors and Neurologist, and several other items in the Resource Guide. More information on what a Chapter Social Worker can do for you and an introduction from Danny is on page 2 of the Newsletter. I would like to give Danny a warm welcome to the Michigan Chapter and I hope all of you will as well.

There are several upcoming fundraisers, A Spaghetti Dinner on February 23 in Lapeer, a Hoop-a-thon in Escanaba on March 22. and an ongoing PaperGator Recycling.

The National HDSA meeting will be June 6<sup>th</sup> -8<sup>th</sup>, in Pittsburgh PA at the Omni William Penn Hotel.

We are all part of the HD family and with your support, guidance, and prayers, we will make a difference in each and every person affected by HD, their families, and their friends. God Bless All of You. Dave Stickles

## Michigan Chapter Social Worker



The Michigan Chapter has contracted a new Chapter Social Worker, Danny Berry L.B.S.W., he is a Graduate of Saginaw Valley State University and lives in Saginaw. He is working out of the Midland Office. He can be reached through our helpline voicemail at 1-800-909-0073 or by e-mail at [hdsamisw@gmail.com](mailto:hdsamisw@gmail.com).

The Chapter Social Worker is available for consultation by telephone, and for limited family/home visits. At times, individuals and families can meet with the Social Worker in the Chapter Office in Midland by appointment, or privately before support group meetings around Michigan when he is attending that support group meeting.

The expertise the Social Worker has with "systems" and the dynamics within the family of someone affected by Huntington's Disease are of help when people do not know "what to do next". The Social Worker is often involved at times of diagnosis, and at times when a change in living situation is needed.

These are ways our Chapter Social Worker can help you and your family:

- \* Provide an "in-service" for caregivers in adult foster care or nursing home settings.
- \* Advocate to get a person into appropriate services
- \* Help locate an experienced doctor or neurologist
- \* Help the family as a group cope with HD
- \* Help find local resources for respite, placement, or in-home help
- \* Listen on the Chapter Help line
- \* Provide information and guidance for caregivers, helping to prevent "burnout"
- \* Help connect family with resources throughout the state and possibly in other parts of the country
- \* Assist or provide ideas for speakers at Support Groups.
- \* Coordinate communications between health care providers and the family.

Hello, my name is Danny Berry and I have been a Social worker for the past three years. I graduated from Saginaw Valley State University with my Bachelors degree in May of 2005 and just recently I received my license through the State of Michigan. I have worked in various areas of Social Work and have enjoyed them. I have worked in a residential facility for troubled youth or "at risk" and I have also been a counselor for both adults and adolescents.

Being a Social Worker is a life long learning process. We are constantly learning new etiologies, procedures, policies, etc. With this in mind, I'm going to do my best to learn about all of the proper ways to help each individual I come across with Huntington's Disease. I have acquired a lot of information throughout my studies thus far; however, I know I'm still novice and like I alluded to before we are all life long learners. We need to "keep the faith" and I hope and pray that some day their will be a cure for this devastating disease. This is a disease that does not just happen to an individual, it happens to an entire family.



**Save the Date**  
**23rd Annual Convention**  
**June 6th - 8th, 2008**  
**Omni William Penn Hotel**  
**Pittsburgh, PA**

**Registration Fees:**

**Early Bird Registration**  
**(Now - May 16, 2008)**

2008 Convention Gala Only \$70  
Friday Only Registration \$85  
Saturday Only Registration \$85  
National Youth Alliance (29 years and younger) \$80  
Non-NYA Member (Children 18 and younger) \$85  
Adult Individual \$155  
Adult Family (2 or more adults) \$120 per person

**Late or On-Site Registration**  
**(May 17, 2008 and later)**

2008 Convention Gala Only \$70  
Friday Only Registration \$85  
Saturday Only Registration \$85  
National Youth Alliance (29 years and younger) \$80  
Non-NYA Member (Children 18 and younger) \$85  
Adult Individual \$230  
Adult Family (2 or more adults) \$180 per person

\* 2008 Convention Gala (previously called Generation 2000 Dinner)  
\*\*Friday and Saturday registration does not include the 2008 Convention Gala.  
All other registration does include the 2008 Convention Gala.

Online Registration and Information:

<http://www.hdsa.org/site/PageServer?pagename=convention2008>

# 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.firstgiving.com/hdsami08](http://www.firstgiving.com/hdsami08)

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

PLEASE TAKE A MOMENT TO COMPLETE & MAIL THE SECTION BELOW

YOU MAKE THE DIFFERENCE!


