

How to Apply for Disability Benefits

A Self-Help Guide for Women with Vulvodynia

Presented by the
National Vulvodynia Association
through an unrestricted educational grant from
Purdue Pharma, L.P.



Table of Contents

Introduction to Career Options

Section I: Overview of Social Security Disability Benefits Program

Section II: Applying for Social Security Disability Benefits: A How-To Guide

Section III: Suggestions for Women with Vulvodynia Seeking Disability Benefits

Section IV: Vulvodynia Fact Sheet

Section V: Glossary of Social Security Terms

Resources

Acknowledgement:

Legal assistance in preparing this guide was provided by Scott B. Elkind, Esq., Elkind & Shea, The Disability Law Firm, www.disabilitybenefitslawfirm.com, 301-495-6665 or 1-800-NEED-LTD. Special thanks to Andrea Hall, Esq., for researching and writing this guide, and to Mary Mahon, Esq., for her valuable comments.

The National Vulvodynia Association is not a medical authority and strongly recommends that you consult your own health care provider regarding any course of treatment or medication.

This publication is copyrighted by the National Vulvodynia Association and fully protected by all applicable copyright laws. Copyright © 2010 by the National Vulvodynia Association. All rights reserved.

Introduction to Career Options

If you suffer from chronic pain, the goal is to work at a level that allows you to manage your pain and care for yourself, while maintaining adequate health insurance and financial security. Before seeking disability benefits, you may want to investigate your company's human resource policies to see if alternatives to full-time employment, such as those options described below, are available to you.

Part-Time Employment

Part-time employment allows time for medical visits and trying new treatments, without having to worry about missing work or how a new treatment's side effects may affect the quality of your work. Of course, your salary will be reduced and part-time status could affect eligibility for continued benefits.

Job-Sharing

Consider opportunities within your company to create a unique position. Depending on your employer's flexibility, you may be able to modify your schedule or share a position with another part-time employee.

Family and Medical Leave Act (FMLA)

Companies with more than 50 employees must provide up to 12 weeks of unpaid leave for a serious health condition. For information on your eligibility, visit <http://www.dol.gov/whd/fmla/>. Before choosing FMLA, make sure you understand your company's policies regarding reinstatement, years-of-service accrual and maintenance of benefits during your leave.

Consulting/Temporary Employment

The benefit of this option is that you can control your work schedule. The disadvantage is that it can be stressful, because you are completely responsible for generating your income, as well as paying taxes, social security and health insurance premiums.

Resignation

If your employer is inflexible about modifying your schedule, you can mention that you might be forced to resign, which may or may not result in the negotiation of a reasonable alternative. A major disadvantage of resigning is that, in most states, it will make you ineligible for unemployment benefits. You may, however, qualify for a continuation of health benefits under COBRA (up to 18 months at your expense). COBRA insurance is a topic that the human resource staff should be able to explain to you. Additional information can be viewed online at: <http://www.dol.gov/dol/topic/health-plans/cobra.htm>.

Disability

Applying for disability insurance may be necessary if your pain is severe and incapacitating. First, check if your company maintains its own disability income policy. The remainder of this guide will focus on obtaining disability insurance from the Social Security Administration.

Section I: Overview of the Social Security Disability Benefits Program

The Social Security Administration (SSA) operates two programs that provide disability benefits. The first, Social Security Disability Insurance (SSDI), pays benefits to disabled people under age 65 who are “insured,” as determined by their payment of Social Security tax on their earnings. (The SSA uses the term “insured” in a very specific manner. It refers to your earned work credits, not to your health insurance. Please see Glossary of Social Security Terms for a complete explanation.) SSA also pays benefits to certain disabled dependents of insured individuals. The second program, supplemental security income (SSI), is available to disabled individuals who have limited income and resources. This guide will focus on the first type of benefits, SSDI.

Medicare benefits are also available to people who have been entitled to SSDI for 24 months and to government employees who meet SSA’s definition of disability and are “insured.” Medicare usually pays 80 percent of reasonable hospital or medical bills.

Who is Eligible?

