



Is it time to apply for Social Security Disability Insurance?

What do we do now?

Presenter Disclosures

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The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose or list



Goals of my presentation – **Let's make this a less difficult and less frustrating process!**

- What are the requirements of the Social Security Disability Programs as they relate to HD.
- translate SSA requirements from “bureaucratise” into English,
- explain what can ‘go wrong’ with the disability process,
- **provide tips and guidance to keep the patient, family and medical providers in better control of the decision-making process** , and,
- Plenty of time for questions

Who am I anyway?

- Over 40 years experience in the SSA Disability process
- Disability Examiner in Virginia
- Consultant, Supervisor, Trainer and Executive in Virginia
- DDS Director in both Delaware and in New Jersey
- 12 years in “The Office of Disability Policy” (ODP), the last 4 as Associate Commissioner for ODP, responsible for all medical and vocational policy for SSA
- And now retired, but still involved in SSA disability in non-partisan ways

- Proud to say that HDSA and ODP developed a great relationship for both HD information for SSA and unique case help for HDSA during my tenure

So let's get right to it...
SSA Disability is complicated and
“All Ye Who Enter Here, Leave Logic Behind”



Basics of SSA Disability

- The focus will be on medical and vocational eligibility rules
- I am NOT an expert on the financial requirements of Supplemental Security Income (SSI) or on computing benefits for Disability Insurance (SSDI or DIB)
- The Social Security Administration has a LOT of information posted for you on their web pages

<http://www.ssa.gov/disability/index.htm>

And

<http://www.ssa.gov/dibplan/dqualify5.htm>

Are good places to start (these links are in my handout)

Basics of SSA Disability (2)

- In SSA “disability” is an administrative finding. It combines medical, legal, work and other information into a decision to grant or deny benefits
- **SSA’s definition of disability is very strict**
- It requires proof that the applicant can do NO work in the national economy for at least 12 continuous months:
 - "Disability" under Social Security is based on your inability to work. We consider you disabled under Social Security rules if:
 - You cannot do work that you did before;
 - We decide that you cannot adjust to other work because of your medical condition(s); **and**
 - Your disability has lasted or is expected to last for at least one year or to result in death.
 - This is a strict definition of disability. Social Security program rules assume that working families have access to other resources to provide support during periods of short-term disabilities, including workers' compensation, insurance, savings and investments.

<http://www.socialsecurity.gov/dibplan/dqualify4.htm>

Basics of SSA Disability (3)

- So what is the “Listings” and why does it matter?
- The Listings, if met exactly, or if “equaled”, presumes an inability to work – and an award of benefits is granted.
- For HD, the current Listing is:

11.17 Degenerative disease not listed elsewhere, such as Huntington's chorea, Friedreich's ataxia, and spino-cerebellar degeneration. With:

A. Disorganization of motor function as described in [11.04B](#); or

B. Chronic brain syndrome. Evaluate under [12.02](#).

SSA Links:

<https://secure.ssa.gov/apps10/poms.nsf/lnx/0422001020>

<https://secure.ssa.gov/apps10/poms.nsf/lnx/0434001030>

What's the Bottom Line?

- For Huntington's Disease you need to 'prove' that you have the disease, by either medical and family history or by genetic testing
- AND then show how the symptoms prohibit work
 - Movement disorders
 - Cognitive difficulties
 - Behavioral or emotional symptoms
 - (will discuss how to document these in a bit)
- **Your evidence Must prove BOTH!**

Basics of SSA Disability Compassionate Allowances

- What is a Compassionate Allowance (CAL) – and what it is not...
 - A shortcut that makes the application process for you a bit easier
 - Helpful hints for the Disability Examiner
 - NOT a different program or benefit
- CAL ‘occurs’ when you allege your disability. In this case, **words DO matter so be clear when you apply**. Consider using the following terms:
 - Adults – Huntington’s chorea; Huntington’s Disease
 - Children and teens – Juvenile Huntington Disease; Juvenile HD; JHD; Early-Onset HD
- SSA Links:
 - <http://www.socialsecurity.gov/compassionateallowances/> general information
 - <https://secure.ssa.gov/apps10/poms.nsf/lnx/0423022923> adult HD
 - <https://secure.ssa.gov/apps10/poms.nsf/lnx/0423022785> juvenile HD

What's the Bottom Line?

