

We Are HDSA!



 Huntington's Disease
Society of America

Support Group Newsletter • www.hdsa.org • (800) 345-HDSA • Issue 2, June/July 2014

SUPPORTING Kids And Teens Who Help Care For A Parent With HD

By: Melinda Kavanaugh, PhD, LCSW, Assistant Professor, Social Work, Helen Bader School of Social Welfare, University of Wisconsin – Milwaukee, Family Services Chair, HDSA Wisconsin Chapter Board

"If someone says, 'How's your mom doing,' I'll say, 'Oh, she's doing all right.' But maybe it'd be nice if someone asked me how I was doing. Like, 'cause I will have an answer." (17 year old caregiver to mom with HD)

Many of you could certainly come up with an answer when asked how you, as caregiver, are doing. Living with HD requires much of families, including often strenuous and long term caregiving, which is overwhelmingly provided by family members in the home. When thinking about who provides care, we assume the spouse or perhaps a grandparent or other adult family members, but we often miss the kids and teens in the home acting as caregiver "young carers," like the teenager quoted above.

Approximately, 1.4 million kids and teenagers help take care of a family member in the U.S. These young carers help keep a parent company and often do more intense caregiving such as bathing and toileting their parent, yet have remained hidden from family caregiving and support services throughout the US. Research on young carers shows that they partake in numerous and complicated caregiving tasks, often for many years. While many feel positive about caregiving, stating it makes them feel good about themselves and they like being helpful, more often young carers describe feeling stressed, overwhelmed and isolated with little to no support.

As an HDSA social worker, I saw first-hand many kids and teens over the years helping out in the home, providing care for a parent – all without receiving much attention or support. In order to bring more awareness to these young carers and to understand what they need to be supported, I interviewed 40 kids and teens across the US who are currently providing care for a parent with HD. The interviews addressed several areas, including: caregiving tasks, length of time spend caregiving, and how caregiving affected their school performance, emotional development and family life. What I found was an amazing group of kids and teens who help their parent in many ways, from keeping parent company to

bathing and dressing their parent – often for many years. They are able to attend school, but caregiving impacts how well they are doing in school given the time needed at home. Many kids are missing homework, school activities and are just overall too worried to concentrate on their schoolwork. They want to help, but feel overwhelmed and isolated, including from HDSA. Only 10 participants stated they had any involvement with the NYA, chapter, or with a chapter social worker, yet 36 out of 40 stated they "needed more information about HD." To figure out ways to reduce isolation and increase their support, I asked them what they need for support and how can other people help. Below are the responses describing what they need.

Assistance with caregiving – These kids and teens need actual hands on assistance, from "helping me get him around" to "lifting and re-positioning my dad." They also stated having other people to "spend time with the parent" will allow the child or teen to do homework or work outside the home but will also provide "company" to their often isolated parent, something these kids and teens recognized as very important to the family as a whole. Furthermore, the majority of those interviewed said they needed more information and advice on how best to provide care to their parent. Most participants had no training or guidance and were in their words "winging it," including participants who were administering numerous medications to their parent.

Understanding and support – They need understanding from "friends who get it," and specifically from other kids their own age who are also acting as caregiver. They stated they don't like being "treated like some weird family" and needed to feel a sense of normalcy in their lives. These kids and teens also stated very clearly they wanted support groups that are specific to them. These groups will help them express what it is like to be a young caregiver, as opposed to the adult support groups they go to with their families, which they felt were not applicable to their needs.

(Continued on Page 2)

HDSA Annual Convention:



Miss the HDSA Annual Convention in Louisville? Some of the convention sessions will be available on the HDSA website. To find out more, visit www.hdsa.org/convention.

Coping with Speech and Swallowing Difficulties in HD

The second edition of *Coping with Speech and Swallowing Difficulties in HD* by Karen Bryant, Ph.D., CCC/SLP is now available. This book provides information and resources on speech and swallowing problems associated with HD and offers case studies and potential solutions. To order your free copy, please contact Anita Mark-Paul at amarkpaul@hdsa.org or via phone at (800) 345-HDSA, ext. 219.

Acknowledge caregiving role - The study participants need other adults, specifically school personnel, to acknowledge that they, as caregivers, “simply exist.” In a powerful moment, one study participant reported a teacher slamming a book on the desk of the sleeping teen in order to wake her, but not asking why she was asleep. Had this teacher asked, she would have been told the student was sleeping because she was up all night watching her restless, wandering father while her mother worked the night shift to support the family.