If you have worked in the past and have earned enough credits, you are considered “insured.” (See the Glossary of Social Security Terms.) You may also be eligible for disability benefits if you fall into one of the following categories:

- A disabled widow between the ages of 50 and 60 can claim survivor benefits if her deceased spouse worked enough during his lifetime to be considered “insured.” The survivor disability benefit claim must be made within seven years of the insured spouse’s death.
- A disabled divorced spouse who has not remarried can claim regular or survivor benefits if her ex-spouse had “insured” status. Again, the survivor disability claim must be made within seven years of the insured individual’s death.

SSA considers you disabled if you have a medical or mental condition that is expected to last for at least one year or result in death, and is of such severity that it prevents you from performing your past work or other work available in the national economy. Substantial medical evidence of the disability must be provided. The inability to work includes an economic test in which you cannot be engaged in any “substantial gainful activity (SGA).” SGA is now defined as earnings of \$1,000 or more per month. Social Security pays only for total disability; there are no benefits available for partial or short-term disability under one year in duration with an expected return to work. However, there are benefits payable to any person disabled for any period greater than one year who has returned to work.

Compiling Your Claim

Before you file your disability insurance application, you need to gather medical evidence confirming that you have at least one impairment and describing how it affects your ability to work. This evidence will come from “treating sources,” i.e., medical professionals deemed acceptable by SSA who have treated or evaluated you for the condition causing your impairment. (See the Glossary of Social Security Terms for a complete explanation.) In addition, you must submit copies of relevant medical records from hospitals, clinics or other health care facilities where you have been treated. Relevant records are those concerning medical conditions that resulted in the disabling impairment; records concerning any non-disabling conditions do not have to be provided.

If possible, you should choose an experienced and compassionate treating professional. Ask him/her to submit a report to the SSA, either in the form of a letter or a completed medical and vocational questionnaire, describing your impairment and its severity. Your health care provider should not be asked to render a decision as to whether you are “disabled.” That is for a judge to decide. Instead, he/she should provide a statement about your functional abilities to perform work-related physical or mental activities despite your impairment(s). The letter should outline your medical history, clinical findings (such as the results of physical examinations), laboratory findings and diagnoses; it should also include treatments prescribed, your response to treatment and prognosis. The health care professional should state his/her opinion about your physical and/or mental functioning despite your impairment, based on his/her findings. The letter may describe physical functions, such as standing, sitting, walking, lifting, carrying, handling objects, hearing, speaking and ability to travel. When mental impairment is involved, the provider’s letter should describe your ability to understand, remember and follow instructions, and whether or not you are likely to respond appropriately to supervisors and coworkers.

Additional information needed to apply for benefits includes your Social Security number, W-2 form and birth certificate. You will also need to provide a summary of your work history, education and training, as well as workers compensation information. (See the How-To Guide for a complete list of items you will need.)

Applying for Benefits

Although it is helpful to supply your medical records and assessments, they are not required when making your formal application for benefits. The application process includes completion of the Adult Disability and Work History Report in addition to a formal application for benefits. (See the How-To Guide for specifics.) The application can be completed online at www.ssa.gov. It's a good idea to print a copy of your application before sending it, as it will not be available for copying after transmission. You may also call SSA at 800-772-1213 and make an appointment to apply for benefits in person or over the telephone. This process is easier if you prepare in advance. List your treatment provider's information, your medications and work history for the past fifteen years, and bring the document with you. If you have gathered your medical records in advance, be sure to make copies before submitting them, in case the records are lost.

The Disability Determination Process

After you complete a formal disability benefit application, SSA will send your forms to a state disability determination office for evaluation and initial disability determination. That office may request copies of your medical records from the treating sources listed in your application. The state office will try to make a determination from the medical reports submitted or acquired. However, you may be asked to undergo a consultative examination that is paid for by SSA.

There is a five-step disability determination process:

1. If you are working, are you performing substantial gainful activities? (See Glossary of Social Security Terms for explanation.)
2. Do you suffer from a "severe impairment," as defined by the SSA?
3. Does your condition(s) equal or meet a defined illness and severity, as set forth in the SSA listing of impairments? If so, there is a presumption of disability, but the determination process still continues.
4. Can you still perform any of the jobs you've held in the past 15 years?
5. Taking into account your age, education and prior work experience, plus your impairments, are you able to perform other work that is generally available in the national economy?

