



KNOXVILLE TEAM HOPE WALK



Spring 2017

HELP FOR TODAY. HOPE FOR TOMORROW

Meet HDSA Tennessee Chapter Social Worker Margo Bradley, LCSW

Margo Bradley, LCSW, began work part-time as the Tennessee Chapter social worker on January 3, 2017. She is assisting and supporting HD families across Tennessee with information, referrals, and advocacy on behalf of patients, families, caregivers, and those living at risk. She is also facilitating the Memphis support group. Margo earned her Master's degree in Social Work from the University of Buffalo and has extensive social work experience in behavioral health, developmental disabilities, and hospice.



Margo can be reached by cell phone at (901) 609-9127 and by email at mbradley@hdsa.org. There is no charge for Margo's assistance. She works independently and is not part of or associated with the HDSA Center of Excellence at the University of Tennessee Health Science Center or Vanderbilt Medical Center, any HD Clinics, or any neurology practice. Margo and the Tennessee HDSA Chapter are both very excited about the opportunities this partnership will bring for Tennessee HD families.

A SOCIAL WORKER CAN HELP YOU

- In-services for the long term care facility or home health agency caring for your loved one with HD
- Locating local resources & mental health services in your community
- Finding your local health and human services office
- Applying for disability
- Accessing clinical trials for HD
- Identifying options for long term care placement
- Explain Advanced Directives, POA, Health proxy
- Hospice/palliative care services
- End of life issues
- And much more!

Walk with HDSA at a Team Hope Walk

The Team Hope Walk program is HDSA's signature grassroots fundraising campaign designed to provide hope and support for those touched by this devastating disease. All proceeds support HDSA's mission to improve the lives of people affected by HD and their families. Since their inception in 2007, Team Hope Walks have occurred in over 100 different cities and have raised over \$10 million nationwide. The 17 Team Hope Walks held in Tennessee beginning in 2011 have raised more than \$145,000 to support HDSA programs, including the two Centers of Excellence in Tennessee, the Tennessee Chapter social worker, education for people affected by HD, and advocacy to law enforcement and the community.

The Tennessee Chapter Team Hope Walk year begins May 13 in Nashville. Plan to attend the **Nashville Team Hope Walk** at the Shelby Park Event Field and bring all your family and friends! Shelby Park is one of Nashville's oldest and most elegant parks, including 336 acres of land along the Cumberland River. In addition to the children's activities planned for the walk, there are several cool playgrounds in the park, including a natural play area with scientific activities. Pets are allowed in the park if they are on a leash that is no longer than six feet. In fact, you may have a chance to meet a few service dogs from Retrieving Independence at the walk. In addition to the short walk in the park, there will be loads of fun activities for the kids, entertainment, food, and more. A special attraction at this year's walk will be hot dogs and nachos. You can preregister online at www.hdsa.org/thwnashville and speed up your day of event check in so you can start participating in the morning's activities the minute you arrive. On site check in and registration will start at 9:00 am on May 13 and the walk will kick-off at 10:00. It is fitting that the Nashville Team Hope Walk will take place during Huntington's Disease Awareness Month, a time to raise the profile of Huntington's disease for the community at-large. There is no set participation fee for the Nashville Walk; we ask only that you donate to the extent you can and request your family and friends to donate to help you as you walk to support HDSA's efforts. For more information about the walk or to volunteer to help, call Cindy Ledford at (615) 714-8267 or email Cindy at jesislord_316@yahoo.com.

Next up, take a beautiful walk along the Tennessee River in Knoxville at Volunteer Landing Park (near Calhoun's on the River). The **Knoxville Team Hope Walk** will kickoff at 10 o'clock on Saturday, September 16. After the Knoxville Walk, stick around for a Boot Camp conducted by Prime Wellness Consultants. The Boot Camp is free to everyone who donates at least \$10. To preregister for the walk or for more information, go to www.hdsa.org/thwknoxville. The kids (and kids at heart) can dance in the water fountains and you may see the Tennessee Rambler, a steam locomotive, pass by. History buffs can learn about Tennessee and Knoxville's history from the numerous historical markers along the route and get a great view of the historic open-spandrel arch Henley Street Bridge. For more information, to volunteer to help at the walk, or to learn about opportunities to sponsor the walk, call Kristy Campbell-Hill at (865) 454-0254 or email her at kch@bluespecstrategies.com.

