



# Caregiver's CORNER

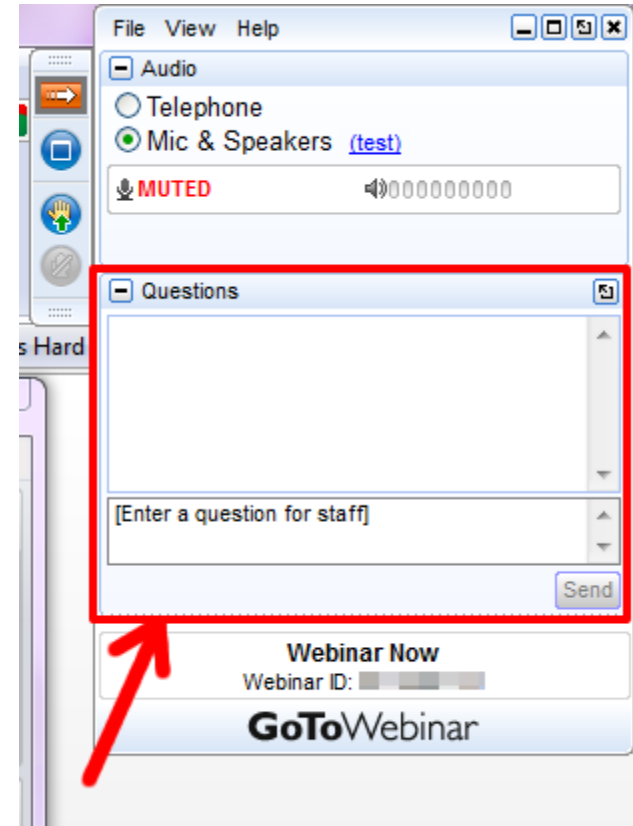
HDSA welcomes you to  
Caregiver's Corner

Funded by an educational grant from



# Questions

- Questions will be answered after the presentation.
- However, you may send a question anytime during the presentation.
- To send a question, go to the control panel that appears on the right side of your screen.
- There will be a panel for typing in a question.
- After typing your question, hit the “send” button



# To View this Webinar Again

- Approximately one week after this webinar is broadcast, you will be able to access it for viewing on the HDSA national website.
- To access this presentation, go to [www.hdsa.org/ccorner](http://www.hdsa.org/ccorner). You will be able to view the webinar recording, as well as download a copy of the presentation as well as past presentations.
- You can find HDSA Lunch & Learn webinars at [www.hdsa.org/ll](http://www.hdsa.org/ll).

# Future Webinars

**Wednesday, June 4:** Talking with Kids about HD

*HDSA Caregiver's Corners can be found at [www.hdsa.org/ccorner](http://www.hdsa.org/ccorner)*

*HDSA Lunch & Learns can be found at [www.hdsa.org/ll](http://www.hdsa.org/ll)*

*Contact Jane Kogan at [jkogan@hdsa.org](mailto:jkogan@hdsa.org) to suggest future topics*



## Building Your Local Care Team

Seth J. Meyer, LMSW  
Community Services and Resource  
Development Manager

Huntington's Disease Society of America

## Building your local care team

- What is a care team?
- How can one start finding members of a local care team?
- What resources are available to my care team?

What is a care team?

## Care Team

- An interdisciplinary team that works together to provide care for a person with HD and their caregiver.
- Not every member of the care team is required at every stage of the disease.
  - Care team members may change based on the needs of the person with HD and their caregiver at any particular time.
- The care team can consist of a mixture of professionals, volunteers, and loved ones.
- If you have a professional that you like who does not know much about HD, that's fine. We can help!
  - It is important for you and your loved ones to find someone who everyone feels comfortable with.