Expect to wait three to five months for a decision, depending upon how long it takes to acquire your medical records, send you for an examination or obtain any other evidence the SSA considers necessary.

Representation

Since you apply directly to the SSA, you don't need legal representation during the application process. If you experience difficulty with the claim process at any time thereafter, it may be helpful to obtain a representative; both attorneys and non-attorneys can perform this function. Your representative can assist you with obtaining information from SSA concerning your claim, acquiring additional evidence to better demonstrate your disability to SSA and appealing your case following any denial of your claim. The most important function of a representative is assisting you in preparing for a hearing and attending a hearing on your behalf. Should you be denied benefits following a hearing and need to proceed in federal court, only an attorney can provide assistance.

If your representative intends to charge you a fee for his/her services, he/she must first file either a fee agreement or a fee petition with SSA. If using a fee agreement, you and your representative must both sign it, and the fee can't be more than 25 percent of past-due benefits or \$6,000, whichever is less. (Higher fees may be available on successful appeal of denial of benefits, which requires additional hearings.) Your representative cannot charge more than SSA approves for his/her services, but can charge you for out-of-pocket expenses, such as medical reports, without SSA's approval. If an attorney represents you, SSA usually withholds 25 percent of your past-due benefits, paying the attorney's fee from this amount, and sends you the remaining funds.

Appealing Claim Denials

If your initial claim is denied, you may appeal. The first appeal, called a "reconsideration," is handled by a state disability determination service, with a different judge reviewing your claim. If this appeal is unsuccessful, you can request a hearing before an administrative law judge (ALJ) within SSA's Office of Adjudication and Review. The ALJ can either allow the appeal based on the first hearing's written record or hold a new hearing. The ALJ may request additional medical evidence or examination(s) before making a decision. If this decision is unfavorable, you may appeal to the SSA Appeals Council. Denial by the Appeals Council may, in turn, be appealed by filing a lawsuit with the Federal District Court in your jurisdiction.

All appeals must be filed in writing within 60 days of an unfavorable determination or decision. Filing can be done by mail or in person at any Social Security office. You must update all of your disability report information for your appeal, using Form SSA-3441. (See the How-To Guide.)

Future Changes in the Appeals Process

Over the next few years, SSA will implement changes to its appeals process by eliminating both the reconsideration and Appeals Council steps. The new system will include new protective safeguards and continuous improvement mechanisms to help administer claims more efficiently. The only step implemented as of January 2010 is the Quick Disability Determination of initial claims.

The new Disability Service Improvement (DSI) process will involve the following proposed steps:

1. Quick Disability Determination (QDD) of all initial claims in the first twenty days, to allow early payment of claims.
2. If a claim is denied at QDD, review by a federal review official may be requested and new evidence may be submitted. The request for this review must be made within 60 days of the unfavorable determination.
3. If the federal review officer denies benefits, you can request a hearing before an Administrative Law Judge. The hearing request must be made within 60 days following decision by the federal review officer.
4. If the claim is denied at hearing, a lawsuit in federal district court must be filed within 60 days, unless the case is referred to the Decision Review Board (DRB). No new evidence is permitted at either of these stages.
5. As part of this entirely new system of administering claims, all files will be handled via the eDIB (electronic disability system), with claim files kept in a paperless electronic database. Stricter deadlines for submission of evidence and restrictions on new evidence will be implemented. A network of experts, known as the Medical and Vocational Expert System (MVES), will be created to assist in claim review.

Continuing to Work

Under Social Security laws, you are allowed to attempt a return to work without losing your right to disability benefits and Medicare. Working for a period of less than six months is considered an “unsuccessful work attempt.” Work continuing for more than nine months will result in benefits being terminated. You are required to notify SSA of any return to work. Otherwise, you face collection action if you are overpaid as a result of failure to report your employment.