ENCLOSE  
IN  
ENVELOPE  
AND MAIL  
TODAY

TO: HDSA Michigan Chapter  
1174 James Savage Road  
Midland, MI 48640-5651

ENCLOSURE: Check or money order made payable to HDSA Michigan Chapter  
\_\_\_ \$15 Individual Annual Membership  
\_\_\_ \$25 Family Annual Membership  
\_\_\_ \$\_\_\_ Additional gift amount to help in the fight against HD

Donations can be made securely online by going to [www.firstgiving.com/hdsami08](http://www.firstgiving.com/hdsami08)

## "Shoot for the Cure" Hoop-a-thon coming to Escanaba

By Bryan Viau

On Saturday, March 22<sup>nd</sup> my family will be hosting the Upper Peninsula's first Hoop-a-thon to benefit medical research for Huntington's Disease. The event will be held at the Escanaba Area High School in Escanaba from 1-4 pm.

For more information, or to make an online donation visit the website [www.hoopathon.com](http://www.hoopathon.com) and click the link to the UP event. If you'd like to contact us about the event you can do so at [hoopathon@yahoo.com](mailto:hoopathon@yahoo.com).

My family has been hosting a hoop-a-thon in Minnesota for the past 10 years and has raised approximately \$500,000 for HDSA from this event. My wife and I were raised in Delta County (Escanaba/Gladstone) and we are very hopeful that this inaugural event will be the first of many more years of exciting fun that raise awareness about the affects of Huntington's Disease.

My wife was diagnosed over ten years ago and most recently was moved to a group home for Huntington's affected residence. Our son, BJ, was the founder of the Twin Cities Hoop-a-thon when he was in 5<sup>th</sup> grade. He and his sister are both at risk and have been very active in fundraising for HD for many years.

This is a fun filled family event for people of all ages. We hope you'll join us along with our family and friends as we "Shoot for a Cure" on Saturday, March 22, 2008 in Escanaba.

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

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

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

They are: Larry Burton - Grand Rapids, Michigan, Chair of the Grand Rapids Support Group, His Wife has Huntington's Disease

Jane Mervar - L'Anse, Michigan, Her Husband has Huntington's Disease and they have three Daughters with Huntington's Disease. Two with active HD and third who tested positive.

Mary Hiatt - Rochester, Michigan, Ruth Lentner's Brother's daughter who is the Caregiver for her Mother with Alzheimer's and her Father who has Parkinson's Disease

I am hoping that by reading these 3 stories that you will agree that ""THEY DO INDEED CARE" and are doing fantastic jobs as Caregivers. My 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 me, write me, fax me, or e-mail me with your stories so we can publish them in future Newsletters.

By Jane Merver

Dear Ruth: This past year has been a very trying one for my family. There have been several times I felt we were coming very close to losing our fight with JHD with our youngest daughter Karli. Fortunately we have been blessed with medical professionals who have been able to restore her quality of life and her health. My husband has been diagnosed with Late stage HD, which includes his own medical issues, and Jacey our 14 year old daughter with JHD hasn't tolerated her treatments to help slow the disease progression so I fear we may have begun a downward spiral with her as well.

I cannot possibly thank each person who has played a role in our families success to continue our fight. However, the stories I can share about the power and strength as a result of compassion from others, as the issues grow, the army supporting us seems to grow stronger as well. I am always taken aside by how this all has unfolded before us. The words you shared with me long ago "God doesn't create disease and destruction, however he does send you an army to help you live through what life hands to you" has more truth and meaning than I can share.

One event with Karli was the week prior to Thanksgiving this past year. After months of watching Karli decline, I was told The time has come for me to decide to place a feeding tube now or make that decision to let her go. Her health was in a serious state. I felt this year was ending with our worst of fears, once again it was feeling all to soon for life to be unfolding as it was, a painful frightening place to be at, many difficult decisions to be made.

I made the best decision for Karli, with ALOT of support by many who cared, she was air ambulated to children's hospital in Milwaukee where she fought hard with much success and we were able to return home for another holiday season. To say goodbye to the past and look forward to the New Year. With our family at home TOGETHER. I felt we couldn't ask for more blessings than this gift itself.

I was at this time basically homebound. For me to shop or bake was a challenge of its own. I had little left in me to even decorate for the holidays, yet I felt so much peace and thanks for the gift we had already received. I couldn't have dreamed to ask for more.

I cannot even begin to describe the events that began to unfold while in the hospital and following our return home. I still think of them throughout the day and somehow know we will all be ok no matter what the New Year brings because it's God working through others reminding us we are not alone. An army to hold us up and continue this fight. This is where I see heroics,...simple miracles...through the compassion and strength of others, not to mention the selflessness and courage of my family members who are inflicted with this devastating disease, and all those who stand beside us each day.