Two weeks after the Knoxville Walk, we will return to Middle Tennessee for the **Mt. Juliet Team Hope Walk/5K** on Saturday, September 30. The full route will be a 5K (3.2 miles) but you can choose to walk a shorter portion of the walk. If you want to complete the full 5K, you can choose to have your run or walk timed with chip timing by A Matter of Timing. The race/walk will begin at 8:30 a.m. with check in and day-of registration beginning at 7:30 a.m. The route, through a beautiful Mt. Juliet neighborhood, is flat and offers a great opportunity for a PR for runners. More information and preregistration are available at www.hdsa.org/thwmtjuliet. Walk Coordinator Gina Becker can be reached at mtjuliet@walkforhd.org or by calling (615) 681-4996.

For the last Tennessee Chapter Team Hope Walk for 2017, we will return to the Tennessee River in Chattanooga at RiverPark, Shelter #4, on Saturday, November 4, for the **Chattanooga Team Hope Walk**. The event will be kid-friendly and the walk route will pass beautiful sculptures and offer an outstanding view of the Chickamauga Dam. To learn more about the Chattanooga Walk, go to www.hdsa.org/thwchattanooga, call Krystle Hillery at (770) 710-6346, or email Krystle Hillery at khillery@hdsa.org.

Register Now for the 2017 National HDSA Convention

The 32nd Annual HDSA Convention is just around the corner. The national HDSA Convention offers a great opportunity to meet hundreds of other people who are living with Huntington's disease and to learn from national experts about the disease, ongoing research, and ways to cope with the disease. The convention begins with a Team Hope Walk on Thursday, June 22, followed by a welcome reception. The exhibit hall will be open Thursday evening, Friday, and Saturday, so you can talk with a variety of organizations and businesses that support the HD community. Friday, June 23, and Saturday, June 24, will offer educational workshops, including the popular Research Forum on Saturday, during which you will hear directly from HD researchers about current and upcoming research. The convention will end with a gala dinner and dance on Saturday evening where everyone can enjoy a very nice seated dinner and no one will care if you drop your fork or miss a step.



This year's convention is at the Renaissance Schaumburg Convention Center Hotel (Chicago). Registration is now open at www.hdsa.org/convention. Early bird rates expire May 12 and all registration fees will be fully refundable until June 9.

Looking Back and Looking Forward

The 2016 year was another year of progress for the Tennessee HD Community. The Huntington Study Group held its annual meeting in Nashville. The Tennessee HDSA Affiliate was recognized as an HDSA Chapter and hired a part-time social worker. The Tennessee Affiliate/Chapter raised more than \$45,000, net of all expenses, to support HDSA's mission of improving the lives of everyone affected by Huntington's disease.

The Huntington Study Group annual meeting in November 2016 offered opportunities to educate the medical community about Huntington's disease at the CME4HD (Continuing Medical Education) and for HD families to meet and interact with HD clinical and research experts from around the world at a joint HDSA-HSG-Vanderbilt Medical Center community education day. The Tennessee HDSA Affiliate, through the generous support of Blue Cross Blue Shield Tennessee Health Foundation, assisted 21 families with travel costs to make it easier for them to attend the annual meeting.

You helped us accomplish our goals of hiring a social worker and being recognized as a chapter each time you volunteered or participated in an HDSA event. Hundreds of you supported the effort to reach those goals when you walked, golfed, bowled, dined and listened to music, and donated to HDSA. Thank you from the bottom of our hearts. Special gratitude goes to Stacey Reed and Tiffany Adams, who initiated our participation in the Down to Earth Festival (Stacey – Memphis) and Goats,



Music, and More Festival (Tiffany - Lewisburg) where we were able to raise community awareness of Huntington's disease. Also, we are particularly thankful to Tiffany Adams (chair - Strike Out HD), Felicia Riner (chair - Cruisin' for a Cure for HD), Cindy Ledford (coordinator - the Nashville Team Hope Walk), Michelle Bates (coordinator - the Chattanooga Team Hope Walk), Mark Bascom (coordinator - the Knoxville Team Hope Walk), Don Saemenes (chair - the 19th Annual Cure HD Golf Tournament), Gina Becker (coordinator - the Mt. Juliet Team Hope Walk), and Kim Sellers (chair of Singing and Supper – A Celebration of Hope). Each of those chairs and coordinators were assisted by countless volunteers who were vital to the success of these activities.

The beginning of 2017 brought more great news. Both the University of Tennessee Health Science Center at Memphis Huntington's disease clinic and the Vanderbilt Medical Center Huntington's disease clinic were recognized as HDSA Centers of Excellence. That recognition signifies that both HD clinics are multi-disciplinary care teams with expertise in Huntington's disease that share an exemplary commitment to bringing comprehensive care.