The agency purports to have “work incentives” to provide continued assistance with benefits and job placement, although these incentives are not regularly offered. Work incentives are expected to be enhanced under the new DSI process.

Section II: Applying for Social Security Disability Benefits: A How-To Guide

Follow these steps to compile and file your claim for Social Security disability benefits:

1. Make sure you are eligible. You are entitled to benefits the sixth full month after your disability begins. Medicare starts 24 months after you are first entitled to disability payments.

- You must be disabled.
- You must be under 65 years of age.
- You (or a parent) must meet the definition of “insured.” (See Glossary of Social Security Terms.)

2. Compile your claim. You need to gather the following items before applying for disability benefits:

- Medical evidence showing that you have an impairment and its severity or impact. This should include:
 - All medical records in your possession from doctors, therapists, hospitals, clinics and other facilities where you have been treated for conditions related to your disability. For records you do not possess, list the names, addresses and phone numbers of all of your doctors and facilities where you have been treated, as well as dates of your visits and patient ID numbers. SSA needs this information to make an effort to obtain these records, which it will do after you complete an Authorization to Disclose Information to the Social Security Administration (Form SSA-827).
 - A letter or questionnaire from your treatment provider describing your impairment and its severity/impact.
 - Drug names, dosages and prescribing physicians’ names for all prescription medicine you take, as well as the names of all non-prescription (over-the-counter) medicine you take.
 - All laboratory and test results in your possession. For test results you do not possess, list the names of the tests, when and where they were performed, and who ordered them. SSA will make an effort to obtain these records after you complete an Authorization to Disclose Information to the Social Security Administration (Form SSA-827).

- Non-medical evidence, including information from other sources that can help show the extent to which your impairment affects your ability to function. Other sources may include information from non-medical witnesses, such as employers or rehabilitation personnel.
- Your Social Security number, as well as those of your current and/or former spouse and children.
- The dates and places of each of your marriages. For marriages that have ended, information on how (divorce, separation or annulment) and when they ended.
- Your birth or baptismal certificate.
- A summary of where you have worked and the type of work you did in the 15 years before you became disabled.
- A summary of your education and training.
- A copy of your most recent W-2 form (Wage and Tax Statement) or, if you are self-employed, your most recent federal tax return.
- Military discharge papers, if you were in the military service, for all periods of active duty. You can provide an original or certified copy (Form DD 214).
- Workers compensation information, including the date of injury, claim number and payment amount.
- Your checking or savings account number, if you have one.
- Name, address and phone number of a person who knows about your condition(s) and can get in touch with you if necessary.

3. Start the application process. This can be done in one of two ways:

- Visit http://www.socialsecurity.gov/pgm/links_disability.htm to apply online using the Adult Disability and Work History Report. Step-by-step instructions and examples guide you through the process; you can work at your own pace, stop when you want and finish it later; or

- Call 800-772-1213 (Monday through Friday 7:00am to 7:00pm EST) and tell the representative that you want to make an appointment to file a disability claim at your local Social Security office or set up an appointment for someone to take your claim over the telephone. You can also contact your local Social Security office directly to set up an appointment (check your local telephone directory for listings). The in-person or telephone interview takes approximately one hour.

4. Obtain and review the Disability Starter Kit. The kit contains a:

- Fact Sheet: What You Should Know Before You Apply for Social Security Disability Benefits;
- Checklist: What You Need For Your Disability Interview; and
- Medical and Job Worksheet.

If you set up an appointment for an in-person or telephone interview, a kit will be mailed to you. If you apply online, the kit is available at http://www.socialsecurity.gov/disability/disability_starter_kits.htm.

5. Complete the Disability and Work History Report (Form SSA-3368), if you have not already done so.

- Complete the form at <https://secure.ssa.gov/apps6z/radr/radr-fe>.
- A printed version of the form will be mailed to you if you contact SSA to set up an in-person or telephone interview. You can print out a copy of the form by visiting the SSA web site at <http://www.ssa.gov/online/ssa-3368.pdf>.

6. Complete an Application for Social Security Benefits. This can be done online at <http://www.ssa.gov/applyfordisability/>. If you are applying for benefits in person or over the phone, the information for this application will be taken during your interview.

