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HDSA Disability Chat Series
November 21, 2019
Questions

• Questions will be answered after the presentation.
• However, you may send a question anytime during the presentation.
• Click on the “Chat” function in the toolbar.
• Type in your question and hit send.
• Only HDSA and panelists will be able to see your question.
To View this Webinar Again

• One week after this webinar, you will be able to access it for viewing on the HDSA national website.

• To access this presentation, go to www.hdsa.org/disabilitychat or HDSA’s YouTube Channel.

• You will be able to view this webinar recording, as well as all new disability presentations.
Upcoming webinars

• **January 16: Starting the Disability Application Process.** What you need to know about preparing to File an Initial Application and Requesting Medical Records.

• **March 19: Debunking Disability Myths.** An in-depth look at common Social Security disability myths at every stage of the disability process.

• **May 21: Disability Red Flags.** What you need to know about the 6 common red flags in a disability claim and how to mediate or avoid them.

• **July 16: Completing Disability Forms (Wk Activity, ADF, Wk Hx, Pain Q, Anx Q).** An overview of what Social Security disability forms you may receive during the disability application process and how to complete them.
The information provided in this webinar series is for informational use only.

HDSA encourages all attendees to consult with their primary care provider, neurologist or elder care attorney about any advice mentioned as part of any presentation.

An in-depth look at the Social Security disability evaluation process, how they examine a Huntington's Disease Application, and what evidence needs to be included in a claim.
Overview

• SSDI versus SSI
• Social Security Disability Eligibility
• 5 Step Social Security Evaluation
• Evidence for Disability Claim
Social Security Act § 223

An individual shall be determined to be under a disability only if his/her physical or mental impairment or impairments are of such severity that he/she is not only unable to do his/her previous work but cannot, considering his/her age, education, and work experience, engage in any other kind of substantial gainful work which exists in the national economy, regardless of whether such work exists in the immediate area in which he/she lives, or whether a specific job vacancy exists for him/her, or whether he/she would be hired if he/she applied for work.

- Disability under Social Security is based on the inability to work.

- [http://www.socialsecurity.gov/OP_Home/ssact/title02/0223.htm](http://www.socialsecurity.gov/OP_Home/ssact/title02/0223.htm)
Benefit Types

Social Security Disability Insurance (SSDI) – Title II

- **Benefits**
  - Earnings requirement
  - Date last insured
- **Resource limit**
  - None (not based on financial need)
- **Payments to dependent children**
  - Available
- **Medicare**

Supplemental Security Income (SSI) – Title XVI

- **Benefits**
  - Based on financial need
  - No earnings requirement
- **Resource limit**
  - $2,000 individual
  - $3,000 couple
- **Payments to dependent children**
  - Not available
- **Medicaid**
There is no standard timeline for applying for disability, you must determine what works best for you

– You can continue working while your application is pending if you meet certain criteria
Social Security Disability Eligibility

• Medically Determinable Impairment
  – Medical Care
  – Suggested Medical Evidence for Huntington's Disease

• Work Credits
  – Date Last Insured

• Onset Date
Medically Determinable Impairment

“An impairment that results from anatomical, physiological, or psychological abnormalities that can be shown by medically acceptable clinical and laboratory diagnostic techniques.”

- Social Security will not approve benefits based on symptoms alone
- There has to be documented clinical evidence of symptoms from doctor’s appointments, medical testing, or medical imaging
- HD without a diagnosis will not qualify for disability benefits
Medical Care

• See physicians on a regular basis
  – Get treatment from relevant specialists
    • Neurologist
    • Psychiatrist
    • Physical Therapy
  – Collect business cards for each
  – Follow prescribed treatments

• Be mindful and honest in speaking to your physicians
  – Don’t undermine or discount symptoms
  – Discuss good and bad days
  – Medication side effects
  – Activities of daily living
  – Limitations due to symptoms
SUGGESTED PROGRAMMATIC ASSESSMENT*

Suggested MER for evaluation:
- Claimant’s medical source(s) records documenting progression of motor, cognitive, and psychiatric symptoms and signs; family history of HD; and abnormal neurological exam findings consistent with HD.
- Laboratory testing showing a CAG repeat in the HD gene (40 or more CAG repeats).
- Brain imaging may provide supporting evidence.
- Psychological or psychiatric reports including neurocognitive testing.