These kids and teens clearly detail some very clear ways we as chapters, board members and families can assist them as they care for a parent. Several chapters have addressed youth programming with support groups and weekend camps, including my own, the Wisconsin chapter. For the past three years, we have had a youth track for our state conference, which have been attended by kids, teens and young adults from across the area. There is also a youth track at the HDSA Annual Convention. Youth programming will also help in developing connections to HDSA and others like themselves, while serving to normalize their situation – things clearly stated as a need for this population. While there are many things we as centers, chapters, boards and support group leaders can accomplish to assist young carers, one is to get more involved in the two organizations that specifically address HD youth – and advocate for programs which directly target young carers.

The NYA (National Youth Alliance) has been in existence for many years and is a great resource for our HD youth. They are a division of HDSA, and have been actively involved in engaging youth in programs for many years. On the day before the convention, the NYA has a special day for youth and young adults to talk to people in similar situations. You can find out more about the NYA and how to get involved by visiting www.hdsa.org/nya. Second is the HDYO (Huntington’s Disease Youth Organization), an international group of teens and young adults, many of whom were young carers, who are dedicated to bringing youth issues to the forefront of support programs and services for families affected by HD across the world. For more information, please visit www.hdyo.org.

Providing care supports and services to families affected by HD is an integral part of HDSA’s mission, thus I encourage us all, families, board members, social workers and HDSA staff continue to brainstorm and listen to our youth about how best to support them and their families.

Starting an HDSA Support Group **IN WEST VIRGINIA**

By Debbie Armstrong, Facilitator of the Charleston, WV support group

Huntington’s disease has always been a part of my life. In my earliest memories, my mom had Huntington’s disease. She died in 1974 when she was 42 and I was 12 years old. Predictive testing wasn’t available when my husband and I decided to have children and “play the hand God dealt us”. That became difficult to do as I lived in fear of having HD. I eventually tested negative for HD. There are a lot of issues related to predictive testing, but one thing that I felt was that I was spared for a reason. God had other plans for me. Among them was helping those with HD. One way to do that was to start a support group in West Virginia.

Starting a support group can feel daunting. I know it did for me. There was no support group in WV. I met a couple of people with HD in their lives and I had the thought that we needed a support group, but I didn’t know where to begin. I also doubted whether I had what it takes to start a support group. But I continued to think about it. I started by thinking of where we could have meetings and since I work in a hospital that was the easy part. We are able to use a conference room in the hospital

(Continued on Page 3)

HDSA E-mail List

Want to get more information about HDSA events and activities? Visit the HDSA website at www.hdsa.org to sign up!

Take Action for HD Parity

Go to hdsa.org/takeaction to raise your voice for the Huntington's Disease Parity Act

Upcoming Webinars

June 4:

Talking with Kids about HD

July 22:

Increasing Caregiver Quality of Life

Register at hdsa.org/ccorner

Upcoming HDSA Educational Events

June 12: Boise, ID

August 9: Tampa, FL

without charge. Then I wondered how I would get the word out to the community that there is a HD support group. I drafted a letter to neurologists and psychiatrists in my area and included a flyer about the group. I contacted all of the newspapers in the area and obtained the information to place a free notice in the section of the paper that lists community events.

Time went by with no action on my part. I was afraid I would start a group and no one would come. I was afraid I would fail. I felt too alone with it and I didn't think I could pull it off. Eventually, I contacted the nearest HD Chapter, which was in Cincinnati. The social worker from that chapter, Mary Beth Bialick, was extremely helpful and supportive to me. She gave advice based on her experiences with the group she facilitates in Cincinnati. I went to Cincinnati to attend one of their meetings and I was moved by the experience. I felt motivated to start the group.

However, more time went by with no action on my part. I met a woman with HD with little support in her life and I knew it was time to pull the trigger. I realized that the only way I could fail was to never try.