7. Complete an Authorization to Disclose Information to the Social Security Administration (Form SSA-827) for each person or facility that will provide information about your impairment to SSA, plus two extra copies. If you are applying in person or over the phone, the forms will be mailed to you. You can print copies of the form from the SSA web site at <http://www.ssa.gov/online/ssa-827.pdf>. Return the completed forms, by mail or in person, to the Social Security office that is servicing your claim.

8. If you choose to use a representative, such as an attorney, you must notify SSA in writing as soon as possible, using Form SSA-1696-U4 (Appointment or Representative). This form can be found at <http://www.ssa.gov/online/ssa-1696.pdf>. If your representative is not an attorney, the person must state his/her name, acknowledge acceptance of the appointment and sign the form. Detailed information on your right to representation is outlined in SSA Publication No. 05-10075. To view this publication please visit: <http://www.socialsecurity.gov/pubs/10075.html>.

9. Prepare for and attend your interview. To ensure that your in-person or telephone interview goes as smoothly as possible, bring all the information and documents listed in Number 2, above, and all completed forms described in Numbers 2, 6, and 7, above. For more information about preparing for your interview, see <http://www.ssa.gov/online/ssa-16.html>.

10. Expect to wait three to five months, or longer, for a decision. You can check the status of your claim at <https://secure.ssa.gov/aaps6z/IAPS/applicationStatus>.

To appeal a negative determination:

1. All appeals must be filed in writing within 60 days of an unfavorable determination or decision, by mail or in person, at any Social Security office. To do so, you must file SSA Form 3441. To download the form and view information on how to complete it, visit: <http://www.ssa.gov/online/ssa-3441.html>. You can also complete this report over the phone by calling 800-772-1213 or your local Social Security office, or in person at any Social Security office.
2. With any appeal, you must submit evidence showing why SSA's determination regarding your disability was incorrect, including copies of any medical records that were not considered in SSA's previous determination.
3. For all appeals, file a copy of Form SSA-827 (see Number 7 above), Authorization to Disclose Information to SSA, for each treating source you list, plus two extra copies.

4. To request a “reconsideration” after an unfavorable first decision, use Form SSA-561-U2, Request for Reconsideration. To download this form visit: <http://www.ssa.gov/online/ssa-561.pdf>. A reconsideration is a complete review of your claim by someone who did not take part in the first decision. Most reconsiderations involve a review of the files without the need for you to be present.
5. To appeal an unfavorable reconsideration, request an administrative law judge (ALJ) hearing, using Form HA-501, Request for Hearing by Administrative Law Judge. This form is located at: <http://www.ssa.gov/online/ha-501.pdf>. The ALJ may request additional medical evidence before making a decision.
6. An unfavorable ALJ decision can be appealed to the SSA Appeals Council.
7. If the decision of the Appeals Council is unsuccessful, you may file a civil lawsuit in federal district court.

SSA is in the process of changing its appeals process by eliminating both the reconsideration and Appeals Council steps. For a description of the new system, see Future Changes in Appeals Process in the previous section.

Sometimes, after you begin receiving benefits, SSA may determine that you are no longer disabled and may send a letter informing you of that decision. To appeal this determination, use Form SSA-789, Request for Reconsideration – Disability Cessation. You may download the form from: <http://www.ssa.gov/online/ssa-789.pdf>. You will also need to file forms SSA-3441 and SSA-827 (referenced above) and compile evidence showing why you are still disabled.

