Vulvar Conditions & Management:

An Educational Booklet for Patients



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The University of Michigan Center for Vulvar Diseases

University of Michigan Medical Center Department of Obstetrics and Gynecology 1540 E. Medical Center Drive Von Voitlander Women's Hospital 9th floor Ann Arbor, Michigan 48109-0384 (734) 763-6295

CLINIC INFORMATION

The University of Michigan Center for Vulvar Diseases was founded in 1993 as a consultation and referral center for complex vulvar problems. The Center for Vulvar Diseases provides a comprehensive set of services to each individual. Members of our multidisciplinary staff attend each patient during a visit. The team approach has been created as the basic structure in recognition of the necessity to provide this intensity of care and expertise to patients who have already demonstrated that they are afflicted by a resistant and chronic illness, or an unusual vulvar condition.

The following people are actively involved in your care at the Center for Vulvar Diseases:

CARE PROVIDERS AT THE CENTER FOR VULVAR DISEASES

Hope K. Haefner, M.D.

Dr. Haefner is a Professor in the Department of Obstetrics and Gynecology. She received her medical degree and completed her obstetrics and gynecology residency and a fellowship in gynecologic pathology at the University of Michigan Medical Center. Dr. Haefner is board-certified in obstetrics and gynecology. She is interested in vulvar diseases and is a specialist in vulvoscopy. She is a member of the International Society for the Study of Vulvovaginal Diseases (ISSVD) and the American Society for Colposcopy and Cervical Pathology (ASCCP). Dr. Haefner is active in vulvar disease research. She offers skilled, perceptive support and detailed instruction to her patients.

Natalie Saunders, M.D.

Dr. Natalie Saunders is an Assistant Professor in the Department of Obstetrics and Gynecology. She received her medical degree from the University of Michigan in 2002. She then continued on at the University of Michigan where she was chief resident. She completed a residency in obstetrics and gynecology in 2006. Her practice includes general obstetrics and

gynecology with a special interest in vulvar diseases. She is a member of the International Society for the Study of Vulvovaginal Diseases (ISSVD).

Samar Hassouneh, MD

Dr. Samar Hassouneh received her medical degree from Harvard Medical School in 2007. She graduated from the University of Michigan residency in obstetrics and gynecology in 2011 and joined as faculty. Her practice includes general obstetrics and gynecology, located at the Livonia health center within the University of Michigan Health system, with a special interest in vulvar diseases.

Ebony Parker-Featherstone, MD

Dr. Parker-Featherstone is a clinical lecturer in the departments of Family Medicine and Obstetrics and Gynecology at the University of Michigan. She received both her Doctorate of Medicine in 2006 and completed a residency in Family Medicine at the University of Michigan in 2009. She also completed a fellowship in Women's Health through the department of Obstetrics and Gynecology in 2010. In addition to her clinical focus on vulvar diseases, Dr. Parker-Featherstone's practice includes full-spectrum Family Medicine including obstetrical and gynecology care at the Briarwood health center within the University of Michigan Health System.

Rosalyn Maben-Feaster, MD

Dr. Rosalyn Maben-Feaster is a Michigan native who earned her undergraduate degree at the University of Michigan. She then pursued a dual degree in medicine and public health at the University of Michigan Medical School and School of Public Health. Dr. Maben-Feaster completed her residency training in Obstetrics and Gynecology at the University of Michigan. She then worked as a general obstetrician gynecologist in the Metro-Detroit area prior to returning to the University of Michigan to join the Women's Health Division in 2015. Her practice encompasses general obstetrics and gynecology, with a focus on vulvo-vaginal diseases. Clinical interests include family planning, vulvo-vaginal diseases, health education and health policy.

Resident Physicians

The University of Michigan is a teaching institution where resident physicians are an important part of patient care. Senior residents will be participating in your evaluation and treatment.

Casey O'Gara, LMSW, RN, CST

Casey is a Clinical Social Worker and Certified Sex Therapist at the University of Michigan Sexual Health Counseling Service. She works with women, men and couples with any concerns related to sexuality also treating anxiety and pain with Cognitive Behavioral Therapy. Casey is also a registered nurse.

Lindsay Matthews, LMSW

Lindsay is a Clinical Social Worker at the University of Michigan specializing in Sexual Health. She works at the Center for Sexual Health, the Center for Vulvar Diseases, and the Adult Medical Emergency Department. Lindsay also works in private practice in the local Ann Arbor community and enjoys serving diverse populations with a focus on strength based positive sexuality.

Elizabeth Hall, RN

Beth Hall is a registered nurse at the University of Michigan Medical Center. She received her nursing degree from Eastern Michigan University. She coordinates nursing care and follow-up for the Center for Vulvar Diseases.

Medical Assistants

The medical assistants at the University of Michigan Center for Vulvar Diseases play an important role in your health care. They will be taking you to the examination room, checking your vital signs and questioning you on your disease process or progress.