I found out that my feelings of being alone with it were not even close to being reality. Mary Beth attended a meeting as a guest in our first year. I receive ongoing support from her and she is attending another meeting later this year. Upon seeing a notice in the paper about the HD support group, I received a call from the president of the WV Alzheimer's Association letting me know their group is for Alzheimer's and other related disorders, of which HD is included. She offered their resources and guest speakers to our group. Anne Leserman, a social worker in the national office of HDSA attended a meeting as a guest and she provides ongoing support as well. She has conference calls with support group leaders so we can grow and learn from each other's experiences. With the help from our Regional Development Director, we held a fundraiser. The fundraiser was named "Dine for a Cure," a dinner and silent auction. We raised approximately \$5,000. The current mid-Atlantic Regional Development Director, Shawn Supers is also very supportive. We now have a second support group in WV. It is in Morgantown and was started by Kathy Savage, who is the facilitator. Kathy, with help from Shawn is planning a team hope walk on May 31. To the best of my knowledge it will be the first team hope walk in WV. The Lundbeck rep, Ron Wonsettler has been very attentive and supportive to me and our group. He provides me with literature and information. He has attended our meeting, and I know he supports the Morgantown group as well. He spreads the word about our group to the physicians that treat HD patients. There is support throughout the HD community. I have never felt alone.

Our support group has been a wonderful experience. The members are very supportive of each other and care about one another. Like other groups, we have had members that have come for a while then stop, and members who attend intermittently, as well as members that consistently attend meetings. There are absolutely no expectations regarding group attendance. The group will be there for those who would like to attend. We meet once a month and members are able to communicate via email in between meetings. Our members are quite spread out geographically so sometimes email is a good alternative. Any way support can be shared is encouraged.

I didn't anticipate that in the process of starting a support group I would receive so much support. I can understand why someone would feel hesitant about doing something new and I can understand the fear of taking a risk. However, within the HD community one should never feel alone.

To find out more about starting an HDSA support group, contact Seth J. Meyer, Community Services and Resource Development Manager, at smeyer@hdsa.org or via phone at **(888) HDSA-506**.

Understanding Behavior

Understanding Behavior (Second Edition) by Jane Paulsen, PhD and Arik Johnson, PsyD, is now available!

Thanks to a generous educational grant, HDSA is able to offer this updated guide available to HD families and their medical professionals at no cost.

Since the first edition of *Understanding Behavior* was published in 2000, much has been added to our understanding about HD including behavioral changes that take place along the continuum of the disease.

Written specifically for medical professionals, this second edition contains strategies that can be shared with caregivers as well as case studies that illustrate many of the most challenging behaviors associated with HD.

To obtain a copy of *Understanding Behavior* for your physician, psychiatrist, therapist or family counselor, contact Anita Mark-Paul at amarkpaul@hdsa.org

Hasta La Vista!!

By: Barb Heiman, HDSA Center of Excellence at Ohio State University

Has it really been 510,710,400 seconds since I started working with HDSA??? ! As of June 22, 2014 it will be. As they say, "Seems like only yesterday."

It was 8,511,840 minutes ago that the HDSA Central Ohio Chapter decided to take a chance and hire me "part time". When the Center of Excellence opened at The Ohio State University in 2000, I became a Dual Social Worker, serving both the Central Ohio Chapter and the Center of Excellence in Columbus Ohio. I have been doing "part time all the time" ever since.

A mere 5,911 days ago I committed to do my best to serve the HD population of Central Ohio. I was preceded by a dedicated, resourceful, knowledgeable and much-loved Social Worker, Gladys; a small woman with BIG shoes! I wondered how I would fill them!! And now Sarah Grim has begun to walk the path that Gladys and I have walked for Central Ohio HD families. I welcome Sarah along with the rest of you and I am confident Sarah's shoes are just the right size!

I have stayed around for 844 weeks and 3 days because of the HD families I have had the privilege of working with. They have taught me lessons that would never make it to the medical journals. They have become more than patients and I often call them "my families". I have now been around long enough to see the third generation come to us for information, support and treatment. To be able to be a part of their journey has been an honor for me. They have allowed me into their lives – the good, the bad and the ugly. Their stories and struggles will remain with me always.

At the end of a career some say "it has been a great ride" or "these were the best years of my life" or perhaps "I'm glad it's over!" With HD you wonder how much longer until a cure is found! How many more families will have to face the devastation of this disease? Will I be around to help our families celebrate the long awaited "Cure"??

I thank the families and patients who have taught me so much about life and love and determination. I thank the excellent clinic staff that serves the HDSA Center of Excellence at OSU. Thank you all.

Now 16 years, 2 months and 6 days later I am stepping down from this "part time all the time" job. Goodbye, So Long, Au Revoir, and Hasta La Vista!

Thank you Auspex



QR Code

Please scan here to visit the HDSA website

