

# We Are HD SA!



Huntington's Disease  
Society of America

Support Group Newsletter • [www.hdsa.org](http://www.hdsa.org) • (800) 345-HDSA • Issue 3, Oct/Nov 2014



## Maureen Ryan asks **THE BIG QUESTIONS**

Maureen "Mo" Ryan is best known as the LaGrange Park, IL based television critic for The Huffington Post. But her last few years have been tough and she dubbed them the "Parent Apocalypse."

Four years ago, her mother was diagnosed with HD. Last year Ryan's father died, leaving her and her siblings to look after her mother's health and affairs.

At the time of the podcast conversation with friend and fellow reporter, Robert Elder, on July 31, 2014, Ryan had chosen not to get tested for HD.

She's remarkably focused on what brings her joy and how to deal with grief. Below, Ryan offers 12 strategies for coping with grief and coming to terms with death. For such a dark subject, there is much laughing on this podcast.

Here is Mo Ryan's list of the "The Big Questions". Please also take time to listen to the entire podcast by finding "The Big Questions" on iTunes, YouTube or SoundCloud. "The Big Questions" is part of Sun-Times Media Local's Podcast Network.

### **1). Ask for help**

I didn't know about Huntington's disease. I didn't know how you interact with someone with dementia. I didn't know how cancer treatments work. That's a really hard thing to go through, feeling completely at sea when someone you love is in a crisis.

One thing that I have found, and everyone's coping strategy is different, is that it's very easy to let yourself get caught up in the hamster wheel of doing tasks FOR people and not just being WITH people.

### **2). Give yourself permission to escape**

Give yourself space to process. That might happen in weird ways. You will find methods of escapism that will surprise you. One of my big ones is just playing solitaire on my phone. I can do that for literally hours, but your brain needs a place to go.

Give yourself mental space. Give yourself permission to escape at times, because, otherwise, you really are no good to anybody.

### **3) See the person, not the disease**

My mom was given this tremendously scary diagnosis and yet I see her laughing with her grandchildren. I see the pleasure that she takes in going out to a restaurant. She does enjoy being with her family. She is super grateful. There is value to her life. There is quality to it.

### **4). The Law of Inversion**

The things that I feared the most - how I would respond to these things- it actually made me stronger in those arenas.

All the biggest fears I had were inverted. I think I am a better parent; I think I am a more patient parent. I hope I am a more giving spouse.

### **5). Reframe**

Please try to see yourself as a hero and not someone who is falling down on the job. Going through a personal crisis affects you deeply on an emotional level.

On top of that, in crisis mode, you have to call this doctor. You have to call that pharmacy. You have to make sure this delivery gets made. There's millions and millions of "admin" things that get dumped on you. What you do is enough.

### **6). Feel the emotions**

Unless you have fully experienced the terrible emotions, the hard things, and experience them on their terms - not on yours - you will not experience the great, fun, enjoyable emotions to the same degree. You don't get one without the other.

### **7). Find your people**

Loving people is hard. Having loved ones in your life means that you will experience pain. You will experience loss, trauma, fear, and it gives people an excuse to share and to be there for each other. There for me, certainly. The amount of support that I got was mind-blowing. It really helped me. It really did.

*(Continued on Page 2)*

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The universe teaches you what you need to know. And it sends the people into your life that need to teach you that.

### 8). Get moving

Having a physical outlet is huge. I go to the gym and I lift weights and I have been taking a weight training class for four years now. I take the class because that's kind of a community for me now.

Think about how you can treat yourself better because if nothing else, you are no use to anyone else if you are not functional, physically or mentally.

### 9). Do one thing at a time

Very big jobs can get broken down into smaller jobs. And those smaller jobs get done over time. And then the big job will be done. Just do one thing at a time.

### 10). Identify what your grief process looks like

Grief is an unpredictable beast. And it's going to be different day to day. But some things will recur. Patterns will recur. Respect that. Respect those grief processes because grief is another form of love. And if you've experienced deep love and a deep bond, the grief is going to be very deep and complex. And it's not something you can control. So figure out what those emotions are, or what those dealing or non-dealing modes are for you. It is just unpredictable.

### 11). Be here now

That intimacy with mortality has changed me a lot. I am living day to day. I don't really look that far ahead or I try not to.

I'm really, really, really trying to do the things that are meaningful to me – continue to maintain and grow the relationships that matter to me. And so I have a really good sense of what I'll be thinking about on my deathbed.

### 12). Just sit

Sometimes when somebody's sick, all you can do is just sit and be there. And you know going back to that quality of life thing, it is like, "What is the quality of life that I can impart to others?" And really "doing" is such a great distraction. But sometimes just "being" is all that you can do – just sitting with someone and holding their hand.

Here is the link to the Chicago Sun Times article and the podcast.

**[buffalogrove.suntimes.com/2014/07/31/  
big-questions-12-strategies-dealing-grief](http://buffalogrove.suntimes.com/2014/07/31/big-questions-12-strategies-dealing-grief)**

## HUNTINGTON STUDY GROUP

### 8th Annual HD Clinical Research Symposium and HD Education Day for Families

**Saturday, November 8, 2014 8AM-3:30PM**

Minneapolis Minnesota

Featuring updates on the most recent clinical findings and HD research

Register now at **[www.huntington-study-group.org](http://www.huntington-study-group.org)**

## HDSA Law Enforcement Education Program

### For Family Members & Caregivers

*Caregiver Guide to working with Law Enforcement:* This booklet contains general guidelines for working with law enforcement.