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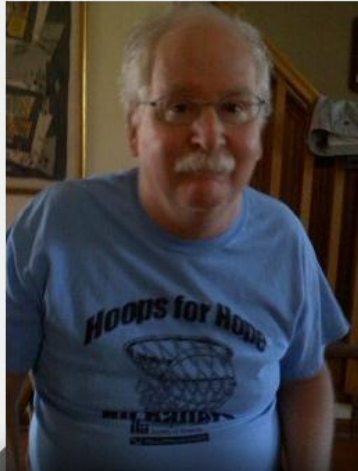
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## FACES OF HD Meet Bob

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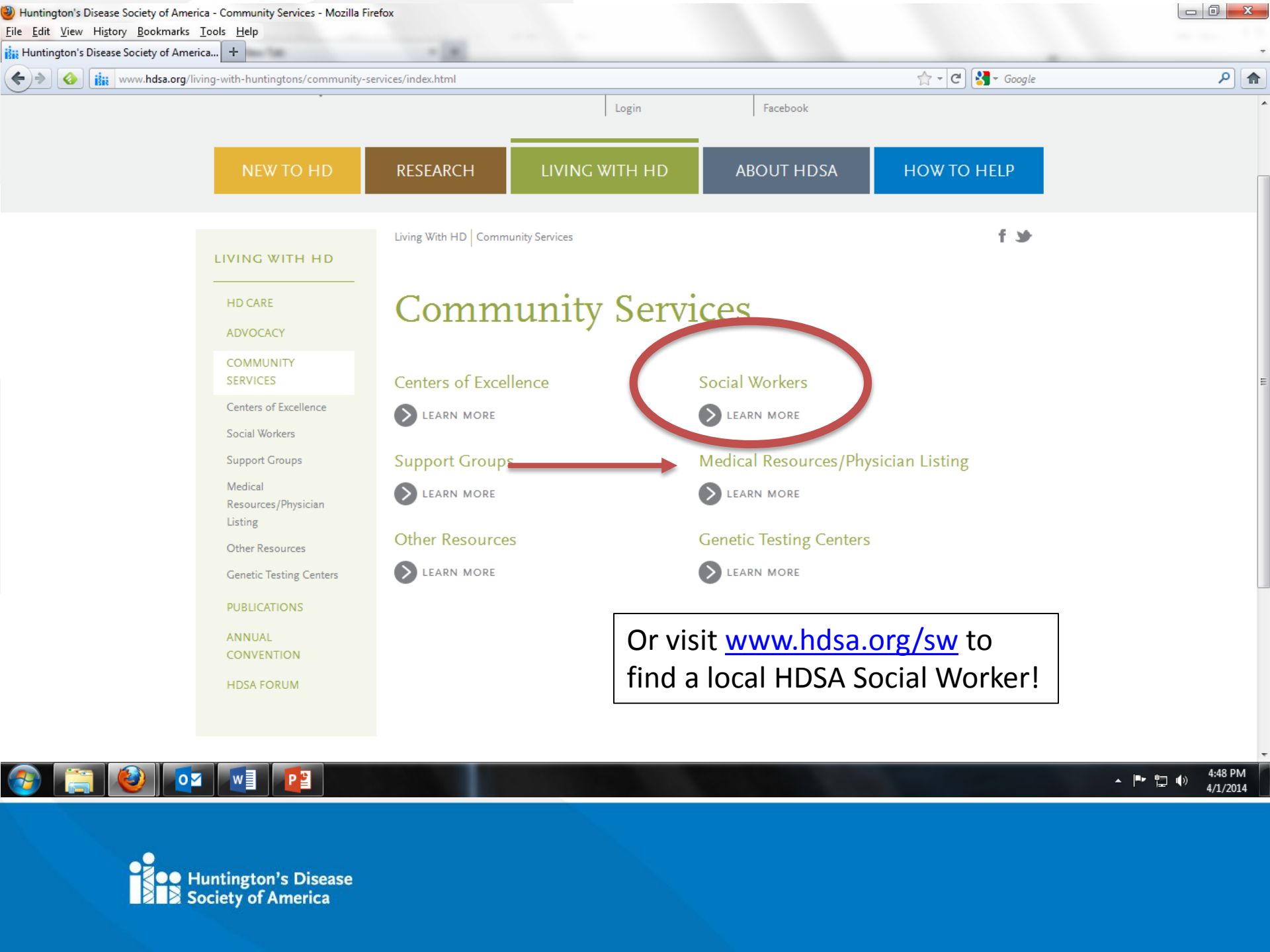
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## Finding Professionals

- Every person with HD is unique.
  - You may not click with every professional, no matter how good they are.
  - It is important to find a professional that you or your loved one like.
- HDSA Social Workers can talk to you about different professionals they have worked with in the past.



