We Are HDSA!

Huntington's Disease
Society of America

Support Group Newsletter • www.hdsa.org • (800) 345-HDSA • Issue 3, June 2013

Diplomat **Profiles**

Cheryl

I am an HDSA Clinical Trials Diplomat because I want to be instrumental in helping the HD Researchers find a treatment or a cure as quickly as possible. I am hoping that, by making more people in the HD Community aware of all the trials that are currently available and recruiting people, the increased number of participants will make the researchers be able to find a favorable outcome sooner!

HDSA Clinical Trials Diplomats are HD family members who believe that clinical trials are important to advancing HD research.

Invite an HDSA Diplomat to your support group or educational event! Contact Jane Kogan, Education & Advocacy Manager, at **jkogan@hdsa.org** for information about scheduling an HDSA Diplomat as a speaker.

Help HDSA spread the message of research & hope! Contact Jane Kogan to learn more about how YOU can become an HDSA Clinical Trials Diplomat

Judi

I am an HDSA Clinical Trials Diplomat because I care about all Huntington's families and I want to offer hope.

Jeanette

I signed up to be an HDSA Clinical Trial Diplomat because I didn't sign up for HD! There are a LOT of out-of-control things regarding HD. But finding a cure? ... This is something we have control over. We didn't sign up for HD but we can sign up to make it end!

Caregiver's Corner Webinars

June 12: Estate Planning

July 23: Financial Planning

August 20: Driving Cessation

Register and watch archived webinars at **www.hdsa.org/ccorner**

New Resource Highlights

This month, HDSA is premiering two new resources:

Handbook: *Talking with Kids about HD*

HDSA Family Guide Series: *Advance Directives & HD*

Order your copy online at **www.hdsa.org/publications** or contact Anita Mark Paul at **amarkpaul@hdsa.org** to request.

Advocacy

Please contact your Representative and Senators about the *Huntington's Disease Parity Act*, legislation that would improve access to financial benefits and healthcare for individuals disabled by HD. Go to **www.hdsa.org/takeaction** to participate.

Internet Resources for the HD Community

By Karen Tarapata

It makes sense to become informed about HD; know your rights, learn your options for respite and long term care, etc. But where can you find this information? The Internet provides access to vast amounts of material on just about any topic. The difficulty is finding it. Search engines like Google and Yahoo may give results that are too broad to help answer your specific question.

The HDSA website has been designed to help you begin your online research into HD-related topics. For example, you can find many HDSA publications for download or purchase on the Publications page. These materials include Fast Fact pamphlets and the full range of Family Guides, as well as longer guides on various aspects of clinical care. The Publications page can be found at **www.hdsa.org/publications**. Links to online resources on the HDSA website can be found at **www.hdsa.org/onlineresources.** Exploring the HDSA website can provide you with many resources that can help you, your family, and others you know.

While HDSA has made an effort to provide links to reputable websites, inclusion of a link in the HDSA Resource Directory does not constitute endorsement by HDSA and the links are provided for informational purposes only. That brings up an important issue - how can you tell if information you find online is factual?

Here are a few ways to determine if a website is reliable:

- Does the URL end in .gov, .edu, or .org? This is usually a good sign. A website ending in .gov indicates a government website, .edu means the site is affiliated with an educational institution such as a college or teaching hospital, and .org indicates that the website was created by a not-for-profit organization.
- Is it a blog or personal website? Blogs are wonderful for essays on personal experiences and opinions, but medical information is another story. Anyone can publish on the Internet. If a website offers you medical advice, check the author's credentials. Do they have a degree in the field? Are they affiliated with an recognized organization or institution?
- Are they trying to sell you something? Many websites will post truthful information, but then try to sell you legal services, supplements or other goods. Be very wary when the information is tied to making a sale.
- Does what they say sound too good to be true? If someone writes about a miracle cure or a treatment that is being "suppressed," be cautious. The research community is working very hard to develop treatments and cures for HD, not to keep them from the public.
- Is it a "wiki?" Wikis, such as Wikipedia, the online encyclopedia, are often excellent sources of information and additional links, but be aware that anyone can edit a Wikipedia article and that incorrect and untrue information may be posted on a wiki. Double check important information, if you can.

If you have questions about information you have found online, bring it to your support group, post it to an online HD forum or talk to your HDSA social worker (find a listing of HDSA social workers at **www.hdsa.org/sw**). Someone may be able to verify or disprove what you have read or offer another resource you can check. On the other hand, you may have discovered something new and useful that you can share with the community.

HDSA Information

28th Annual HDSA Convention
June 21-23, 2013

To find out more information about the convention or to register please visit **www.hdsa.org/convention.**

JAX
2013
Huntington's Disease
Society of America
28TH ANNUAL
CONVENTION
Jacksonville, FL June 21-23, 2013

Live Stream

Can't come to Convention? HDSA will be live streaming selected workshops from this year's Annual Convention. They will then be archived on the HDSA website. Find out more at **www.hdsa.org.**

We Are HDSA!

Like *We Are HDSA!?* Then sign up to receive it by e-mail! Send an e-mail to Seth J. Meyer at **smeyer@hdsa.org** with your e-mail address and ask to be signed up for the *We Are HDSA!* e-mail list today. Past issues of *We Are HDSA!* can be found on the HDSA website.

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!

GETTING HELP from JAN

By Anonymous

I work in advertising as an Account Manager, specifically for a photography studio. My day to day responsibilities are to make sure my clients are getting what they need on time and under budget. I have been in this industry for my entire working career and I know the business very well. Among my peers, I am well known, liked, and respected.

