

SOUNDINGS

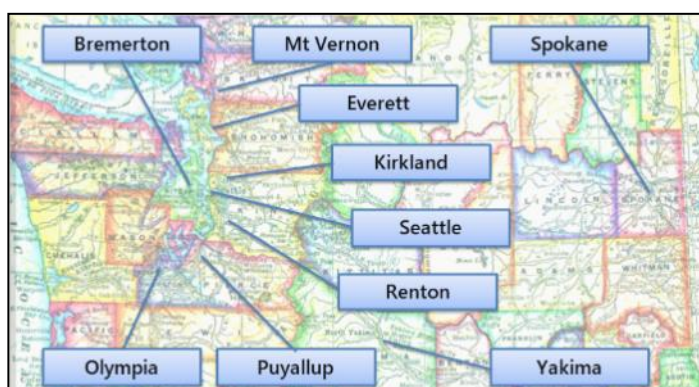


Social workers help families navigate the storms of Huntington's disease

by Vickie Biggs.

The job of social workers is central to HDSA's mission to provide support for HD patients and their families. Social workers, by training, provide resources for housing, medical care, transportation, nutrition support, and, of course, support groups. Social workers become familiar with resources available in a local area as well as those available from the larger HDSA organization. They can answer questions about housing, medical care, transportation, nutrition and, of course, support groups.

Social workers also provide supportive counsel for patients and their family members. As we all know, HD is a complex and sometimes mystifying disease. Families face big issues such as genetic testing, changes in behavior, how to provide daily or long-term care, or when to discuss HD with young children. Social workers can assist individuals and family



The Washington State Chapter oversees many support groups in the area. The group in Yakima was launched earlier this year.

members trying to navigate these difficult waters.

The Washington State chapter of HDSA is fortunate to have a number of support groups available for HD individuals and family members. (See map.) Most support groups are facilitated by a social worker. Support groups provide time for each member to 'check in' with other members, allowing the person time to express feelings and events in a safe environment. All group discussions are confidential. Support groups are a place where members may ask for information, help with problem solving, or share concerns about the progression of HD. Support groups are also, most importantly, a source of comradery and laughter, trust, shared concerns and successes, and inspiration.

More information about local support groups can be found at <http://washington.hdsa.org/about/wa-support-groups>

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Huntington's Disease
Society of America

New chapter president *JUMPS RIGHT IN!*

By Shahilene Dillon, the recently elected board president for the HDSA Washington State Chapter

Happy November! Welcome to the first “2018” edition of our chapter’s newsletter, the SOUNDINGS.

Yes it’s true—I’m the new chapter president. But let me *JUMP RIGHT IN* and point out that we have several new board members and new officers as well. I’m excited to have their new enthusiasm, hard-working spirit and expertise to help this cause.

(For a complete list of new board members and their roles, please skip ahead to page 8)

The rest of the board and I are honored to support HDSA’s mission: to make assistance available to anyone affected by Huntington’s disease.

I also want to share some of the great things we’ve been doing and planning on behalf of all of our HD community.

We sponsored our semi-annual research symposium in February, with the second symposium coming later this month. And in April, we held our most successful Celebration of Hope to date, having brought in twice as



Shahilene Dillon (left) and Melissa Jeng (right) met with Dr. Nancy Wexler at this year’s HDSA National Convention in June. (photo by Jim Bridges)

much money as previous events. So we offer a big **thank you** to all who came and contributed and also to our volunteers who *JUMPED RIGHT IN* and worked so hard!



*This September, Magnusson Park became the base for the annual Team Hope Walk. Once again we gathered for fun, food, and fundraising. Once again we faced off—team against team—family against family. Once again sponsors and vendors mingled with participants and volunteers. And as always, it’s never too late to **support the team**: <http://do.nr/h483m>*

Record-breaking *Celebration of Hope* features food, giving, and live music

By Kathleen Albro

The third annual Celebration of Hope was held on April 7, 2018 at the Resonance in Bellevue. The event was an expansion on last year's event and the results were

exceptional. The silent auction had over 20 items, all of high caliber, and the attendance was over 60 attendees. The highlight was the opportunity to honor two outstanding individuals who have worked tirelessly to spread the word about HD. Dr. Thomas Bird and EJ Garner were acknowledged and then given the chance to share about their role in supporting the HD community.

The evening's silent auction included some very nice items including wine tastings, chocolate tastings, upscale restaurant gift cards, yoga classes, massages, music venues and more. There was also a dessert auction that rewarded the high bid per table group for 10

absolutely decadent cakes and pies. Chocolate indulgences abounded.