We received a whole community of prayers and thoughts cards and gifts, groceries, a gas card, beautiful hand made quilts for the girls, so many people signing cards in support of our family, making donations to help us have the best holiday I believe any family could ever have. A beautiful hand made nightlight, A VERY SPECIAL CD sang and recorded for Karli herself by a dear local musician and her cousin. I can honestly say many people I don't even know who they are, many I do. Each day I couldn't possibly have imagined what was in store for our family. This was all topped off when SANTA HIMSELF came to our home on Christmas eve day to deliver the gifts personally.

Words alone cannot possibly capture this holiday season, and this story is one of many leading up to this event I could share, somehow I find it would be improbable this holiday could ever be topped in our moments of strength given by others. I felt in the past, events and care in which others gave strength and memories in support of our family were unable to be outdone. As the issues of care have grown so has the compassion of others, one of the everyday miracles others shared/given our family.

To see the smiles on everyone's faces and hear little Karli squeal with so much excitement as Santa came through the door, that little girl was so excited she could barely open her gifts, and finally after several years of waiting she was able to give Santa a special present she had made for him as well, I believe everyone including Jacey smiled for days to come. The thought and care of others took our tears and turned them to smiles. Just when I thought we couldn't be surprised anymore than we had in past moments.

The year I thought could end in despair became the end to a Year we will hold tight to for many to come. I used to believe miracles were something as significant as a miraculous healing. I find that like heroes, "everyday heroes", miracles come in times and places through the hearts of others in much an "everyday way" holding strength and love hope and compassion for each of us in a time of need often we might not even be aware of the need, I know I could never possibly thank each person who has made such a positive impact in our lives.

When the day or night feels long and trying I look back to these events and smile knowing that we are truly not alone and I am doing exactly what I need to do, reminded life isn't about anymore than caring for each other and not so much about what we take when we go, rather what we leave behind when were gone.

Ruth, even Karl shook his head with a smile saying unbelievable, perfectly spoken! This is one of the many thoughts that run through my head when others say "how do you all do it?". I call it grace! The everyday miracles and heroes who know its not what we take, but what we do leave behind!

Much love, appreciation, and thanks to all of you!

Jane Mervar and family

By Larry Burton

My name is Larry Burton. I am the chair of the Grand Rapids Area Huntington's Disease support group. I have been the chair or co-chair for many years. It is only a designation. I have always had support in my efforts, and have never done anything alone. There are so many people that have been there for me, my wife, and our extended support group family. Every person that I have been involved with, whether it is on the local level, or the state level, has been a big part of why I can write to you today and say that without these people and the faith I have in our Lord Jesus Christ - I would not have been able to continue my desire to do my best to serve those in our HD community. This has been a long journey for me and my family. When Laura (my wife) was first diagnosed almost 18 years ago we didn't know where to turn. With God's help and guidance we eventually joined the GR support group, and have been blessed ever since. There have been so many people along the way, whether a social worker, or a caregiver, or a PHD themselves, I have received the help and inspiration that I needed as a caregiver to continue on as God said in His Word - "I was sick and you cared for me". I am not going to list those people because they know who they are, and I wouldn't want to leave anyone out (it's a memory thing).

Some people ask me - how do you do it? The answer is simple; with faith. Some of us choose God to guide us, and put our trust in him. Some get angry at Him and push him away, but He is always there when you are ready. There have been many resources that have been presented to us over the years that I have taken advantage of. We had a woman from HHS ( Home Health Services), who put us on the right path to daycare, homecare, and a go bus service for our needs, It also included meals on wheels, and an alert button for Laura to wear in case she fell while at home alone. It seems that everyone who was put in our path was inspired by God, or may have themselves been an angel sent by Him. I once told a young man who had HD in his family that I thank God for Huntington's Disease. We were on a spiritual weekend at the time, and the next day he came to me and agreed with me. You see HD led me to Him. When I started reaching out to others using my experience and sharing my faith, I received more blessings than I can count, and I am pretty good with numbers.

In recent years with my wife Laura now in a nursing home I have been able to be involved in other activities including support and prayer for the unborn, as well as those in the end stages of life. You see I can see Jesus in those that I am surrounded with at the nursing home. Even those with the most severe kinds of dementia and Alzheimer's have that look of Christ in their eyes. We only need to look closer to see that. God has designed us for a special purpose, and He continues to fulfill that in all of us if we only let Him. Recently Laura's second roommate passed away. She had said before her stroke that she was ready to be with God. It still was difficult to lose her as a friend in Christ. We shared our faith, and our families, and became close friends. This became more evident in the days following her passing, and we still miss her and Laura's previous roommate. Whenever we go to a funeral of an HD family member we see how God has used them to send His message to all who want to here, We thank God for giving them to us, even if it is for a short time. The sad part is that after they have gone on to be with the Lord we lose contact with most of the families. I am looking for a way that we can continue to reach out to them, whether HD families or families of nursing home patients.