Most of our outstanding events will return this year. See the article elsewhere in this newsletter for more information about the four Team Hope Walks planned for 2017. Cruisin for a Cure, our car, truck, and motorcycle show in Fayetteville will take place at Lincoln County High School on Saturday, May 13. For more information, go to www.hdsa.donordrive.com/event/cruisin2017. We will tee off at the 19th Annual Cure HD Golf Tournament at Mirimichi Golf Club again this fall and you can look forward to an outstanding evening of entertainment at the Fourth Annual Singing and Supper – A Celebration of Hope at Old Spencer Mill in Burns on July 15, 2017. Check our website and follow us on Facebook to keep up to date on these events.

The future is bright and we are excited about our role in providing *Help for Today* and *Hope for Tomorrow* for people and families affected by Huntington's disease.

Why Should You Consider Attending an HD support group?

Support groups provide far more than a place to vent. HD support groups offer many benefits. Members of support groups meet others familiar with the effects of HD, share caregiving strategies, learn self-help strategies, and receive knowledge about reliable community care and resources. An effective support group has involvement from the HD community, people spreading the word about the group, members willing to participate in a group setting and share experiences, and cooperation and collaboration among members. Being a part of a support group offers you an opportunity to give support and to get support. Attending a support group may open many doors and offer connections. As a member of a support group, you decide whether, when, and how much to participate. You can choose to just sit and listen, contribute to discussions, or ask questions.



Currently, there are two HD support groups in Tennessee. Both groups welcome anyone affected by HD - individuals at risk, caregivers, family members, and others whose lives are affected by HD. The Nashville Support Group meets the second Thursday evening of the month 6:30PM-7:30PM at Skyline Medical Center in Auditorium A on the ground floor. The facilitator is Melissa Darnall (HDadvocate.Melissa@gmail.com, (615) 714-6519). The Memphis Support Group meets the third Saturday of every other month (the even-numbered months – February 18, April 15, June 17, August 19, October 21, December 16) from 10:00 a.m. to 11:30 a.m., at the Memphis Public Library, Cordova Location, Meeting Room A, 8457 Trinity Rd. Cordova, Tennessee 38018. The

facilitator is Margo Bradley, MSW, LCSW (mbradley@hdsa.org).

At this time, there is not an HD-specific support group in East Tennessee. There is, however, a caregivers' group in Knoxville that is not Huntington's disease specific. The group is focused on caregivers, families, and friends of people with neurological diseases. Loved ones visit with a medical center staff member in a separate room during the caregivers' support group meeting. The Knoxville Caregivers' group meets the fourth Thursday of each month from 3:30 pm to 5:00 pm, in the Health Information Center at the University of Tennessee Medical Center, 1924 Alcoa Highway, Knoxville, TN 37920. For more information about the Knoxville caregivers' group, call Cole Neuroscience Center at 865-305-6740.

Are there ways you can help your friend who has HD?

Absolutely!

- Modify the way you talk to the person with HD to accommodate her slower mental processing and loss of the motor control needed to speak. The effects of HD can slow the person's ability to hear and process a question or statement, formulate a response, and say the response. Control of the muscles needed to speak can become difficult.
- Be willing to repeat what you say if he did not understand you the first time. Be very patient to allow the person a lot of extra time to think and express his thoughts. Unless you are pretty sure he did not hear you, don't repeat the question; that often just "starts the clock" again and the person with HD has to re-start the process of hearing, processing, formulating a response, and saying the response.
- If your friend begins to have difficulty focusing, make eye contact before starting a conversation and continue to face her so she can see your lips and expression. As the disease progresses, many people with HD are unable to focus on more than one thing at a time. If she is doing something or looking or listening to something else, get her attention before you begin speaking.
- If it becomes very difficult for your friend to speak, ask yes-no questions and be prepared to wait much longer for a response than you would normally.
- Visit or call your friend. Even if your friend does not respond to what you say, talk to him about the same things you talked about before HD. Did the two of you enjoy football, theater, music, golf, or movies? Talk about the game you watched yesterday or the great new movie coming to the theater. Watch a race on television with your friend who follows NASCAR or take a DVD of a new movie or a favorite old movie to watch with your friend.
- If your friend can go with you to activities, take her to sporting events, a movie, for coffee, or out to eat. She is likely to still enjoy being in your company and doing things with you even when she can no longer converse about it. Keep in mind that one symptom of HD is a tendency to show no emotion. Even though she may be very happy, she may not smile or react.
- If your friend lives too far away to visit, send a card, letter, or email as often as you can. Tell him what you have been doing lately or send a cute joke or picture.
- Continue to visit with your friend even when she is no longer able to communicate well. Memory loss with HD is different from the memory loss with many types of dementia. The HD patient continues to know who you are and to hear and understand what you are saying, even when she can no longer respond.