Section III: **Suggestions for Women with Vulvodynia Seeking Disability Benefits**

- **Educate yourself** about obtaining disability benefits and the claims process. The more you know, the better the results.
- **Be proactive.** If you have a question, ask an SSA employee. Don't be embarrassed to ask a question or to explain that you have a problem.
- **Find a competent, compassionate physician.** Tell the physician that his or her involvement in applying for your disability benefits claim is critical. Be open and honest. Provide the physician with all relevant information.
- **Use the NVA as a resource.** A subscription to the NVA's newsletter, *NVA News*, provides you with valuable information on the diagnosis and treatment of vulvodynia, as well as articles on emotional and sexual issues related to having vulvodynia.
- **Keep a diary** of how vulvodynia affects your life on a daily basis. Use select information from the diary in the medical evidence portion of your disability benefits application. Rate your pain on a scale of 1 to 10 and describe how it affects your daily activities and functioning. It's easier to record your pain and how it impacts you on a daily basis, rather than try to remember it weeks or months later. (To download a sample pain diary, visit <http://learnpatient.nva.org/pdf/PainDiary.pdf>.)
- **Keep accurate and organized records.** List all medications, dates of medical appointments (including the name and phone number of the doctor), symptoms, activities that you cannot perform, and any accommodations or items you need in the course of a day.
- **Contact a lawyer** with experience in obtaining disability benefits for clients, if you are unable to file for benefits on your own. Contact the National Organization of Social Security Claimants' Representatives to locate an attorney in your area and to obtain more information. (See Resources section.)
- **Don't give up** if your claim is denied. Most claims are denied initially. File your appeal on time, along with the proper forms and information.

Section IV: Vulvodynia Fact Sheet

What is Vulvodynia?

Vulvodynia is a chronic condition characterized by pain and burning in the vulva in the absence of infection or other known disease. The most commonly reported symptoms are burning, stinging, and/or rawness. Some women describe the pain as “acid being poured on their skin” or as “constant knife-like pain.” The condition varies in persistence and location. Pain may be constant or intermittent, localized or diffuse. Vulvar Vestibulitis Syndrome (aka Provoked Vestibulodynia), one subtype of vulvodynia, refers to pain experienced primarily when pressure is applied to the vulvar vestibule, the area surrounding the vaginal opening; this pain typically occurs with sexual intercourse, tampon insertion, a gynecological exam or simply sitting. In Generalized Vulvodynia, the other major subtype, pain is relatively constant and occurs spontaneously, but may be exacerbated by pressure.

Who Suffers?

Vulvodynia affects women of all age groups, beginning as early as adolescence. According to an NIH-funded Harvard study, almost 16 percent of US women suffer from vulvodynia at some point during their lives, with more than 90 percent reporting ongoing pain for many years. Approximately six million women in the United States currently suffer from vulvodynia. In adult women, the incidence of symptom onset is highest between the ages of 18 and 25, and lowest after age 35 (Harlow BL, Stewart EG, JAMWA, 2003). New studies indicate that the condition may be highly prevalent in adolescents. Once considered a condition that affects primarily Caucasian women, several recent studies have shown that African American and Hispanic women are equally likely to develop vulvodynia.

Burden of Illness

Living with vulvodynia imposes serious limitations on a woman's ability to engage in normal daily activities. In many cases, the pain is so severe and unremitting that it forces women to resign from career positions, abstain completely from sexual relations and limit many physical activities, often destroying their self-image. In addition, because genital disorders are not openly discussed, many women with vulvodynia feel isolated and hopeless. According to an NIH-funded study at Robert Wood Johnson Medical School (Arnold LD, et al, AJOG, 2007):

- 75% of women with vulvodynia feel “out of control” of their bodies
- 60% report that it compromises their ability to enjoy life

What Causes Vulvodynia?

Vulvodynia is not caused by an active infection or a sexually transmitted disease. Through continued research efforts, we are getting closer to understanding the underlying cause(s) of vulvodynia. Researchers speculate that one or more of the following may cause, or contribute to, vulvodynia:

- An injury to, or irritation of, the nerves that transmit pain and other sensations from the vulva
- An increase in nerve fiber density in the vulvar vestibule
- Elevated levels of inflammatory substances in the vulvar tissue
- An abnormal response of different types of vulvar cells to environmental factors such as infection or trauma
- Altered hormone receptor expression in the vulvar tissue
- Genetic susceptibility to chronic vestibular inflammation and/or chronic widespread pain
- Genetic factors associated with inability to combat vulvovaginal infection
- A localized hypersensitivity to Candida (yeast) or other vulvovaginal organisms
- Pelvic floor muscle weakness or spasm

Diagnosis and Treatment

According to the Harvard study cited above, 60 percent of women consult at least three doctors in seeking a diagnosis. Astoundingly, 40 percent of those who seek professional help remain undiagnosed after three medical consultations.