In the past couple of years or so our attendance at support group meetings has dwindled. It is hard to continue the programs and support. But we who still attend are blessed to have the support of those still attending. Last fall at the second annual Porsche race at Grattan Raceway Northeast of Grand Rapids, Michigan, my parents and I helped with the breakfast fundraiser with the West Michigan Porsche Club. Karleen Curry from the Traverse City support group was the chair of the fundraiser, and she gave me an idea for our support group, which now meets quarterly. She said that in the Traverse City area they were having the same problem with attendance. What they did was meet for a meal at a local restaurant, and then proceeded to go visit PHD's at area nursing homes. That sounded like such a great idea that we decided to do that with our GR support group. So we gathered at my house and carpoled to a restaurant for breakfast, and proceeded to visit my wife Laura at one nursing home, and then other PHD's at other area nursing homes. Helen Mikula had prepared gift bags for the men and women, and they were all happy to receive them. It was our Christmastime meeting, and was such a fulfilling day that we intend to continue this format every quarter. This way we can take the meeting to those who can't come to us. We are still available by phone to offer any help that we can give, as well as referrals to the Michigan Chapter 800 number and services. I bring Holy Communion to my wife every Sunday, and when we pray the Lord's prayer together, even with her ability to speak being limited she still, sometimes starts it with me - Our Father Who Art In Heaven... Just remember - He is faithful if we are faithful. God Bless, and have a great year. Larry Burton

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## Paper Recycling Fundraiser—PaperGator

Raising Money for

# **Huntington's Disease Society of America Michigan Chapter**

PaperGator Bin 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

By Mary Hiatt

Loved ones, please lift my dad up in your prayers today. I took him into the ER at Troy Beaumont on Tuesday afternoon as he had become very confused and disoriented. They admitted him at about midnight for observation. As of now, the only diagnosis is something called encephalopathy. Essentially, the brain is not functioning normally. His CT scan is normal for his age, ruling out stroke. The neurologist feels that it could be caused by an infection, although all blood work so far is normal. She was ordering additional tests as of last night. His chest x-ray in the ER was clear on Tuesday, but he has now developed a cough. Another chest x-ray was ordered last night. I'll get the results when I visit today. Pneumonia is always a concern. They have had to put "mittens" on his hands to keep him from pulling out his IV and other wonderful things they stick you with when you can't get to the bathroom (if you know what I mean!). He's a little Houdini, though, and has managed more than once to remove the mittens. Additional tape seems to help. When I'm there I remove them so his hands can be free. A bit reminiscent of past hospital stays.

I am so thankful so many things at this time - the parking garage at the hospital being one of them, as I didn't have to battle snow on the car when I left last night! Starbucks in the lobby being another, as a hot drink warms you from the inside. And for you, my loved ones, for your continual support over the last few years, your love for the Lord and your willingness to pray for us. Thank you. The kids and I are going to visit my mom now, as I haven't seen her since I left with my dad on Tuesday and then I spent the afternoon at the hospital trying to get answers. Please pray for Tim as he works for home to care for our family. Friends, my precious Aunt Ruthie has been added to my e-mail list as I just got her e-mail address (Hi Aunt Ruthie!). She is my dad's baby sister and just an amazing woman. I would ask that you keep her in your prayers also, as she travels this road with us. I love you Aunt Ruthie! My love and thanks to all of you!

Friends, Thank you so much for your prayers! We are journeying out of the storm... I have reduced visiting my parents to every other day now and it seems to be a good balance. Yesterday was a marvelous day singing with my mom and just being silly. It's amazing what the mind can retain even though it's lost so much. We sang "You are My Sunshine" over and over. Another resident found us extremely amusing and it was fun to engage with her as well. My visit with my dad was brief, but he was very affectionate and appreciative. He is slowly returning to his "normal" as the days carry on. Tomorrow it will be two weeks since the move.

I have found a great ministry opportunity within the walls of Sunrise and great personal growth in my journey as a caregiver. I have met another daughter that has become my eyes and ears when I can't be there. She has written her story and it will be published this summer. Her dad, Woody, is a precious, precious man. Thought Mary Ellen's story may interest some. Check out this NY Times article from a few years ago... [www.nytimes.com/2005/11/24/national/24daughter.html](http://www.nytimes.com/2005/11/24/national/24daughter.html) A dear friend just lost her mother to Alzheimer's on Sunday. I am blessed in many ways to still have my parents with me, despite the trials. Thank you for keeping our family near to your hearts. Prayer Warriors, Most of you have traveled the road over the last few years with my parents, and I am so grateful that God sees me fit enough to send me a legion of angels.