Suggested Listings for Evaluation:

<table>
<thead>
<tr>
<th>DETERMINATION</th>
<th>LISTING</th>
<th>REMARKS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meets Listing</td>
<td>11.17 or 12.02</td>
<td>Listing level neurological and/or cognitive findings must be documented; <strong>diagnosis of HD or laboratory testing results alone do not meet listing severity.</strong></td>
</tr>
</tbody>
</table>
Date Last Insured

• DLI lets you know if you are still eligible for SSDI benefits
  – Can create a mysocialsecurity.gov account to determine eligibility

  ![Disability](image)

  You have worked enough credits to qualify for disability benefits.
  If you become disabled right now your estimated payment would be:  $1,189 a month

  ![Apply Online for Disability](image)

• DLI is based completely on YOUR personal work history
• Disability Credits Expire
  – Generally have 5 years to apply once you stop working
  – Gaps in work history will impact DLI
• Must call Local or National Social Security office
• Example:
  – March 31, 2020
  – June 30, 2020
  – September 30, 2020
  – December 31, 2020
Onset Date

• Date you allege your disability started
  – Required for disability application

• Things to consider:
  – When you stopped working
  – When you had medical evidence of your condition – HD gene test is not enough

• Date is very important and can be the difference between getting approved or denied
5 Step Sequential Evaluation

- Step 1: Financially eligible?
- Step 2: Severe impairment?
- Step 3: Meets or equals medical listings?
- Step 4: Are you unable to perform past work?
- Step 5: Are you unable to work at all?

Approved! Denied!
Step 1: SGA

Is the person engaged in substantial gainful activity? (SGA)
Step 1: SGA

- Work does not have to be on a full-time basis to be substantial
  - Can continue to work while applying for disability
- Substantial = involves doing significant physical and/or mental activities
- Gainful = usually done for pay or profit
- Monthly SGA amounts
  - 2019
    - Statutorily blind individuals: $2,040 gross
    - Non-blind individuals: $1,220 gross
  - 2020
    - Statutorily blind individuals: $2,110 gross
    - Non-blind individuals: $1,260 gross
- Unsuccessful Work Attempt (UWA)
  - 6 months or less
Step 2: Severity

Does the person have a medically determinable impairment or a combination of impairments that is considered “severe”?
Step 2: Severity

• **Severe**
  – Impairment or combination of impairments is considered “severe” if it significantly limits an individual’s physical or mental abilities to do basic work activities, **and**

• **Duration**
  – Impairment is expected to result in death, have lasted at least 12 months, or be expected to last 12 months or longer
Step 3: Medical Listings

Does the person’s impairment or combination of impairments meet or medically equal the criteria of an impairment listing?
Step 3: Medical Listings

- Describes, for each major body system, impairments considered severe enough to prevent an individual from doing any gainful activity.

<table>
<thead>
<tr>
<th>Meets A Listing</th>
<th>Equals a Listing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Claimant has the specific test results, symptoms, or limitations specified in the corresponding listing.</td>
<td>Claimant does not meet the specific qualifications outlined in the listing. Claimant must argue that their test results, symptoms, or limitations are equal in severity to a listing.</td>
</tr>
</tbody>
</table>
Step 3: Medical Listings

<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.00</td>
<td>Musculoskeletal System</td>
</tr>
<tr>
<td>2.00</td>
<td>Special Senses and Speech</td>
</tr>
<tr>
<td>3.00</td>
<td>Respiratory Disorders</td>
</tr>
<tr>
<td>4.00</td>
<td>Cardiovascular System</td>
</tr>
<tr>
<td>5.00</td>
<td>Digestive System</td>
</tr>
<tr>
<td>6.00</td>
<td>Genitourinary Disorders</td>
</tr>
<tr>
<td>7.00</td>
<td>Hematological Disorders</td>
</tr>
<tr>
<td>8.00</td>
<td>Skin Disorders</td>
</tr>
<tr>
<td>9.00</td>
<td>Endocrine Disorders</td>
</tr>
<tr>
<td>10.00</td>
<td>Congenital Disorders that Affect Multiple Body Systems</td>
</tr>
<tr>
<td>11.00</td>
<td>Neurological Disorders</td>
</tr>
<tr>
<td>12.00</td>
<td>Mental Disorders</td>
</tr>
<tr>
<td>13.00</td>
<td>Cancer (Malignant Neoplastic Diseases)</td>
</tr>
<tr>
<td>14.00</td>
<td>Immune System Disorders</td>
</tr>
</tbody>
</table>
Listing 11.17: Huntington’s Disease

Mandates that a person must exhibit either:

(A) Disorganization of motor function in two extremities, resulting in an extreme limitation in the ability to stand up from a seated position, balance while standing or walking, or use the upper extremities.