Over the past couple of years, it has become increasingly hard to keep everything straight. The most surprising aspect to me is that I don't have the sense of urgency to do so. It's very hard to explain, but it's almost like staying out past your curfew and knowing that you will get in trouble, but you stay out anyway. Being the Account Manager, I am ultimately responsible for the state of any of my accounts. If a deadline is missed, a product not shot or a model not booked, it eventually becomes my responsibility.

I could tell that my boss was getting increasingly frustrated with the mistakes that I was making and the increased time that it was taking me to get things done. I decided to disclose my HD status in hopes that we could find a way to work together. Months passed and it didn't seem to sink in to him that this was a real issue for me. He would just get annoyed and say things that made me feel inferior, incompetent and very upset. I would end up in tears at least 3 or 4 times a month after work, when I was alone. Every day was an uphill battle to just "get by" in my position. I knew that it wasn't going to get any easier, as the disease progresses slowly for a very long time.

One particularly trying day, I was driving back from a clients office when I received a call from Jane Kogan at HDSA regarding some advocacy issues. I told her about the trouble that I was having at work. She suggested that I call the Job Accommodations Network (JAN). I never considered that because I'm not "symptomatic", they would be able to help me. Jane explained that they are there for exactly that reason. They want to keep us in the workforce as long as possible. Early intervention could save my job and the humiliation of being fired for poor performance.

The people at JAN were wonderful from the first phone call. I told them about my difficulty concentrating and that I am easily distracted. They suggested that I speak to my boss and ask if he could offer me certain accommodations that would make my day to day work less stressful. They made the following suggestions:

- Move my cubicle to a less trafficked area with a floor to ceiling wall so that I could concentrate better. Taller walls to help cancel noise.
- Use a noise canceling headset.
- Change my work hours and/or lunch hour to have a quiet time in the office.
- Suggest a job restructure.
- Set specific times that I can turn the ringer off on my phone and not be interrupted.

They explained to me that my boss also has a say in the process. Does he feel like he is getting from me what I was hired for? Does he require a note from my doctor to consider these accommodations?

JAN also gave me their website information (**www.askjan.org**) and a toll free number (**800-526-7234**) to call if I had any questions. They followed up with me two or three times to see how my meeting went and if my boss was agreeable. They also followed up just to see how things were working out at the office.

I would strongly suggest that if you are experiencing any issues at work, especially these early stage, ambiguous, frustrating issues, that you give JAN a call. They listened with understanding, which is exactly what I needed, and helped provide realistic changes that allowed me to continue working.

In the **THICK OF IT**

What You Need to Know About Thickened Liquids

By Ann Gaba EdD, RD, CDN, CDE, Assistant Professor of nutrition at the CUNY School of Public Health

Why are some people with HD told to drink only thickened liquids?

Coughing, choking, and having beverages "go the wrong way" is a common problem for people with HD. This is most likely to happen with thin liquids, like water, because these are the most difficult for the throat muscles to control during swallowing. An evaluation by a Speech Pathologist can determine why this is happening and recommend the consistency of liquids that would be best to decrease this problem.

Having problems with swallowing foods or beverages is sometimes called "dysphagia". The National Dysphagia Diet (NDD) is the standard of care for adjusting diets for people with swallowing problems. Once you have a recommended diet consistency, a Registered Dietitian (RD) can use the NDD guidelines to help you create a menu that incorporates your favorite foods in a way that reduces your risk of coughing or choking.

Thickened liquids are an important part of a diet for safer swallowing. Some descriptive terms for thickened liquid consistencies that you may hear include: "nectar thick," "honey thick," and "spoon thick."

"Nectar thick" liquids have slightly more body than thin liquids, but still can pour easily. Some examples include tomato juice, pear nectar, peach nectar, apricot nectar, and some bottled fruit smoothies.

"Honey thick" liquids are liquids that pour slowly, like honey or molasses. When you tip a spoonful of a "honey thick" liquid, the liquid slowly drizzles off. An example would be a very thick milkshake.

"Spoon thick" liquids you can eat with a spoon, like pudding or custard. If you tip a spoonful of a "spoon thick" liquid, it will come off the spoon very slowly or not at all. Spoon thick liquids are too thick to drink with a straw.

If I need thickened liquids, how can get them?

Many stores sell brick packs of pre-thickened liquids that are labeled as to the specific consistency of the product. They look much like a typical juice box and are handy to grab when you'll be away from home. Some examples of pre-thickened liquids available in this form are milk, lemonade, fruit juices, and even thickened water. If you are unable to find these at a store near you, they can also be purchased on-line and delivered to your home.

You may prefer to create your own customized thickened beverages. If so, there are products that you can add to any liquid you choose to achieve the desired consistency. Some examples are "Thicken Up" and "Thick It". These are widely available in drug stores or can also be purchased on-line. Be sure to follow the package directions for best results.

If you are already a master manipulator of food consistencies, you may want to try some other tactics for thickening your liquids. For example, for shakes or smoothies you may want to add pureed fruit instead of juice, or maybe a mashed banana. Adding powdered banana is also an option. Be sure to blend it thoroughly for the best consistency and taste.

For hot liquids such as soup, try instant mashed potatoes or instant baby rice cereal, stirred in while the soup is heating. Cornstarch or flour can also be used to thicken hot liquids, but should not be added directly because they can cause lumps. Dissolve the flour or cornstarch in a little cold water first, or stir it into melted butter or oil (what the French call a roux), before adding it to your product.

Once you know the basics, you can experiment to individualize the best consistency for you. Enjoy all you favorite flavors and swallow safely!

1. National Dysphagia Diet: Standardization for Optimal Care. National Dysphagia Diet Task Force (2002). Chicago, IL: American Dietetic Association.

Moving Together
Lundbeck

Thank you

HDSA thanks Lundbeck for the educational grant that made this newsletter possible.

Scan here to visit the HDSA website