Once again, I need prayer... We moved my parents this past Wednesday to Sunrise of Rochester. Mom is doing great and seems to be adjusting well. The memory care program there is wonderful! Dad on the other hand has regressed and is traveling a path reminis-

cent of past hospital stays. He has become extremely paranoid and is fearing for his life. He is refusing to eat or drink, stating that evil things are happening and that he will not fall prey to their devious ways (the caregivers) and abandon all that Christ has done for our sins. He is truly in a dark place. I have been here before and am always uncertain of where this road ends as far as my dad's frame of mind goes. I do know, as my dad reminded me today, that the Lord will never leave us or forsake us. I am most certain that this altered state of mind, or state of delirium, is a result of his environmental changes. Although, he had begun to hallucinate more frequently and elaborately prior to the move (one of the reasons we felt he needed more managed care). The staff noted a marked change in him today at lunch when he needed to make an announcement. The announcement was a public proclamation of faith and a total denouncement of the activities that were being performed. He truly thought they were trying to make him "drink the Kool Aid". The mind is so mysterious and a place where Satan finds a weakness and weasels his way in. My dad is a man of such strong faith and has been at this spiritual battleground before. I can only reassure him of God's presence and his is unfailing love. This is the only truth he knows at this time. I have such great joy as I write this (hard to believe, I know!). I have the joy because the Lord is my strength and my shield and I can laugh in the face of Satan and declare victory even before the battle has ceased. The Hiatt's do have a crazy life, but God always shows up and showers me with a peace that surpasses all understanding. Thank you for your love and your continual support for our family.

Love to all, Mary Hiatt

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By Christine Salewsky

The Menominee Outreach Support Group is doing well.

We had a meeting on Saturday February 2. We were a small group that meet to visit and laugh. We watched a video called "A Twisted Mind" with comedian Ken Davis. His videos are so good. And we all need a good laugh. I highly recommend his videos for a fun meeting.

Also want to let you know that my Husband Lawrence is now in a Nursing Home. It is only 3 blocks from where I am living.

I wanted to tell you that he has a wonderful Broda chair. He is with Hospice now and they provided the chair for him. I asked for one and they looked into getting one. Hospice rented the chair from the Broda Company. I only had to pay for the extra padding I wanted on it. I got the pads to protect his feet. It is so great for him. It is also easy to push and I can take him for rides around the Nursing Home. He is doing well there. And as a caregiver I am also doing well. I can enjoy my visits and not get upset or frustrated or short with him. As a result he is in better moods also.

I guess I wrote this to let people know that if their Person with HD is with a hospice that if you want or need anything just ask them and they will try hard to provide it. Hospice has been great. They also supply all his meds and diapers/pullups and leg and arm protectors.

Christine and PHD Lawrence, Marinette, Wisconsin, Co-Leader with Sandy & Greg of Menominee, MI Outreach HD Support Group, [csalewsky@centurytel.net](mailto:csalewsky@centurytel.net)

*In Loving Memory*

Bruce DeForest

Margaret Duhn

Bessie Edwards

Herb Hills Sr.

Wilma Matthies

Nancy (Mikula) McWilliams

Carol Miller

Lottie Nowakowski

Mary Nowakowski

William Olzewski

Carol (Mikula) Simmons

Don Spencer

Christina (Nowakowski) Wallace

*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.

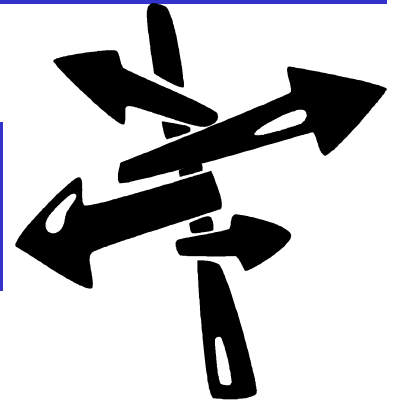
Though you can't see or touch me, I'll be near.  
And if you listen with your heart, you'll hear,  
All of my love around you, soft and clear.

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

"Welcome Home"



# HD Information to Share



**SHARE THE INFORMATION BELOW WITH FAMILY, FRIENDS, DOCTORS, CAREGIVERS, LEGISLATORS, NURSES, MEDIA AND ANYONE ELSE YOU MAY KNOW**

**Huntington's Disease** is an inherited (97-98% of the time) progressively degenerative brain disorder which results in a loss of both mental capability and physical control. Over a period of 10-25 years, the ability to think, to speak and to walk is greatly diminished in persons with the disease. It can affect people from 2 to 80 years old. The prevalence of the disease is 1 in 10,000 and for those at risk it is 1 in 1,000.

Presently there is no effective treatment or cure. Although medications can give some partial relief, no drug can stop the disease's steady progression.