OR

(B) Marked limitation in physical functioning; and one of the following:
   1. Understanding, remembering, or applying information; or,
   2. Interacting with others; or,
   3. Concentrating, persisting, or maintaining pace; or,
   4. Adapting or managing oneself
Marked Limitation

• Marked limitation = you are seriously limited in your ability to function independently, appropriately, effectively, and on a sustained basis in work settings
  – Complete inability to perform the activity is not required
  – Does require difficulty and limitations performing the activity on a sustained basis
Physical Functioning

• Seriously limited in your ability to start, maintain, and complete work related physical activities:
  – Standing
  – Balancing
  – Walking
  – Using both arms for fine and gross movements
    • Lifting/Carrying
    • Reaching
    • Grasping
    • Writing/typing

• Medical Evidence
  – Unified Huntington's Disease Rating Scale
  – Tinetti Mobility Test
  – Physical/Occupational therapy records
Physical Functioning

• Questions to think about:
  – Where do you experience chorea/involuntary movements?
  – How often do you trip or fall?
  – What issues do you have with balance?
  – Do you walk into walls or furniture?
  – Do you use an assistive device like a cane, walker, or shower bar?
  – Do you need to sit down to get dressed?
  – How often do you drop things?
  – What kinds of things do you drop?
  – Do you have trouble using your hands?
  – Can you write or type?
  – Has your ability to write or type changed?
  – Are you able to shave?
  – Are you able to use buttons or zippers?
Understanding, Remembering, or Applying Information

- **Ability to learn, recall, and use information to perform work activities**
  - following one- or two-step oral instructions to carry out a task
  - remembering how to perform job tasks
  - asking and answering questions and providing explanations
  - recognizing a mistake and correcting it
  - using reason and judgment to make work-related decisions
  - remembering to keep track of appointments and responsibilities

- **Medical Evidence**
  - Montreal Cognitive Assessment
  - Neuropsychological Testing
Interacting with Others

• Ability to relate to and work with supervisors, co-workers, and the public
  – cooperating and handling conflicts with others
  – asking for help when needed
  – initiating or sustaining conversation
  – understanding and responding to social cues (physical, verbal, emotional)
  – responding to requests, suggestions, criticism, and challenges
  – keeping social interactions free of excessive irritability, sensitivity, argumentativeness, or suspiciousness.

• Medical Evidence
  – Patient Health Questionnaire 9 (PHQ)
  – Generalized Anxiety Disorder 7 (GAD)
  – Global Assessment of Functioning (GAF)
  – Neuropsychological Testing
Concentrating, Persisting, and Maintaining Pace

• Ability to focus attention on work activities and to stay on-task at a sustained rate.
  – initiating and performing a task that you understand and know how to do
  – working at an appropriate and consistent pace
  – completing tasks in a timely manner
  – ignoring or avoiding distractions while working
  – working close to or with others without interrupting or distracting them
  – sustaining an ordinary routine and regular attendance at work
  – working a full day without needing more than the allotted number or length of rest periods during the day.

• Medical Evidence
  – Montreal Cognitive Assessment
  – Neuropsychological Testing
Adapting and Managing Oneself

• Ability to regulate emotions, control behavior, and maintain well-being in a work setting
  – responding to demands
  – adapting to changes
  – managing your psychologically based symptoms
  – distinguishing between acceptable and unacceptable work performance
  – setting realistic goals
  – making plans for yourself independently of others
  – maintaining personal hygiene and attire appropriate to a work setting
  – being aware of normal hazards and taking appropriate precautions

• Medical Evidence
  – Neuropsychological Testing
  – Global Assessment of Functioning (GAF)
Cognitive Functioning

• Questions to think about:
  – Do you have difficulty learning new things?
  – If you read a 10 page book, would you be able to tell me what you read?
  – Would you be able to listen to a book on tape?
  – What kinds of problems have you experienced with your memory?
  – What is worse, short term or long-term memory?
  – If you had multiple appointments in a given week would you be able to keep track of where you needed to be and when?
  – How do you keep track of places you need to be and things you need to do?
  – How long can you concentrate at one time? 30 minutes? 60 minutes? 2 hours?
  – Do you have trouble with motivation?
  – Do you have difficulty following instructions?
  – Are you able to finish what you started?
Related Listings

12.02: Neurocognitive Disorders

12.04: Depressive, bipolar, and related disorders

12.06: Anxiety and obsessive-compulsive disorders

https://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm
Listing 12.04: Depressive Disorder

• (A) Mandates that a person must exhibit five or more of the following:
  – Depressed mood;
  – Diminished interest in almost all activities;
  – Appetite disturbance with change in weight;
  – Sleep disturbance;
  – Observable psychomotor agitation or retardation;
  – Decreased energy;
  – Feelings of guilt or worthlessness;
  – Difficulty concentrating or thinking; or
  – Thoughts of death or suicide