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Or visit [www.hdsa.org/sw](http://www.hdsa.org/sw) to find a local HDSA Social Worker!

# The HD Care Team

## Speech-Language Pathologists

- Can help provide guidance concerning swallowing issues.
  - Provide swallowing tests.
- Can provide help with information on communication devices.
- How to find a local SLP.
  - Visit [www.asha.org/findpro](http://www.asha.org/findpro).
  - Search based on state or city.

## Physical Therapy

- Can help provide therapies to manage certain symptoms of HD.
  - Exercises can sometimes help manage balance and gait of people with HD.
  - Helps promote coordination and ambulatory skills in the later stages of HD.
- The amount of time spent with a Physical Therapist depends on need and availability.
  - Some people might be able to do programs at home while others may need to see a PT more regularly.

# Move Forward.™ *Physical Therapy Brings Motion to Life*

- Symptoms & Conditions
- Why Physical Therapy?
- Patient Resources
- Find a PT**
- For Health Professionals

Search our resources  Search >



### Down Syndrome

Learn how physical therapists help children with Down syndrome.

[More »](#)

1 2 3



### Symptoms & Conditions

Browse by symptoms, conditions, or diagnoses to learn how a physical therapist can help you. [Move Forward!](#)



### Interactive Body

Browse by body part to learn how a physical therapist can help you. [Move Forward!](#)



### Tweets

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 **Move Forward** 11 Apr  
@MoveForwardPT  
"You may have a significant amount of pain but that doesn't mean you have a significant amount of injury" @joebrenc9 [bit.ly/PUi8un](http://bit.ly/PUi8un)  
[Expand](#)

 **Move Forward** 10 Apr  
@MoveForwardPT  
The top 9 things you should know about pain by

### Did You Know?



Every 25 seconds, a youth athlete heads to the emergency department.

### Move Forward Radio



Find a PT and more information about Physical Therapy at [www.moveforwardpt.com](http://www.moveforwardpt.com)



Find an AlterG near you

**ALTER G**



## Occupational Therapy

- Provides help in maintaining and improving quality of life for a person with HD.
  - Makes recommendations on modifications concerning the physical or cognitive symptoms associated with HD.
  - You can look for “Occupational Therapist” under [Healthgrades.com](https://www.healthgrades.com) to find one near you and see how other people have felt about their experiences.



## Primary Care Physician

- A PCP can help provide support with other issues a person with HD might be having.
  - HD does not happen in a vacuum.
  - Everyone should have a Primary Care Physician to go to for issues.
  - HDSA has a section for doctors to learn more about Huntington's disease.
  - Talk to your insurance company to find local doctors.
  - Ask your friends about their Primary Care Physician.

## Psychiatrist

- The psychiatric disorder associated with Huntington's disease can sometimes be more debilitating for the person with HD and more difficult (sometimes traumatic) for the caregiver than the movement disorder.
  - A Psychiatrist can work with the person with HD to prescribe medication to manage certain symptoms of Huntington's disease.
  - There are many websites for finding a Psychiatrist, but the best way is to ask friends, doctors, and neighbors.
    - It is important to find someone that the person with HD likes. HDSA can provide the Psychiatrist with help and information on treatment.
  - A Psychiatrist is a physician who can write prescriptions.

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2013  
Research Investor's Report

RESEARCH

# 2013 Research Investor's Report

Read more about HDSA's research  
investments for 2013

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## Registered Dietician Nutritionist (RD/RDN)

- Over the course of HD, nutritional needs may change for a variety of reasons.
  - People with HD sometimes lose the ability to swallow liquids and solid foods, which leads to choking.
  - People with HD will generally require significantly more calories.
- A dietician or nutritionist can help prepare a caregiver for different aspects of HD and making eating a more enjoyable process for the person with HD.
- An RD/RDN is generally seen as needed as opposed to consistently.

Home > Public



## Your Food and Nutrition Source

# It's About Eating Right

It's All About Eating Right  
You realize the importance of making informed food choices and developing sound eating and fitness habits. The Academy of Nutrition and Dietetics and registered dietitian nutritionists, the food and nutrition experts, are here to help you find accurate information to support your healthful lifestyle.