The event raised over \$20,000 gross, which doubled the take of any previous Celebration



This chapter's third annual Celebration of Hope event featured a silent auction as well as a dessert auction (below) . And above, the evening's jazz ensemble played some great music for the event. (photos by Jim Bridges)



of Hope event for this chapter. The venue allowed for easy movement to stay close to the bidding process and the menu was heavy hors d'oeuvres which also allowed

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Nora Guthrie never stopped hoping for progress, and is impressed by recent news

by Gene Veritas, aka Kenneth P. Serbin. Gene has a well-known blog called "At Risk for Huntington's Disease." (<https://curehd.blogspot.com/>)

The cause to defeat Huntington's disease came full circle at the recent HD Therapeutics



Nora Guthrie (right) being greeted by Sarah Tabrizi, FRCP, Ph.D., with Blair Leavitt, MDCM, FRCP (left) and Gregory Suter looking on (photo by Gene Veritas, aka Kenneth P. Serbin)

Conference, where keynote speaker Nora Guthrie recalled the brave struggle against the disease by her father, iconic folk singer Woody Guthrie, and the ground-breaking advocacy of her mother Marjorie, the founder of the Huntington's Disease Society America (HDSA).

"We are the hoppers and the changers," said Nora, 68, quoting her father, to the audience of 350 scientists, drug company representatives, and family advocates gathered at the 13th annual meeting in Palm Springs, CA, in late February. "The note of hope is the only note that keeps us from falling to the bottom of the heap of evolution, because about all a human being is anyway is just a hoping machine."

The conference was sponsored by CHDI Foundation, Inc., the non-profit virtual biotech dedicated to developing HD treatments. Like a

number of past keynoters, Nora preferred not to have her presentation recorded. She interweaved her father's music – he wrote "This Land is Your Land" – with the family's struggles against HD.

However, Nora agreed to an interview with me in which she reflected on the early days of HDSA – started in 1967, the year her father succumbed to HD, when she was 17 – and the progress towards treatments.

A vast HD 'tribe'

I was thrilled to meet Nora. Watching and interacting with her helped me connect with a giant of American history as well as with what she called the vast HD "tribe" that Marjorie had started.

Before our formal interview, in conversations with Nora, I also relived key moments in my personal journey with HD.

After her keynote, filled with emotion, I hugged Nora, telling her that my mother had died of HD.

Nora was at first befuddled by my pseudonym, "Gene Veritas." I explained to her that it meant "the truth in my genes," a reflection of my condition as an HD gene carrier.

During one dinner, I told how, in the late 1990s, my efforts to get background on the disease and the cause led me to study Woody's life and watch the 1976 film *Bound for Glory*, based on his autobiography and portraying his early phase as a drifting folk singer. Nora recalled her personal impressions while on the set.

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John the Time Traveller and Linda: Holiday in SPACE?

By John Carlson -- In the spirit of #LetsTalkAboutHD, here is a tale of one day's journey with Huntington's disease—through the lens of a Doctor Who fan and his human companion...

RIGHT! EVEN TIME TRAVELLERS NEED A VACATION! SO, MY DEAR, HERE WE ARE FOR SOME **FUN IN THE SUN !**

ZEEP!
ZUURP!
ZUUURP!

BUT DOES THE BRAVE TIME TRAVELLER HAVE HIS **PASSPORT** WITH HIM?

YOU'RE THINKING OF **LAST TIME** WE TRIED TO GO ON A TRIP. THIS TIME I'M PREPARED! SO LET'S HIT THE **BEACH!**

YOU MEAN, LET'S CHECK OUR BAGS, BECAUSE UNLIKE REAL TIME TRAVELLERS, WE STILL NEED TO **CATCH A PLANE...**

HALT! ...MUST... **EX**-AMINE...TICKETS...

ALERT! PAYMENT **EX**-PIRED!!
HALT OR BE **EX**-TERM-I-NATED!

I THINK YOU BOOKED THE TICKETS... IS IT POSSIBLE YOU FORGOT TO PAY?

WHAT, ME FORGET?
...WAIT, COME TO THINK OF IT...
I PROBABLY DID FORGET TO PAY...

WHAT? OUR TICKETS AREN'T PAIDFOR ??

WELL, SUPER-SCIENTIST'S SOMETIMES FORGET THINGS... BUT I CAN GO **BACK IN TIME**

TO FIX THIS

UM, RIGHT, OR WE COULD TRY THIS THE HUMAN WAY.

WHAT?... WELL..... OK, WHY NOT?

EVENTUALLY,

.....SO, ANY CHANCE WE CAN FLY TODAY **WITHOUT A RESERVATION ?**

TODAY? LET ME CHECK

IT'S MY FAULT. I CAN'T KEEP TRACK OF THINGS LIKE I **USED TO**.

THE DOCTORS CALL IT **HUNTINGTON'S DISEASE...**

YOU KNOW WHAT? I THINK MY GRANDMA HAD

ANYWAY, TAKE A LOOK-I THINK THIS FLIGHT WILL WORK FOR YOU...

PERFECT! YOU SAVED OUR VACATION!

Nora Guthrie, member of HDSA founding family, reflects on recent research news

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"I feel a spiritual connection with you and your family," I told Nora at the outset of our interview. "Thank you for being here, and thank you for speaking out for us, just as your father spoke out for so many people."