AND

• (B) Extreme limitation of one, or marked limitation of two, of the following:
  1. Understanding, remembering, or applying information; or,
  2. Interacting with others; or,
  3. Concentrating, persisting, or maintaining pace; or,
  4. Adapting or managing oneself
Step 4: Ability to Perform Past Work

Does the person have the residual functional capacity to perform the requirements of his/her past work?
Step 4: Ability to Perform Past Work

- **Past relevant work (PRW)**
  - Performed within the last 15 years
  - Must have been substantial gainful activity
  - Performed the work long enough to learn the job tasks
  - Different jobs have different skill levels
    - **Unskilled:** requires little or no judgment to perform simple tasks and can usually be learned in less than a month; often requires strength
      - **Ex:** Toy stuffer, ticket taker, usher, assembly line
    - **Semi-skilled:** takes between three and six months to learn; usually requires the ability to remain alert and pay attention to detail and/or protecting against risks.
      - **Ex:** Waiter, taxi-driver, construction worker, cashier
    - **Skilled:** It takes at least six months and often many years to train for and learn a skilled job; requires specific qualifications, the use of judgment, and knowing how to perform mechanical or manual tasks to create a product or material (or provide a service).
      - **Ex:** Lawyer, doctor, engineer, teacher, plumber
Step 5: Ability to Perform Other Work

Is the person able to do any other work considering his/her residual functional capacity, age, education, and work experience?
Step 5: Ability to Perform Other Work

• **Level of Work**
  - **Very Heavy**: lifting objects weighing more than 100 pounds at a time with frequent lifting or carrying of objects weighing 50 pounds or more.
  - **Heavy**: lifting no more than 100 pounds at a time with frequent lifting or carrying of objects weighing up to 50 pounds.
  - **Medium**: lifting no more than 50 pounds at a time with frequent lifting or carrying of objects weighing up to 25 pounds.
  - **Light**: lifting no more than 20 pounds at a time with frequent lifting or carrying of objects weighing up to 10 pounds; requires a good deal of walking or standing or involves sitting most of the time with some pushing and pulling.
  - **Sedentary**: lifting no more than 10 pounds at a time and occasionally lifting or carrying articles like docket files, ledgers, and small tools; a certain amount of walking and standing is often necessary in carrying out job duties.
Step 5: Ability to Perform Other Work

- **Residual functional capacity (RFC)**
  - Your residual functional capacity is the most you can still do despite your limitations
  - Physical
    - Exertional
      - weight you can lift and carry
      - hours you can sit, stand, and walk in an 8 hour day
    - Nonexertional
      - balance, stoop, kneel, crouch, crawl, or climb
      - exposure to temperature extremes, fumes, chemicals or dust
      - use hands to write, type, or reach or handle objects, and
      - see, hear, or speak
  - Mental
    - Unscheduled breaks during the day
    - Amount of time off task
    - Days absent from work
    - Interact with supervisors, coworkers, and the public
Step 5: Ability to Perform Other Work

- The “burden of proof” shifts to SSA
  - To show that work, other than what the individual performed in the past, exists in significant numbers
  - Considers the limiting effects of the individual’s impairment, age, education, and work experience
Evidence for Disability Claim

- Medical Evidence
- Work History
- Activities of Daily Living
Medical Evidence

• Medical Records
  – Medical tests
    • Montreal Cognitive Assessment (MOCA)
    • Unified HUntington's Disease Rating Scale (UHDRS)
    • Neuropsychological Testing
  – Physician notes
    • Neurologist
    • Psychiatrist
    • Primary Care Physician
    • Therapy (Physical, Occupational, Talk)

• Medical Letters
  – Should come from specialist that treats HD
  – Neurologist or Psychiatrist

• Medical Source Statement
Work History

• Jobs for past 15 years (Resume)
  – Job title
    • Job description and job tasks
    • Rate of pay
    • Physical activities performed
  – Name of business
  – Dates worked (months and years)

• Why you cannot work now
  – How do your symptoms keep you from working?
    • Can you concentrate at work?
    • Do you remember how to perform job tasks?
    • Do you need unscheduled breaks?
    • Are you having difficulty working with coworkers or supervisors?

• Letter from former employer or coworker
Activities of Daily Living

• How do your symptoms and limitations impact your daily life?
  – Talk about your symptoms from the perspective of a bad day
    • Do you need to sit down when getting dressed?
    • Do you struggle with buttons or zippers?
    • Do you need to take breaks when completing chores?
    • What chores can you complete BY YOURSELF?
    • Has your cooking ability changed?
      – Are you able to cook food from scratch?
      – Do you only reheat prepared meals?
    • Can you follow a recipe from start to finish?
    • Do you have any limitations grocery shopping?
  – Be honest about symptoms and limitations and get help if you need it
• Letters from friends and family
Questions?
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