## **SYMPTOMS APPEAR SLOWLY AND INCLUDE:**

- Personality changes
- Depression and withdrawal
- Increasing forgetfulness
- Slurred speech, progressing to not being able to talk
- Reasoning and judgment become impaired
- Swallowing problems
- Walking problems

HD affects individuals of both sexes as well as all races and ethnic groups throughout the world. It is now recognized as one of the more common of hereditary diseases. Every member of a HD family is challenged emotionally, socially and economically:

- The HD affected person, with trying to cope with the illness
- The Children facing the prospect of inheriting the disease (50/50 chance), fear passing the HD gene to the next generation (it doesn't skip), and fear marriage, career and life decisions.
- Spouses and family members trying to hold the family together face severe financial and emotional strains, often with little relief.

## **THERE IS HOPE FOR THE FUTURE!**

In 1993 the HD gene was found after a 10 year search! Today, at risk people can take a blood test to determine whether they carry this defective gene. Counseling is suggested before and after the test. Research is continuing today to find a cure or a treatment that will slow or stop the progression.

**CONTACT HDSA MICHIGAN CHAPTER HELPLINE FOR MORE INFORMATION, EDUCATION, OUR CHAPTER SERVICES, AND ON HOW YOU CAN HELP**

**1-800-909-0073**

**HDSA MICHIGAN SUPPORT GROUP MEETINGS**

<b>AREA</b>	<b>WHEN</b>	<b>WHERE</b>	<b>CONTACT</b>
<b>Ann Arbor Area</b>	2nd Thursday Quarterly (Check With Coordinator for Months) 7:00 pm to 9:00 pm	St. Joseph's Hospital 5301 E. Huron River Dr. Education Building Parking Lot P Ypsilanti	Doug Cameron 734-677-0258
<b>Grand Rapids &amp; Western MI</b>	3rd Saturday Quarterly (Check With Coordinator for Months) 1 pm—3 pm	St. Anthony of Padua 2150 Richmond St. NW Grand Rapids MI 49504 Room C	Larry 616-791-6468
<b>Greater Genesee County Area</b>	1st Monday 7:00 pm	Genesys Regional Medical Center, West Campus 3921 Beecher Rd. Flint	Jean or Barb 810-659-4548
<b>Kalamazoo</b>	Quarterly Meetings Fourth Tuesday 7:00 pm (Check with Coordinator for Months)	Borgess Hospital 1521 Gull Road	Sara 269-381-7725
<b>Lansing</b>	3rd Saturday Quarterly (Check With Coordinator for Months) 1 pm—3 pm	St Stephens Lutheran Church 2900 N Waverly Rd. Lansing MI 48906	Ruth 989-835-9933
<b>Living Positive Support Group Grand Rapids-New</b>	4th Monday 7:00— 9:00 pm (for HD Gene Positive and at Risk Individuals)	Cascade Wellness Center, 4550 Cascade RD suite 101, Grand Rapids, MI 49546	Deb 616-874-5477 hm 616-916-0240 cell livingpositive2008@sbcglobal.net
<b>Macomb County Caregivers Group</b>	2nd Tuesday 7:30 pm	4571 Reflections Drive Sterling Heights	Deanna (Dee) Sadlowski 586-997-3089
<b>Menominee</b>	1st Saturday Quarterly (Check With Coordinator for Months) 1:00 pm	First Baptist Church, 350 Stephenson Ave. Peshtigo, WI 54157	Chris 715-732-2133 Greg 715-789-2526
<b>Mt. Pleasant</b>	2nd Tuesday 7:00 pm	Coldwell Bankers, 304 East Broadway, Mt. Pleasant MI 48858	Ann 989-561-5023 Dave 989-496-3273
<b>Royal Oak</b>	3rd Saturday (2007 -Nov 17, 2008 - Jan 19, April 19, July 19, Nov 15) 1 pm—3 pm	Wm. Beaumont Hospital Administration Building Conference Room A/B/C 3601 West 13 Mile Rd.	Karen 586-792-6579 Krissi 586-822-1730
<b>Taylor &amp; Down-river</b>	1st Friday 7:00 pm	American House 25250 Eureka Rd. Taylor MI	Betty 734-947-1058 David 313-272-5493
<b>Tri-Cities Area</b> Please note Meeting Location change each month, Feb TBD	1st Thursday 7:00 pm	Saginaw Township Fire Dept. 4930 Shattuck Rd - Dec 153 N. Center Rd - Jan Saginaw MI	Ruth 989-835-9933 Dave 989-496-3273
<b>Traverse City</b>	Sat Quarterly (Check With Coordinator for Months) 10 am—12 Noon	College Terrace Wesleyan Church, 2825 S. Airport Rd. W.	Karlene 231-943-8570 Stacey 231-275-7795

## HDSA MICHIGAN SUPPORT GROUP MEETINGS

Greater Genesee County—1st Monday

Living Positive Support Group—Grand Rapids

(This is a New Support Group for HD Gene Positive and At Risk Individuals)

February 25, March 24, April 28, May 19

Menominee

Next Meeting April 5.

