

# We Are HDSA!



 **Huntington's Disease  
Society of America**

Support Group Newsletter • [www.hdsa.org](http://www.hdsa.org) • (800) 345-HDSA • Issue 4, September 2013

## Frank Facts About Long-Term Care Insurance

*By Jesse Slome, Executive Director  
American Association for Long-Term Care Insurance ([www.aaltci.org](http://www.aaltci.org))*

Before sitting down to write this, I admit having to think long and hard. While we are an independent organization striving to create heightened awareness, insurers who sell long-term care insurance may be understandably sensitive about what is said.

Concern is justified because insurers paid out \$6.6 billion last year in claims, with the largest claims well in excess of \$1 million. Certain diseases and conditions account for proportionately higher claim incidence and larger claim payout amounts.

Offering coverage without any health qualifiers would dramatically raise the cost of coverage for all. An attempt to offer guaranteed issue long-term care insurance as part of the CLASS Act was, in large part, the reason the Department of Health and Human Services pulled the program. Premiums would have been so high as to make coverage unaffordable for the vast majority of Americans.

### **Health Qualifying: The Most Important Factor**

Everyone who purchases long-term care insurance 'anti-selects' against the insurance company. Simply said, people buy this presuming they have a real risk of using the coverage one day. That's why a significant proportion of those seeking insurance start the process immediately after a physician visit. Very often, that's too late. Being informed that one has the gene that causes Huntington's disease will result in a decline for long-term care insurance from almost all insurers. Some insurers (not all) will require applicants to answer questions regarding family history and providing false information could invalidate your policy come claim time.

One means of obtaining long-term care insurance, when there is concern about future health risk, is to apply at a younger age prior to any diagnosis or gene tests. And today, features available in certain policies can be an especially effective way to minimize costs for those buying at younger ages.

One in particular is the Guaranteed Purchase Option (sometimes referred to as the Future Purchase Option). The GPO provision allows an individual to purchase coverage that can be added to periodically in the future without having to meet health requirements. A 30-year old male could buy \$182,000 of current coverage (5 years of coverage) for between \$350 and \$500-yearly. Periodically, the insurer will offer additional coverage amounts that, if accepted, will increase the cost of coverage.

The ability to lock in health insurability, with the periodic opportunity to add to coverage without having to meet new health requirements, is a significant advantage of this option that adds about five percent to coverage. Provisions of the GPO options vary by insurer, which makes the selection of insurer especially important. Some will cease offering the buy-up option if the policyholder declines a certain number of offers while others do not have this requirement.

In addition, for those with existing health diagnoses, some LTC insurance carriers today are offering limited amounts of coverage. While not considered the equivalent of full blown, traditional long-term care insurance, the future access to \$100,000 of benefits (often the maximum amount of coverage available) could provide a meaningful financial supplement for a period of time.

Today, costs for long-term care insurance coverage, available policy features, and required health standards vary significantly from one insurer to another. Since insurers do not directly sell to the public, it especially pays for those with health sensitive issues to work with a knowledgeable specialist who has access to policies from at least five or six of the leading insurers.

To locate a designated specialist who is a member of the American Association for Long-Term Care Insurance, call the organization's offices at **(818) 597-3227**.

## HD Education Days

**October 5:** Birmingham, AL UAB

**October 12:** Golden Valley, MN  
Albany, NY  
Allentown, PA

**November 2:** Portsmouth, NH  
(New England)

**November 16:** Rosslyn, VA

## Webinars

**October 16:** Planning for Incapacity

**November:** Family Planning

Register at [www.hdsa.org/ccorner](http://www.hdsa.org/ccorner)

## 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](http://www.hdsa.org/takeaction) to participate.

## QR Code

Please scan here to visit the HDSA website



## The Health Insurance Marketplace is Coming

*By Karina Aguilar, US Public Health Service Public Affairs Specialist,  
Department of Health & Human Services*

No doubt you've started to hear about the new Health Insurance Marketplace, a key part of the health care law that will be open for business on October 1st. But you probably still have questions, such as what is the Marketplace and can you really get health insurance? Well we've got answers.