### In This Section

- [Healthy Weight](#) »
- [Food & Nutrition Topics](#) »
- [Diseases, Allergies & Health Conditions](#) »
- [Children's Health](#) »
- [Women's Health](#) »
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### Popular Diet Reviews

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Mouse over these links to get a quick glance at important featured content:

- [Videos](#)
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### LATEST ACADEMY FOOD AND NUTRITION INFORMATION

#### Happy Passover!



A staple of many Passover meals is matzah, a thin, cracker-like unleavened bread. Tradition states matzah served during Passover should be made with only water and flour, but year-round versions can include flavoring like onions and garlic.  
[Learn More »](#)

#### Sautéed Herbed Wild Mushrooms Recipe



Fresh from the market mushrooms, add B vitamins, vitamin D, potassium and selenium to dishes, yet with few calories and essentially no sodium or fat. Enjoy these sautéed herbed mushrooms over polenta, tossed with pasta, spread over pizza crust, or as a side for meat, poultry and fish.  
[Learn More »](#)

#### Grow Your Own Food



Nothing compares to the taste of a tomato just picked from the vine or a cucumber from your own backyard. Gardening is a fun physical activity, provides you with great tasting produce and ultimately, saves you many trips to the store.  
[Learn More »](#)

#### Eat Right and Drink Responsibly



Alcoholic beverages such as beer, wine and spirits have been enjoyed by people throughout recorded history, and today is no different. For some, a single drink may add enjoyment to a meal, but the key to potential health benefits has always been moderation.  
[Learn More »](#)

Find out more about Nutrition and Dieticians at [www.eatright.org](http://www.eatright.org)

Your source for scientifically-based health and nutrition information you can trust to help your child grow healthy.

#### What's New:

- [Perfecting the Breast-feeding Technique](#)
- [Eat Together as a Family](#)
- [Fruited Bulgur Breakfast](#)
- [Getting Breakfast on the Table](#)

#### Watch and Learn [More How Do I...»](#)



## Psychologist

- A psychologist can help a family manage the psychiatric symptoms of HD.
  - While a Psychiatrist might provide medication management, a Psychologist may provide other ways for the person with HD and the family to help manage the symptoms.
  - A Psychologist can help provide a safety plan along with interventions for managing aggression and other dangerous behaviors.
  - As with a Psychiatrist, it is best to talk to friends, professionals, and neighbors for people they have worked with. The most important thing is to find someone the person with HD and the caregiver feel comfortable with.



## Dentist

- Dental care can be difficult due to the movement disorder associated with Huntington's disease.
- It can be tough to find a dentist in your area.
- Dental Lifeline Network ([www.dentallifeline.org](http://www.dentallifeline.org)) can sometimes provide free dental care for people with medical conditions.
  - There is often a waitlist between a couple of months and a couple of years.
- Organizations such as ARC and AHRC sometimes have dentists that they would recommend for their clients.

## Hospice Team

- End of life care is very important.
  - Hospice can be utilized to help make sure that your loved one is comfortable.
  - Support for both the caregiver and the person with HD is provided in hospice.
- There are many services that open up once hospice gets involved.
  - Have early conversations about what the person with HD wants at the end of their life.





# National Hospice and Palliative Care Organization

Email... Password... GO

Create new account Forgot Password?

Search NHPCO... GO

ABOUT NHPCO	MEMBERSHIP	REGULATORY	ADVOCACY	QUALITY	RESOURCES	EDUCATION	PRESS ROOM
<b>Hospice &amp; Palliative Care</b> ----- <a href="#">History of Hospice Care</a> <a href="#">Key Hospice Messages</a> <a href="#">Hospice FAQs</a> <a href="#">Facts and Figures</a> <a href="#">Medicare Hospice Benefit</a> <a href="#">Palliative Care</a> <a href="#">Find a Care Provider</a> <a href="#">Advance Care Planning</a>	<b>Labyak Institute</b> ----- <a href="#">Mary J Labyak</a> <a href="#">Institute Centers</a>	<b>Access</b> ----- <b>Children's/Pediatrics – ChiPPS</b> ----- <b>Veterans – WHV</b> ----- <b>Advance Care Planning</b> ----- <b>Hospice Statistics &amp; Research</b> ----- <b>Inclusion and Access Toolbox</b> ----- <b>End-of-Life Care Resources</b> ----- <b>Hospice Provider Start Up Guide</b> -----	<b>Caregiving</b> ----- <b>Grief and Bereavement</b> ----- <b>Rural Providers</b> ----- <b>Corrections</b> ----- <b>Outreach Tools</b> -----				