Mt. Pleasant -

February and March , No meeting

April 8 - Open Discussion

Royal Oak -

Saturday April 19, 2008 - Estate Planning

Saturday July 19, 2008 - tbd

Saturday November 15, 2008 - Dr. Garbern (Wayne State)

Taylor & Downriver—1st Friday

Tri-City -

March 6, April 3, May 1

### 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.

*FUNDRAISER TO HELP WITH RESEARCH FOR*

*HUNTINGTON'S DISEASE*

*SPAGHETTI DINNER*

*DONATION AT THE DOOR SATURDAY, FEBRUARY 23RD*

*5.00 PM TO 9:00 PM*

*ELBA TOWNSHIP HALL*

*4717 LIPPINCOTT RD., LAPEER, MI 48446*

*(THE HALL IS AT THE CORNER OF LIPPINCOTT RD. & HADLEY RD.)*

Many of you may ask  
"What is Huntington's Disease?"

Huntington's Disease is a hereditary terminal neurological disease,  
that has no cure or treatment!  
just prayers, and research!

Our Daughter, is 24 years old, but was diagnosed when she was  
only 19, and her Biological Father, passed away from this illness in  
March 2003.

Any sickness is terrible, and when it hits your own family, it makes  
you take a step back and open your eyes. This illness affects your  
ability to walk, talk and have a normal life.

Unless, we find a cure for not only our Daughter Christina, but for  
the thousands that this illness affects, the outcome is not good.

Please help to save our Daughter and others!

if you can't attend the dinner but would like to donate, you may  
make it payable to "HDSA Michigan Chapter" and send it to me at

Connie Jenkinson 163 Sarah Fern Ct, Lapeer, MI 48446

or you can donate online at <http://www.firstgiving.com/spaghetthdmi>

We will be having a silent auction on some items and raffling off other  
items throughout the evening.

If you have any questions, please call me at 810-338-4887!

Thank you very much for your thoughts, prayers, and donations!

Connie & Jerome Jenkinson

## CAREGIVER...

It's a hard job...It's a loving duty...It's an emotional responsibility...

It's *so much more* than all that....and now, it's you..

But did you know, it's not just about the care of the recipient...

***What care are you taking for yourself?***

Really, what care are you taking for yourself? Being a caregiver, especially to one with Huntington's Disease, can take it's toll on anyone! Even the strong, independent and most organized person, can become frustrated and stressed when given the responsibility of the care of another person...or sometimes, as in the case of HD, the care of several other persons! Run down, worn out, upset and frustrated will become a part of you...it's a given. Accepting *that* fact, may be harder than accepting the fact that you've become a caregiver in the first place! The best way to give your loved one the best care possible, is to make sure you take care of yourself! Like I said, you *will be* run down...you *will be* worn out...you *will be* upset at times and undoubtedly, you *will be* frustrated a lot! But, taking steps to take care of yourself, will help you come through those times without becoming sick or depressed yourself.

**Take time away from care giving!** Now, this doesn't mean run to the grocery store, the bank or the pharmacy. It means take time to do something specific for yourself...a time to recharge your self! For everyone, that thing will be different. It may be a walk. It may mean Chinese lunch with a friend. It may mean locking the door to the bathroom, turning up the radio, lighting candles and sinking into a warm bubble bath! Whatever your thing is...**DO IT!** A rechargeable battery is a brilliant invention, only if it gets recharged! Otherwise, it's just dead like the other batteries.

**Make support groups and/or counseling sessions mandatory for yourself!** This support is so crucial to our own mental health as care givers. In these groups or sessions, you will be offered the safety net of speaking freely, crying uncontrollably, venting angrily, and being accepted openly! Friends and family are great support tools, but don't limit yourself to just those tools. Find tools that do the same job as you and hang around with them from time to time! You'll be glad you did!

**Find laughter!** Laughter is one of the most healing powers there is! Mark Therrien, a social worker for almost 20 years, and speaker, says " No matter what illness, disease, or handicap you may have, (or have to deal with) if you can laugh at yourself, you are one of the healthiest people on the planet. When we can laugh at ourselves, we can begin to forgive ourselves for not being perfect...you are funny, even if it's not on purpose! So laugh... None of this in any way says that serious illness or caring for someone with serious illness is funny. You know it's not funny!...I urge you in the most difficult times of your life to look for the laughter, to look for the joy." Go to a funny movie with a friend, check out a good book, take time in a support group to share your most embarrassing moments and LAUGH!

## **Mentally ill need treatment, not prison, coalition says**

By Pat Shellenbarger, The Grand Rapids Press

With the state Corrections Department gobbling up more than \$2 billion a year -- one-fifth the state's budget -- a statewide coalition of judges, police, social service officials and others say there is a better way to spend taxpayers' money -- treat the mentally ill rather than lock them up.