- For Compassionate Allowances, use the 'right' words when you apply
 - Huntington's Disease with increasing limitations
 - Juvenile Huntington's Disease or Early-Onset HD

- Hint, when filling out the application for disability benefits, if your allegation is 'captured' by the CAL program, there will be NO questions about your past jobs, which can save you time in the application

How can you help get the right decision?

- **You can make the job of the Disability Examiner easier, and get the determination that you want!**
- Before you apply, **gather your own medical evidence**, reports, hospitalizations, tests, etc.
 - HDSA has an excellent format for your medical team to use in preparing a statement
 - Ensure that the evidence clearly proves the HD diagnosis and discusses the specific HD symptoms that keep you from working
- Submit this evidence when you apply (but always keep copies!)
- And...

How can you help get the right decision? (2)

- **... get the determination that you want!**
- **Activities of Daily Living (ADLs)** Keep a diary of what you can do and what you have difficulty doing.
- You will focus on the impact of movement disorders, cognitive problems, and behaviors or emotions that interfere with independent activities
 - Be matter of fact, and this does not need to be pages and pages long!
- **You trying to explain what your medical evidence may not clearly show! You are trying to make it easy for the DE to support an allowance!**

Activities of Daily Living. In HD focus on:

Physical and movement symptoms might include:

- jerky and uncontrollable movement that may be seen at first as restlessness or lack of coordination
- rigidity or twisting of the body
- loss of muscle control, which can lead to:
 - difficulty swallowing, difficulty speaking, not being steady on your feet, abnormal facial expressions, and eating problems that can cause weight loss or malnutrition
- problems sleeping, and
- seizures.

Cognitive symptoms might include:

- decrease in the ability to complete functions such as setting up a schedule or solving a multi-step problem
- loss of short-term and long-term memory, and

Mental symptoms might include:

- personality changes
- anxiety
- depression
- reduced display of emotions
- irritability
- egocentrism (focusing only yourself and not caring about others)
- aggression
- compulsive behavior
- difficulty being able to tell if others are upset by their expressions, and
- increased suicidal thoughts or attempts.

What's the Bottom Line?

- For ADLs:
 - Keep a diary and describe what you can or can't do.
 - It is often best if a family member or friend keep this diary
 - Example:
 - John had trouble getting up out of the chair today, and stumbled a few times. I helped him shop for groceries, and checked over his bills before we paid them together since he is not as sure in keeping to his budget. John was irritable this afternoon and asked the kids to play elsewhere
 - Keep it matter of fact and in the end SUMMARIZE the symptoms (the changes) caused by HD

But what if it goes wrong? **What if your claim is denied?**

- As hard and frustrating as it is... **relax... you can fix this!**
- Remember that you are fighting a system of “mass justice” ... a bureaucracy. This is NOT personal, and you will “win” on appeal
- The “denial letter” may sound like it’s written in a foreign language and may be hard to decipher. You may not be able to figure out exactly WHY the claim was denied
- So, this might be the time to work with your HDSA partners who have applied or appealed before
- **Review your saved copies and ensure that (1) HD is CLEARLY diagnosed, (2) that your physical, mental or emotional limitations are CLEARLY explained, and (3) that your ADLs describe what you can and cannot do in a clear manner**

But what if it goes wrong? **What if your claim is denied? (2)**

- You have time to go over these things, and prepare the appeal materials
- Get updated medical evidence (if you have any) and consider asking your doctor to explain why he/she believes the denial is wrong
- BUT, remember that you have about 60 days to make an appeal. **DO NOT miss this deadline**, since a timely appeal protects your benefit amounts and future appeal rights

The SSA HDSA Partnership

- HDSA has worked hard to explain HD to the SSA staff involved in policy development. Don't stop! Writing policy is slow and laborious and can be very frustrating (a case of three steps forward and two steps back)
- BUT your input will keep SSA on the straight and narrow path
- AND SSA has helped the HDSA resolve problem HD claims decisions, and I hope that continues!
- And I will continue to work with HDSA staff to provide my perspectives and insight to members of your fine organization!

Thank you!

- Questions?