*I have HD Card:* A wallet card with information about HD.

*HD Profile Card:* A form that can be personalized with an individual's photo and identifying information.

*My Crisis Template:* A form that can be personalized with emergency numbers.

### For Police & First Responders

*HDSA Law Enforcement Training Guide:* This booklet contains an introduction to HD, and information about managing the motor disorder, the cognitive disorder, and the psychiatric disorder.

*Key Points for Law Enforcement:* A one-page document containing key points for law enforcement.

You can also order a free copy of the toolkit (one per person) by contacting Anita Mark-Paul at [amarkpaul@hdsa.org](mailto:amarkpaul@hdsa.org) or via phone at (800) 345-HDSA.

View the law enforcement materials on our website: [www.hdsa.org/lek](http://www.hdsa.org/lek)

## Lauren Holder HDSA Person of the Year, 2014

A common thing that happens in the Huntington's community is people mistaking a person with Huntington's as a "drunk person". This usually leads to arrests of being drunk in public or disorderly conduct because the person with HD gets agitated with the officer who is trying to arrest him/her for something he/she hasn't done. There are other issues that come up on a regular basis – domestic disputes within the home, a person with HD running off or missing, problems with driving, etc. All of these end up involving law enforcement officials who know nothing about Huntington's disease.

This became very personal for me when my father went missing for 12 hours in Florida. I live in North Carolina, and when I contacted the local police department in my dad's area, they were unwilling to help me or even take information about Huntington's disease. This was unacceptable to me! It is also what motivated me to reach out to law enforcement in my own area to educate them about HD and the many situations that a law enforcement officer or even EMS might encounter.

I reached out to my local law enforcement in Winston-Salem, NC, first. I took the HDSA Law Enforcement Kit to them and discussed HD with the officer I met with and told him my personal story. It was a very successful meeting and the officer promised to work the information into their training.

I wanted to do more. One of the HDSA NC Chapter board members had mentioned reaching out to the National Alliance on Mental Illness (NAMI). So I did. I contacted several different NAMI affiliates in several counties via email and told them my story as well as offering to send them the HDSA Law Enforcement Kit. I then contacted the state level NAMI board to see how I could get the material from the Law Enforcement Kit into the Crisis Intervention Training they provide to law enforcement in NC. I was invited to speak at the Crisis Intervention Training Committee meeting. This was extremely beneficial. I told my story and explained HD and what I was trying to do. I got an overwhelming response to help. I've now been invited to many different CIT meetings across NC to present the material myself. I also gave the Law Enforcement Kit to all the trainers who were present that day.

All it took was an email. All it took was showing someone else why I am so passionate about this, why it mattered to me and why it should matter to others. All it took was caring enough to speak up. The motto, "Help For Today. Hope For Tomorrow" should not be just words. In order to turn those words into action and help today, we must speak up, we must participate, we must make those words mean something – to ourselves and to others. When we do that, we provide hope for a better tomorrow.

## Understanding Behavior

*Understanding Behavior* (Second Edition) by Jane Paulsen, PhD and Arik Johnson, PsyD.

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* please see our website or contact Anita at [amarkpaul@hdsa.org](mailto:amarkpaul@hdsa.org)

[hdsa.org/living-with-huntingtons/publications/understanding-behavior-1.html](http://hdsa.org/living-with-huntingtons/publications/understanding-behavior-1.html)

## What is the Pride-HD Study?

The purpose of this randomized, double blind study is to see what effect the investigational drug, pridopidine, has on movement, thinking, and behavior, compared to placebo, in people with Huntington disease after 26 weeks of receiving either pridopidine or placebo. In addition, information will be collected about safety and tolerability of pridopidine in people with HD.

## Who is running the Pride-HD Trial?

Pride-HD is a joint collaboration between the Huntington Study Group (HSG) and the European Huntington Disease Network (EHDN). 400 participants will be enrolled globally at approximately 51 study sites. Participants will receive either pridopidine or placebo for 26 weeks.

The study is sponsored by Teva Branded Pharmaceutical Products.

## Who is eligible to participate in the Pride-HD Trial?

You may be eligible to participate in the study if you meet the following requirements:

- You are over the age of 21
- Have a diagnosis of Huntington disease
- Have a caregiver willing to attend study visits with you
- Have no history of significant heart disease, epilepsy or seizures within the last 5 years, or serious medical illness
- Have not been treated with tetrabenazine within 6 weeks of study screening.

## How can I learn more about the Pride-HD Trial?

For more information, call or email the **Huntington Study Group 1-800-487-7671** or [info@hsglimited.org](mailto:info@hsglimited.org), or visit [www.huntington-study-group.org](http://www.huntington-study-group.org)

## Thank you Auspex



### QR Code

Please scan here to visit the HDSA website



## TEAM HOPE Walks - Nov. Dec.

### Walk City & State

### Walk Date

### HDSA URL

Holyoke, MA	10/18/2014	<a href="http://www.hdsa.org/thwholyoke">www.hdsa.org/thwholyoke</a>
Mt. Juliet, TN	10/18/2014	<a href="http://www.hdsa.org/thwmtjuliet">www.hdsa.org/thwmtjuliet</a>
Dallas/Ft. Worth, TX	10/19/2014	<a href="http://www.hdsa.org/thwdallas">www.hdsa.org/thwdallas</a>
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