Citing what it called "a growing statewide crisis," the new group, called the Michigan Partners in Crisis, today released a list of six initiatives it said would improve treatment of the mentally ill, reduce the state's prison population, save money and lower the crime rate.

"It's a wiser investment of state dollars," said Michael Reagan, a member of the coalition's advisory board and president of the nonprofit Proaction Behavioral Health Alliance, based in Grand Rapids.

Besides, he said, "It's the humane thing to do, and it makes our communities safer."

While no recent figures are available, coalition members believe more than half the inmates in Michigan's prisons and jails suffer some form of mental illness, often undiagnosed and untreated. That is partly due to a decision by state officials over the past few decades to "deinstitutionalize" most mental patients by closing state mental hospitals.

While the coalition is not calling for reopening of the mental hospitals, it said the state failed to provide enough resources to treat the mentally ill in communities. As a result, some commit crimes and end up incarcerated, where they usually do not get proper treatment and often deteriorate.

"We have not deinstitutionalized the mentally ill," said Mark Reinstein, a coalition member and president of the Mental Health Association of Michigan. "We have 'transititutionalized' them," shifting them from hospitals to jails and prisons.

The coalition, asserting that most crimes committed by the mentally ill are nonviolent, called for the creation of mental health courts that would send mentally ill offenders into treatment programs rather than jails and prisons.

Diagnosing and treating mental illness before a crime occurs would be even better, Reinstein said.

For those who still need to be incarcerated, the state should improve treatment programs in the prisons to stem the high recidivism rate for mentally ill inmates, he said.

"These aren't places that fit in with treatment," Reinstein said. "What we have now isn't anywhere near what it ought to be. We have a horrible epidemic problem here."

The group called on state leaders to commission an independent study to determine how common mental disorders are in Michigan's county jails, state prisons and juve-

nile facilities. Last fall, the state Corrections Department estimated 16 percent of its inmates have been diagnosed with mental health problems.

"I think that's a low number," said C. Patrick Babcock, former director of Michigan's Department of Mental Health.

Deinstitutionalization was a good idea, he said, but, after the state closed most mental hospitals, "too many people fell through the cracks."

He cited the case of Timothy Souders, who died of dehydration while shackled to a bed in a Jackson prison in August 2006. Because of his mental illness, Souders, 21, could not follow prison rules, and his condition deteriorated while he was locked in solitary confinement.

The coalition is calling for an end to solitary confinement as punishment for mentally ill inmates.

Nationally, about 64 percent of county jail inmates and 56 percent of state prison inmates suffer some form of mental illness, the group said, and 75 percent of those in juvenile facilities have emotional disorders.

The current state budget includes \$400,000 for a study to determine what portion of the state's 51,000 prison inmates are mentally ill.

The last independent study two decades ago found 40 percent of Michigan's prison inmates had some form of mental illness, including schizophrenia, bipolar disorder and major depression.

A 1998 study by Wayne State University found that 45 percent of Kent County's jail inmates were mentally ill.

State prison officials generally agree with the coalition's goals, Corrections Department spokesman Russ Marlan said.

"We've always said we don't think prison is the best place to treat the mentally ill," he said. "We've said all along we have to take who we get, and we do the best job that we can before releasing them.

## Comparing costs

Per-day cost of handling a person with mental illness:

**State prison:** \$130, according to Michigan Department of Corrections

**County jail:** \$125, according to American University Technical Assistance Report on Cook County (Illinois) jail

**Mental health court:** \$33, according to Florida Council for Community Mental Health

**Community treatment:** \$13, according to Michigan Department of Community Health fiscal year 2006 Demographic and Service Report

Huntington's Disease Society of America  
MICHIGAN CHAPTER

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MIDLAND, MI  
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1174 James Savage Road  
Midland, MI 48640

**\* ADDRESS SERVICE REQUESTED \***

**CHAPTER HELPLINE:  
(800) 909-0073**

**CHAPTER OFFICE:  
(989) 832-4170 \*\*New Number\*\***

**FAX: (989) 832-4171 \*\*New Number\*\***

**WEB: [www.hdsa.org](http://www.hdsa.org) Click on MI  
Chapter or go directly to our New  
Chapter Web Site by going to:  
[www.hdsa-mi.com](http://www.hdsa-mi.com) or ([www.hdsami.org](http://www.hdsami.org))  
Old web site is not being updated**

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Editing rights apply**

This newsletter is an official publication of the Michigan Chapter of the Huntington's Disease Society of America, 1174 James Savage Road; Midland, MI 48640.

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.

**This chapter wishes to express its appreciation to The State of Michigan for its grant in support of our chapter's programs!**