**INTENSIVE**  
June 16-17, 2014

Hospice Action Network

- April 7, 2014  
Regulatory Round Up - March 2014
- April 7, 2014  
National Volunteer Week



- [Conversations Before the Crisis \[PDF\]](#)
- [If You or Someone You Love is Very Ill...Ask Tough Questions \[PDF\]](#)
- [Artificial Nutrition and Hydration at the End of Life \[PDF\]](#)
- [Communicating End-of-Life Wishes \[PDF\]](#)

### Caregiving

- [How to Support Someone Caring for Another \[PDF\]](#)
- [End-of-Life Caregiving Booklet \[PDF\]](#)

### End-of-Life Care

- [What is Hospice? \[PDF\]](#)
- [Choosing a Quality Hospice for You or Your Loved Ones \[PDF\]](#)
- [Hospice Care: A Consumer's Guide to Selecting a Hospice Program \[PDF\]](#)
- [Hospice Care and the Medicare Hospice Benefit \[PDF\]](#)
- [Hospice Volunteers: Helping People LIVE \[PDF\]](#)
- [What is Palliative Care? \[PDF\]](#)
- [How Can Palliative Care Help Me? \[PDF\]](#)
- [The Dying Process-A Guide for Family Caregivers \[PDF\]](#)

### Grief

- [Supporting Someone Who is Grieving \[PDF\]](#)
- [There is no Wrong or Right Way to Grieve After a Loss \[PDF\]](#)

### Pain

- [How to Manage Your Pain \[PDF\]](#)
- [Using Narcotics Safely \[PDF\]](#)

### Pediatric

- [When Your Child is in Pain \[PDF\]](#)
- [Talking With Your Child About His or Her Illness \[PDF\]](#)
- [Talking to Your Child's Doctor: When Your Child Has a Serious Illness \[PDF\]](#)
- [When a Child Dies: A Guide for Family and Friends \[PDF\]](#)
- [Helping Children Cope with the Loss of a Loved One \[PDF\]](#)

### Professional Resources

- [A Guide for Clinicians \[PDF\]](#)
- [Advice for Physicians Caring for Dying Patients \[PDF\]](#)
- [Palliative Care: Information and Resources for Healthcare Professionals \[PDF\]](#)