Vulvodynia is diagnosed when other causes of vulvar pain, such as yeast or bacterial infections, or skin diseases, are ruled out. Upon examination, the vulvar tissue may appear inflamed and swollen or perfectly normal. Currently there is no cure for vulvodynia. Treatment directed at symptom relief includes drug therapy to “block” pain signals, e.g., tricyclic antidepressants or anticonvulsants, and occasionally nerve blocks. Women who have associated pelvic floor muscle spasm or weakness may also benefit from physical therapy, biofeedback and/or Botox injections. When the diagnosis is vulvar vestibulitis, vulvar surgery to remove the painful tissue may be recommended.

For additional information, please visit www.nva.org and <http://learn.nva.org>.

Section V: Glossary of Social Security Terms

- Insured** You must be “insured” to qualify for disability benefits from the SSA. The SSA uses the term “insured” in a very specific manner. It refers to your earned work credits, not to your health insurance. You must have worked long enough and recently enough and have sufficient credits, which are based on your total yearly income, for up to four credits per year. In 2010, you can receive one credit for each \$1,120 of wages or income you earn. The number of work credits needed to qualify for disability benefits depends upon your age when you become disabled. Generally, you need 40 credits, 20 of which were earned in the last 10 years. Workers under age 62 can qualify with fewer credits; for example, if you become disabled before you turn 24, you generally need 1.5 years of work during the three-year period ending with the quarter your disability began. For a detailed explanation and a chart illustrating these rules, see SSA Publication No. 05-10029 at <http://www.ssa.gov/pubs/10029.html>.
- Substantial Gainful Activity** Work that involves significant and productive physical or mental duties for pay or profit. To determine whether you are performing SGA, the reviewer will consider the work you did, any dates you couldn’t go to work, changes made in your job duties, extra help you received at work and extra work expenses incurred because of your condition. See SSA Publication No. 05-10003 at <http://www.ssa.gov/pubs/10003.html> for additional information.
- Treating Sources** Medical personnel who have evaluated or treated you for the impairment. These must be medical professionals deemed acceptable by SSA, which generally include licensed physicians (medical or osteopathic), licensed or certified psychologists, licensed optometrists, licensed podiatrists and qualified speech-language pathologists.

Resources

Books

- Mike Davis, *How to Get SSI and Social Security Disability: An Insider's Step-by-Step Guide*, 2000
- Douglas M. Smith, *Disability Workbook for Social Security*, Seventh Edition 2008. Available from Physician's Disability Service, Inc. (see below) for \$19.95 plus S&H. Also available from Amazon.com. (Includes worksheets to help you gather information to support your claim.)
- David Morton, MD, *Nolo's Guide to Social Security Disability: Getting and Keeping Your Benefits*, 2003
- David Morton, MD, *How to Qualify for Social Security and Protect Your Rights*, 1991 (Information on how SSA looks at medical reports and how yours should be written. Currently out of print; check your library or Amazon.com.)
- David Morton, MD, *Medical Proof of Social Security Disability*, 1996 (Written for lawyers working in the SSD area. Also sold to doctors and judges. Not available in bookstores; call 800-328-9352; \$81.)

DisabilityInfo.gov: A web portal to the federal government's online resource for Americans with disabilities.

National Organization of Social Security Claimants' Representatives (NOSSCR): This organization has a free brochure describing their services and answering questions about the claims process. Call 800-431-2804 or 201-444-1415 or access online at www.nosscr.org.

Physician's Disability Services, Inc. (PDS) offers free resources at www.disabilityfacts.com/resources/index.htm. To order any of the following PDS publications, call 410-431-5279 or visit www.disabilityfacts.com.

- *PDS Disability Facts*. A quarterly newsletter to help with Social Security cases. \$19.95 per year.
- Worksheets from the *Disability Workbook* (see books above). Six disability worksheets in e-book form, \$5.