The best place for the latest, most accurate information on the Marketplace is the updated website, **HealthCare.gov**. At that site, you can learn what the Marketplace is, who can apply for insurance, how to get insurance, how to lower your costs, and more. If you own a small business, there's information for you, too.

Starting this fall, the Marketplace will help you find health insurance that fits your budget and meets your needs with less hassle.

No matter where you live, you can buy insurance from private health plans that cover a comprehensive set of benefits, including doctor visits, hospital stays, preventive care, and prescriptions. Plans in the Marketplace must treat you fairly; they can't deny you coverage or charge more because of a pre-existing condition.

With a single application, you can also see if you qualify for Medicaid or the Children's Health Insurance Program, or savings you can use right away to lower your health insurance premiums.

### Enrollment Begins October 1, 2013. Visit **HealthCare.gov** to Get Ready

**HealthCare.gov** is your best source of information about the Marketplace. You can read information that pertains to you, print checklists, and watch videos to help you get ready to apply and enroll.

You and your family can explore every qualified health plan in your area and fill out an application when you're ready. You'll be able to take control with better information, including details about benefits and prices presented in clear language you can understand, so you'll know what your premiums, deductibles, and other costs will be before you make a choice.

Once you've decided on a plan, you don't need to go anywhere else. Starting in October, you'll be able to enroll in the Marketplace directly for coverage that begins as soon as January 1st, 2014.

### Want help or need more information?

As you explore your options on the Marketplace, you may want to get some help. You can participate in an online web chat on the website or call a toll free number, 1-800-318-2596, to speak with a trained customer service representative. There will also be people in your local communities who can give you personal help with your choices.

Visit **HealthCare.gov** now to get all the information you need about the Marketplace. Come back October 1, fill out an application and enroll. It's that easy.

To learn more about the Health Insurance Marketplaces, please visit **[www.hdsa.org/advocacy](http://www.hdsa.org/advocacy)**. There, you'll find the resources and information that will help you and your family prepare, including documents on what to think about when choosing a plan and how to protect yourself from fraud. For questions about the Affordable Care Act and the Marketplaces, please contact Jane Kogan at [jkogan@hdsa.org](mailto:jkogan@hdsa.org).

## HDSA Annual Convention

Miss the HDSA Annual Convention? Thanks to a generous grant from Lundbeck, HDSA has a free DVD of all the live streamed workshops. To order, please contact Anita Mark-Paul at [amarkpaul@hdsa.org](mailto:amarkpaul@hdsa.org) or via phone at (800) 345-HDSA, ext. 219.

## Amaryllis



## Growing a brighter future.

To place your order please contact your local chapter/affiliate or visit [www.hdsa.org/amaryllis](http://www.hdsa.org/amaryllis) \$10 per bulb

## Clinical Trials

For more information on clinical and observational trials happening in your area, visit [www.hdsa.org/clinicaltrials](http://www.hdsa.org/clinicaltrials).

By Seth J. Meyer, LMSW

Community Services and Resource Development Manager,  
Huntington's Disease Society of America.

Between our phones, tablets, and computers, there are more ways than ever to share and upload information. Apps, applications that can be used on one or more of these devices, are ways for you to keep the information you get from you doctors or loved ones and share it with whomever you feel needs it. As more options become available, below are a few questions for you to keep in mind when deciding which app is best for you and your family:

### Do I want a special medical app or just a sharing app?

Some apps are specially designed to upload and share medical information. Some apps, such as Evernote, Dropbox, and Google Drive, allow you to upload and share many types of documents. While not as secure, if the information you would like is not confidential, these free apps may be perfect for you and your family.