As I proceeded to my first question, Nora interjected: "Not just speak out, but speak up."

In that comment, and many of her other responses during the interview, Nora quoted her father or echoed his singular eloquence with her own plays on words and unique phrasing.

I asked Nora what it was like to speak to the scientists.

"For me, it was like a sci-fi movie, because coming from my early years with Huntington's with my father in the late 1940s and early fifties, when there wasn't *one* person you could talk to, not one doctor that knew anything about Huntington's, not one social worker to help you get through it, not one support group," she said. "Our family was kind of inventing how to deal with Huntington's in those days. There were no pamphlets. There were no guidelines. So, we were going day to day, day *by* day, inventing – trying to be creative, trying to be helpful, trying to figure out even what the symptoms were."

Nora recalled the first HD benefit concert Marjorie organized at Carnegie Hall in New

York City in 1968, with Woody's musician friends

Today, Nora said, just at events like the CHDI conference, hundreds of "young, energetic, and smart" people are focused on developing



Folk-artist Woody Guthrie developed HD in the middle of his career. His family went on to found the HDSA to help other families impacted by the disease. His daughter, Nora (right) remains a "hoper and changer" for the HD community^{1, 2}

treatments – all descendants of Marjorie, the "Eve" of the HD movement. To Nora, they represent hope for the community.

A cure: when, not if

I wanted to know what her parents would say about the advances in HD science, if they were alive today.

"I think the most impressive thing for them is an affirmation of their belief in humanity," Nora said. "That people are interested. That people do care. That a cure is down the road. It's just a question of when, not if."

1 Photo from the Library of Congress, public domain.

2 Photo by editrix from NYC - Nora Guthrie at the Brooklyn Book Festival, CC BY-SA 2.0, <https://commons.wikimedia.org/w/index.php?curid=48554346>

Record giving caps exceptional evening

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participants to keep mingling. There was a professional MC who kept things moving and TEVA was a corporate sponsor and several company representatives were in attendance. The company's dedication to supporting HDSA, and various events through underwriting assistance cannot be overstated.

Thanks to everyone who attended this fun and meaningful event!



Dr. Thomas Bird was among those whose legacy was honored at the dinner.

Help make a difference: Volunteers needed!

By John Carlson

HDSA can use your help.

Maybe at the last big fundraiser event you thought, momentarily, "This is a big event, and it sure raises a lot of money. Wonder if they need help?"



Photo by Jim Bridges

Or say that you've been to a couple of support group meetings and found them pretty helpful. Maybe you feel like doing something to give back so the group meet-

ings continue to be available.

Or maybe someone you know who has HD is bewildered by so many big questions they don't know where to start. Then, when you give them the local social-worker hot-line, they ask, how can this be a free call?

The answer to all three questions is surprisingly simple: VOLUNTEERS. The services that HDSA provides are funded through support by donations from people like you and me.

Most of those funds are raised though a small number of events each year, and we could sure use some additional volunteers at each one.

Thanks for your time.



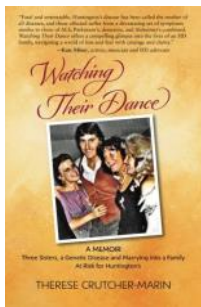
Annual Amaryllis Flower Sale

The Amaryllis flower is a symbol of hope & strength for the HD community . Place your holiday order today!

<http://hdsa.org/shop/flowers-for-hdsa>



 **Huntington's Disease
Society of America**



Watching Their Dance: Three Sisters, A Genetic Disease and Marrying into a Family At Risk for Huntington's

By Therese Crutcher-Marín

Reviewed by Melissa Jeng

First and foremost, I have to humbly admit, I believed this would be an easy fast read. I flew through the first half in one night, which strengthened my belief. I was destined to finish, in no more than 3 nights! Boy. Was. I. Pleasantly. Wrong. Needless to say, twelve nights later, the journey of reading this memoir was complete.

Now, please do not get me wrong, it is an easy, smooth flowing read. It is full of emotion that draws you in, and this is where the slow down stems from. Emotion so real, so raw. Emotion so colorful, so relatable. Some nights I could only read five pages, other nights, I just couldn't get enough.

Therese brilliantly described snapshots of time, events, moments and feelings, that I could not help but to take in the whole story. Snapshots of time, that took me back to similar moments with my mom and my own family. Snapshots of time that made me feel my own feelings, once again. Snapshots of time that helped to accept both the beauty and ugliness of Huntington's Disease.

Therese lovingly tells her story. Lovingly shares vignettes of the various characters within her story. With both grace and mercy, she details the love she has for these characters, her chosen family.

As a member of a Huntington's Disease family myself, I truly appreciate this book and am beyond thankful for Therese and her willingness to share her life love story.

SOUNDINGS



is a publication of the Huntington's Disease Society of America, Washington State Chapter, for the purpose of sharing research news and helpful information for anyone whose life is impacted by Huntington's Disease.

For more information about our chapter: washington.hdsa.org

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