Social Security Administration. For information and forms, call 800-772-1213 or visit www.ssa.gov. Web site highlights include:

- Answers to Frequently Asked Questions
- Disability Evaluation Under Social Security (aka "Blue Book") – SSA Publication No. 64-039
<http://www.ssa.gov/disability/professionals/bluebook/index.htm>
- A listing of benefits publications, with links to documents:
www.ssa.gov/pubs
- The Listing of Impairments (part of Blue Book)
<http://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm>

Self-Help, Pregnancy, Partner and Disability Booklets

NVA has created four educational booklets that can be viewed instantly and downloaded at NVA's Online Resource Center, www.nva.org/join_splash.html. To obtain a printed copy (or copies for your office), please contact the NVA by phone (301-299-0775) or e-mail (gigi@nva.org).

I Have Vulvodynia – What Do I Need to Know?

This self-help guide enables women with vulvodynia to make educated decisions about their health care, build strong partnerships with their health care providers and improve their quality of life. It provides a comprehensive overview of the condition from both the gynecological and chronic pain perspectives. In addition to focusing on the diagnosis and treatment of vulvodynia, it features important self-help tips and coping strategies.

Vulvodynia, Pregnancy and Childbirth

NVA's pregnancy booklet is the first comprehensive resource on the subject for women with vulvodynia who are pregnant or want to become pregnant. It covers material from conception through the postpartum period, dealing with topics such as alleviating pain during pregnancy and minimizing trauma to the vulva during childbirth. The booklet also discusses alternative methods of conception and childbirth options.

My Partner Has Vulvodynia – What Do I Need to Know?

After reading this brief guide, partners should have a better understanding of vulvodynia and the challenges of living with it. In addition to suggesting how a partner can be supportive, it discusses the impact of vulvodynia on relationships and ways to keep sexual intimacy alive.

How to Apply for Disability Benefits

This guide is intended for women who cannot continue to work and are seeking disability benefits from the Social Security Administration. It provides step-by-step guidance that will help vulvodynia sufferers compile and submit a successful claim. Facts and figures on vulvodynia and a list of additional resources are included.

Support the Cause and Get Involved

The NVA, founded by five patients in 1994, is one of the only non-profit organizations in the world dedicated to improving the lives of women who suffer from vulvodynia.

The NVA has many programs and services to help you:

NVA News. NVA publishes its printed newsletter, NVA News, three times a year. More than 40 back issues are available. The newsletter contains detailed articles by medical experts on the diagnosis and treatment of vulvodynia, and features articles on maintaining sexual intimacy and coping with chronic pain. You can view a sample issue and a table of contents for back issues on NVA's web site (https://www.nva.org/order_newsletters.htm). All issues of the NVA's newsletter can be immediately accessed through our Online Resource Center, found at: http://nva.org/index-online_center.html.

NVA E-Update. To keep you informed about recent research advances, Capitol Hill efforts and publicity, NVA publishes an electronic newsletter, NVA Update. You can view past issues and sign up to receive the e-newsletter online at: http://nva.org/email_newsletter/.

Health Care Provider Database. The NVA maintains a database of health care providers who treat chronic vulvar pain disorders. Please see: http://www.nva.org/patient_services/physician_referral.html.

Support Services. The NVA has a support network for women who choose this option. Many women find that speaking to others who have vulvodynia is both a good source of information and the best way to deal with the emotional isolation that can result from having this disorder. Please see: http://www.nva.org/patient_services/support_services.html.

To read more about our other programs and services, and how we can help you, please visit: http://www.nva.org/about_nva/programs.html.

How Can You Make A Difference?

Recent research indicates that millions of women in the United States alone suffer from vulvodynia. By combining our voices and skills into one collective body, we are making a significant impact, changing the future for ourselves and the women who will come after us. Please make a donation, volunteer your time or be a source of encouragement to other sufferers when you are feeling better. To learn more about what you can do to raise vulvodynia awareness, visit: http://www.nva.org/about_nva/awareness.html.

For more information:
National Vulvodynia Association
PO Box 4491
Silver Spring, MD 20914
301-299-0775
301-299-3999 (fax)