### How is my information going to be used for?

While most apps are solely for you to keep information, some may ask you to share your data. How would this data be used? How will the app keep your identity secret? How can you ensure that information about you and your loved one(s) doesn't get into the wrong hands?

### How will my information be kept private?

At minimum, any medical app should comply with HIPAA guidelines and be HIPAA compliant. What safeguards have they put in place to meet these guidelines? Are there any additional security measures added? How does this app make sure that my information won't be stolen?

### Where is my information stored?

Any file system should be stored in a regular server and a backup server in different parts of the country. With this in place, your information is still available in case of natural disaster or other issues with the main server. While this shouldn't be a problem for bigger companies, not all smaller technology companies have this safeguard in place.

### Who can/should see my information?

Can you select who sees what information, or does all the information have to be shared with all people? If you need to change who can see certain pieces of information, how easy (or difficult) is it?

### What file types are supported?

Some app programs may only support their own files or Word documents. Others support picture files, such as pdfs and jpegs. This will allow you to upload test results and MRI results onto your file if you feel that it would be useful.

### What are other people saying?

Every phone and tablet app will have a rating and reviews. Check out what other people are saying. Is the app easy to use? Have people had any difficulty with it? Websites such as cnet.com provides reviews of apps and other programs that might be of use for you and your family.

### What happens if my device is stolen?

One should be careful when keeping sensitive information on any device. Is there a password for the app? How easy is the password to change should your device be stolen?



Huntington Study Group  
Seeking Treatments that Make a Difference<sup>SM</sup>

***Without participants,  
trials cannot happen.  
Trials create the  
knowledge needed to  
find effective treatments  
for Huntington disease.***

**Find a First-HD  
Site Location Near You!**

**US Sites**

Birmingham, AL  
**Fayetteville, AR**  
Los Angeles, CA  
Englewood, CO  
Washington, DC  
Gainesville, FL  
Miami, FL  
Atlanta, GA  
Iowa City, IA  
Kansas City, KS  
Wichita, KS  
Boston, MA  
Baltimore, MD  
**St. Louis, MO**  
Durham, NC  
Camden, NJ  
New Brunswick, NJ  
Las Vegas, NV

**Albany, NY  
New York, NY  
Houston, TX**

Salt Lake City, UT  
Kirkland, WA  
Seattle, WA  
Milwaukee, WI

**Canadian  
Sites**

Calgary, AB  
Edmonton, AB  
Vancouver, BC  
**Toronto, ON**  
Montreal, QC

*\*Additional sites may  
be added  
Sites in bold are  
currently enrolling.*



RSRB University of Rochester-Approved  
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- J 7/10/13 -



**First-HD**  
A Huntington Disease Research Trial

**Facts about the First-HD Study**

- First-HD is a study to determine if SD-809 ER (an investigational drug) is safe and effective in reducing chorea associated with Huntington disease.
- SD-809 ER is a slowly releasing form of tetrabenazine. Tetrabenazine is currently approved in the United States and Canada for the treatment of chorea.

**How long is the study and what will it cost to participate?**

- Participants will be involved in this trial for approximately 4 months.
- At least 8 in-person visits to the study center will be required and 7 telephone assessments will be conducted.
- Study-related examinations and study drug are provided to you at no cost.

**Who can participate in First-HD?**

***You may be eligible to participate if you....***

- Have been diagnosed with Huntington disease and have never taken tetrabenazine.
- Are at least 18 years old or the age of majority in your State or Province, whichever is older.
- Have a caregiver who can come with you to the research visits.

**How can I find out more about First-HD?**

**[www.Huntington-Study-Group.org](http://www.Huntington-Study-Group.org)**

**1-800-487-7671 (North America)**

**[www.auspexpharma.com](http://www.auspexpharma.com)**

**[www.hdsa.org](http://www.hdsa.org)**

**[www.Clinicaltrials.gov](http://www.Clinicaltrials.gov)**