



## News from the Hereditary Disease Foundation

### Meet the HDF Team

#### Julie Porter Celebrates Double Anniversary!

Julie Porter, our director of administration, is celebrating 22 and 44! She's spent literally half of her life with her HDF family on the frontlines of finding treatments and cures for Huntington's disease. As she celebrates her 22<sup>nd</sup> anniversary at HDF, and her 44<sup>th</sup> birthday, she reflects on her journey.

Julie was first introduced to Huntington's disease, Nancy Wexler and the Venezuela Project in her genetics class at Princeton High School.

During college at Columbia University, Julie majored in biology and sociology. "In many of my classes, we discussed Huntington's disease. It always fascinated me – the genetics, biology, sociology and ethics of this complicated disease," she says.



Julie Porter and Nancy Wexler

In her sophomore year, she was thrilled to have a chance to hear Nancy Wexler present the University Lecture, a prestigious talk at Columbia. Julie, an avid Sunday *New York Times* crossword fan, also read about Nancy in that week's *NYT Magazine's* cover story.

Julie recalls that it was one of the last Sunday nights during her senior year that she finally mustered the courage to write and tell Nancy of her longstanding interest in HD and that she would love to meet her.

"I heard back from Nancy the next day that she was looking to hire someone. I was floored! Two days later, I had an interview, and the next day I got the job! I graduated two weeks later. That was 22 years ago."

Monumental developments in HD have happened over the last 22 years. The first animal model for Huntington's diseases was introduced and many more have since followed, the Human Genome Project was completed, and pharmaceutical companies are fueling the search for treatments and cures.

There have been more mundane developments as well.

"It seems hard to believe, but 22 years ago, we did most work by mail or fax. Email and the internet existed, but were hardly commonplace," Julie recalls. "Lots of work was done with pen and paper. Now we're sequencing full genomes in a short period of time at a relatively affordable cost!"

Julie's role at the HDF spans all areas – from fundraising to science administration, from event planning to social media, from donor outreach to corporate sponsorship – she is the 'information center' of the HDF.

Since starting at the HDF, there have also been wonderful personal changes for Julie. She got married and has an amazing 6-year old son.

Nancy Wexler says, "Julie is the star in our firmament! She inspires us all to be better with warmth, humor, compassion and empathy! She gives her all to support HD families and research. We love her!"

"My travels to Venezuela and the Venezuelan HD families inspire me and my work. From 1997 to 2002, I had the incredible opportunity to travel annually to Venezuela for six weeks as a member of the U.S.-Venezuelan HD Collaborative Research Project." Julie's primary job was to oversee the project – managing both the research team and the Venezuelan families who were being examined at the clinic or in their homes. "In my experience, I've witnessed firsthand what life is like for those living – and dying – with HD – both in Venezuela and around the world."

"Twenty-two years ago, I saw the cure in a far-off distant future, if ever. Today, there is a tangible feeling of hope among researchers, pharmaceutical companies and HD families. The cure feels closer than ever! When the cure comes, I plan to be a part of that celebration!"

### **Research Results**

Read exciting news regarding HDF-funded research from Baylor University.

### **Jackie's Walk 4 HD**



Jackie Hamilton (*pictured left*) fought a long battle with Huntington's disease, but she left a legacy of love and compassion to her family and friends. In honor of Jackie, her daughter, Gabrielle Hamilton will hold the 2nd Jackie's Walk for HD on Sunday, October 14, at 10am, at Glen Island Park in New Rochelle, NY.

As part of the Hereditary Disease Foundation's 50th anniversary lineup of events, we invite you to come and join Gabrielle, family and friends for this memorial walk. Fun for the whole family! Entertainment, raffle prizes and more! Visit HDF to learn more and register. Proceeds will benefit the Hereditary Disease Foundation and the Huntington's Disease Society of American Center for Excellence at Columbia University.

### **HDF Symposium and Gala**

We'll continue to mark our 50th anniversary at our Annual Symposium and Gala on Monday, October 22, at 6 pm, at the Harvard Club in New York. Please don't forget to mark your calendar!

For more information, visit [Hereditary Disease Foundation](#)

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