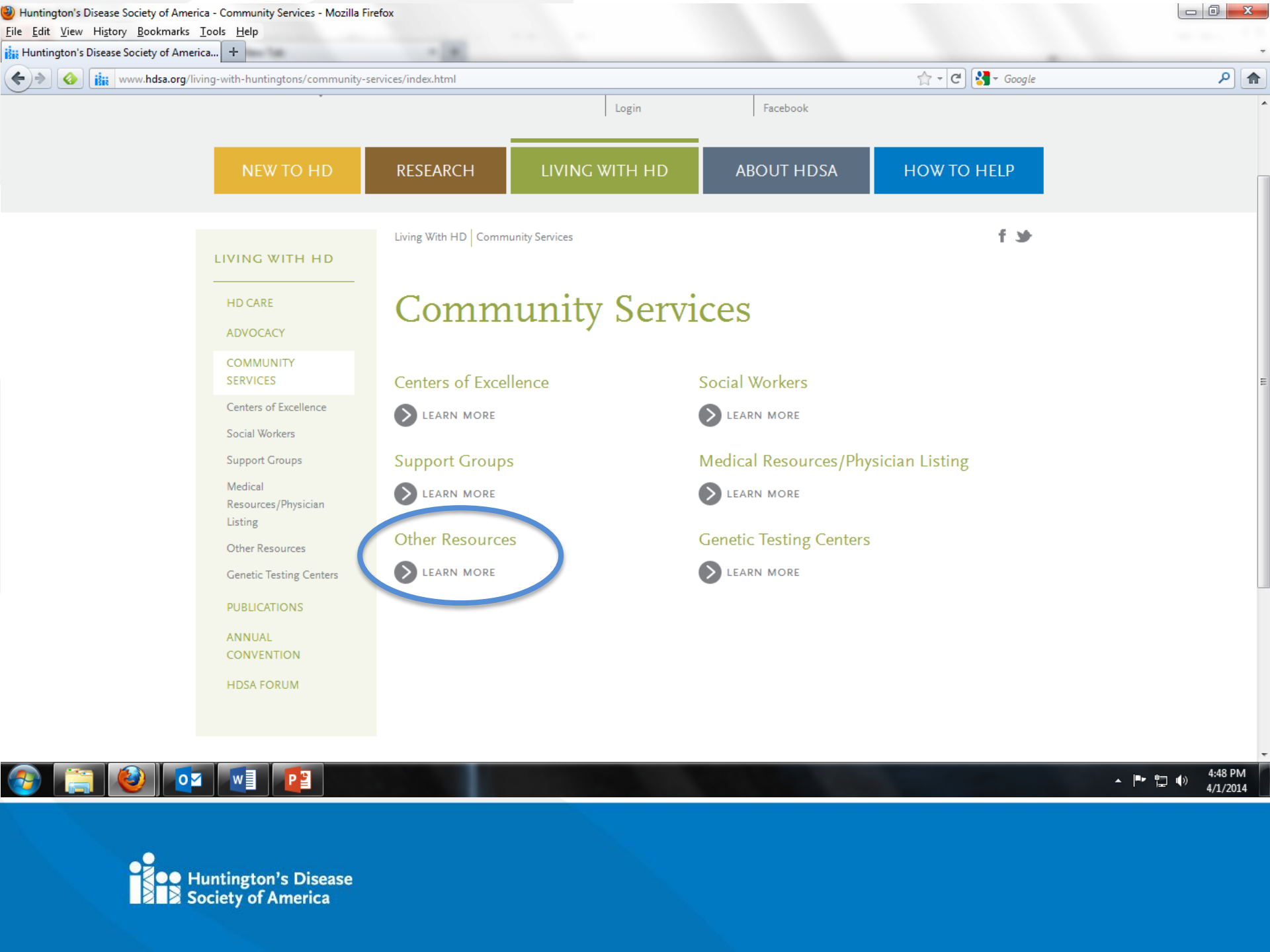


www.caringinfo.org

## Family and Friends

- Not every member of the care team is a professional.
  - Support from family and friends can help you manage caregiving or having a chronic condition.
  - Local chapters provide the opportunity to meet up with other people and families in a social manner.
- Many studies show that people who attend support groups feel more comfortable and confident in managing and caregiving for a chronic condition.
  - HDSA has over 170 support groups around the country, with more being added constantly.
  - Visit [www.hdsa.org/sg](http://www.hdsa.org/sg) to find your local support group.
  - To start a support group, visit [www.hdsa.org/sgapp](http://www.hdsa.org/sgapp).
  - Join the HDSA E-mail List, found at [www.hdsa.org](http://www.hdsa.org), to receive updates on local and national events.

# Resources



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## HDSA Resources

- Past HDSA Caregiver's Corner Webinars ([www.hdsa.org/ccorner](http://www.hdsa.org/ccorner))
  - “Team Management and HD” Dr. Martha Nance, February 2011
  - “PT/OT and HD” Suzanne Imbriglio, March 2011
  - “Gait & Balance” Deb Kegelmeyer, Dr. Sandra Kostyk, Anne Kloos, November 2011
  - “Safety in the Home” Erica Umback, Lara Wilkinson, John Zenker, December 2011
  - “Long Term Care and HD” Seth J. Meyer, September 2013

## HDSA Resources

- HDSA Publications ([www.hdsa.org/publications](http://www.hdsa.org/publications))
  - *Caregiver's Guide to Communicating with Healthcare Providers*
  - *A Caregiver's Guide to HD*
  - *Physical and Occupational Therapy for HD: A Guide for Families*
  - *Nutrition and HD: A Guide for Families*
  - *Understanding Behavior*
  - Past articles in *We Are HDSA!* and *The Marker* (Archived on the HDSA Article Connect)
  - DVD of the 2013 HDSA Annual Convention

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