How can you best help an HD Caregiver?

It is often said that being an unpaid family caregiver is the hardest job in the world. As a general rule, family caregivers wouldn't choose to have it any other way and they don't need or want sympathy. They need and want an occasional break. They need or want a chance to vent without being judged.

Paul Prather, in a January 29, 2017, column in the *Lexington Herald Leader* (<http://www.kentucky.com/living/religion/paul-prather/article129447884.html>) offers these tips for helping caregivers:

Pay attention. Look past the smiles and self-denial that caregivers feel duty-bound to exhibit. Look for the cracks. When the [person with HD] isn't within earshot, ask the caregiver if she's struggling.

Ask specifically what help is needed – and don't just announce what you intend to do. If you simply ask a caregiver what he needs, he'll likely say, "Nothing." And if you just announce what you're going to do, it probably won't be the thing he needs. Instead, make specific suggestions, but without imposing your agenda.

"Would it help if I sat with Edna a few hours so you could run errands?" you might say. "No? How about if I brought you a meal? Yes. Great! Do you prefer homemade fried chicken, or carryout from your favorite restaurant? What night works best?"

Never judge. Caregiving is the hardest thing [most people have] ever done. Nothing else comes close. Unless you've held that job, you have no idea how you'd fare. All the old verities fly out the window. So never judge a caregiver for how she's handling the situation. Is she surly? Has she lost her faith? ... Don't delude yourself that you'd do better. ...

Reassure. Probably the best thing anybody said to me when I was low was, "Man, you're doing a great job. You're my hero. Hang in there." Several friends told me that, and every time it gave me the strength to endure a few more days.

HELPING THE CAREGIVER

PAY ATTENTION.

ASK SPECIFICALLY WHAT HELP IS NEEDED – AND DON'T JUST ANNOUNCE WHAT YOU INTEND TO DO.

NEVER JUDGE.

REASSURE.

Huntington's disease is a fatal, neurodegenerative brain disorder. It robs people of their ability to:

- talk,
- walk,
- swallow,
- think and reason.



General areas affected by HD (International HD Association)

Coming HD Events in Tennessee

(Details and Additional Events can be found on Facebook – (HDSA-TennesseeHDCCommunity) and the Chapter Website (www.hdsa.org/tn))

- Saturday, April 29, 2017 - Knoxville – Morrison’s Conference Room, UT Medical Center, 1924 Alcoa Highway – HDSA Information Day – “ Living with Huntington’s Disease Today – Recognizing Tomorrow’s Hope” <https://hdsa.donordrive.com/event/2017tnedday>
- Saturday, May 13, 2017 – Nashville – Shelby Park Event Field - Team Hope Walk and Family Festival – www.hdsa.org/thwnashville.
- Saturday, May 13, 2017 – Fayetteville – Lincoln County High School. Cruisin’ for a Cure for HD Car, Truck, and Motorcycle Show. www.hdsa.donordrive.com/event/cruisin2017.
- Saturday, July 15, 2017 – Burns – Old Spencer Mill – “Fired Up and Celebrating Summer and Hope for HD.” Barbeque and Music. All proceeds will go to HDSA. Preregistration requested to help us prepare. Donations will be accepted at the door. <https://hdsa.donordrive.com/event/2017tncoh>.
- Saturday, September 9, 2017 – Memphis – Ducks Unlimited Conference Room, One Waterfowl Way. HD Education Day. <https://hdsa.donordrive.com/event/2017tnedu>.
- Saturday, September 16, 2017 – Knoxville – Volunteer Landing. Team Hope Walk for HD. www.hdsa.org/thwknoxville.
- Saturday, September 30, 2017 – Mt. Juliet – Charlie Daniels Park. Team Hope 5K and Walk. www.hdsa.org/thwmtjuliet.
- Friday, October 20, 2017 – Memphis/Millington – Mirimichi Golf Course – 19th Annual Cure HD Golf Tournament
- Saturday, October 21, 2017 (tentative) – Dickson – Greystone Golf Club - Singing and Supper – A Celebration of Hope. Benefit Concert and Dinner.
- Saturday, November 4, 2017 – Chattanooga – River Park, Shelter #4 – Team Hope Walk for HD. www.hdsa.org/thwchattanooga.



Volunteers are always needed and welcome. Current volunteer needs include

- Assistance securing sponsors and auction items for events
- Committee members for Team Hope Walks, the golf tournament, and the Celebration of Hope
- General and administrative duties

Some tasks can be done remotely by computer. If you would like to volunteer some of your time, email us at hdsa-tn@hotmail.com.