Telephone Communications

The staff recognizes the importance of open lines of communication with our patients. However, health care and the decisions relevant to each patient's health problems cannot effectively be carried out over the telephone. Several circumstances exist in which phone calls to the Clinic regarding health care issues are important: (1) to request an earlier appointment than scheduled because of a change in vulvar condition, (2) to obtain advice regarding the development of side effects from treatment, or (3) to provide information that was requested by your provider at your last visit.

All clinical calls are documented and processed by a registered nurse. The nurse will take one of the following courses of action: (1) provide you with advice, (2) schedule an earlier or urgent visit for you at the Clinic, or (3) consult with the health care provider as soon as possible and arrange further communication with you.

The clinic phone number for appointments is (734) 763-6295. The clinic phone lines are open from 8:00 a.m. to 5:00 p.m. to schedule an appointment. Because of the volume of calls that reach the clinic daily, we request that your calls be kept brief. A useful suggestion is to outline your problem before calling and know your medications and dosages and pharmacy fax or phone number, if your call involves these. In your best interest, complex clinical dilemmas must be evaluated in person.

Reporting Progress

Under special circumstances, you may be asked to report progress between visits. This is not in place of regular follow-up evaluations. If you feel your condition has worsened and you require modification of your therapy, it is appropriate to call the clinic and set up an earlier return visit. At times, you will be asked to contact us in one month to report your progress and alter medications. It is very important to call when indicated.

Follow-up Visits

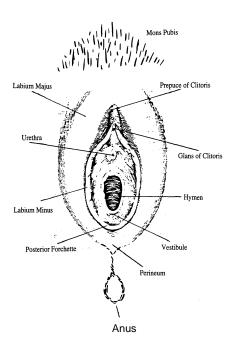
Your provider will determine whether a return visit to the Center for Vulvar Diseases is necessary. All referring care providers will receive a detailed letter about your visit. In certain circumstances, follow-up visits and medication management will be handled by your referring care provider.

Refills of Prescriptions

Prescriptions are carefully calculated so that your medication will last until your next appointment at the University of Michigan Center for Vulvar Diseases or with your primary care provider. In the event that you need medication prior to your next return visit, it is essential that you communicate with the appropriate service regarding this matter prior to running out of your medication. Please allow 72 hours for prescription refills.

The Vulvar Self-Exam

Just as you would examine your breasts or skin for changes, you should examine your vulva. Many diseases of the vulva have similar symptoms. The vulvar self-exam will help you to be aware of any changes in the vulvar area that may need ongoing evaluation. Some changes in the vulva may mean cancer. Tell your health care provider if you see any changes or have symptoms that don't go away, such as itching, bleeding or discomfort. If a problem does occur, catching it at an early stage--when treatment is most successful--is in your best interest. Learning how to do a vulvar self-exam can best accomplish this.



- 1. Wash your hands carefully before you begin. Lie or sit up in a comfortable position with good lighting and a hand mirror (a magnifying mirror may work best). It may help to prop up your back with pillows, or you can squat or kneel. Finding a comfortable position is important so you can clearly see the vulvar area, perineum, and anus. First, just look and learn. Things may appear different from what you expect, and that does not necessarily mean they are abnormal.
- 2. Gently separate the outer lips of the vulva. Look for any redness, swelling, dark or light spots, blisters, bumps or other unusual colors.
- 3. Next, separate the inner lips and look carefully at the area between them for the same changes. Also, look at the entrance of the vagina.
- 4. Gently pull back the skin covering the clitoris and examine the area under the hood at the tip of the clitoris.
- 5. Be sure also to inspect the area around the urethra, the perineum, the anus, the outside of the labia majora and the mons pubis.
- 6. Vulvar self-exam should be performed once per month.

SOME SUGGESTED VULVAR PAIN & ITCHING MEASURES

The vulva is the external genitalia in the female. The skin of the vulva can be quite sensitive. Because it is moist and frequently subjected to friction while sitting and moving, this area can be easily injured. There are various strategies that can be used to prevent irritation and allow the vulva to heal. Keeping this area dry can accelerate healing. Chemicals found in toilet tissues, laundry soaps and detergents that come in contact with the vulva can cause irritation. Avoiding contact with potential irritants that contain chemicals is important. Fabric softeners in undergarments, chemicals in deodorant soaps, bubble baths, feminine hygiene spray and panty liners etc., can all cause irritation to the vulva. The following recommendations are specific measures that can help minimize vulvar irritation.

Wear white 100% cotton underwear and do not wear underwear at night. Do not wear pantyhose, tights, or other close-fitting clothes. Enclosing this area with synthetic fibers holds both heat and moisture in the skin, conditions which potentiate the development of infections. Tight-fitting clothes may also increase your symptoms of discomfort.

After washing underwear, put it through at least one whole cycle with water only. Some women have suffered needlessly from irritants in detergents whose residue was left in clothes by incomplete rinsing. Rinsing clothes thoroughly is more important than which detergent is used although to be on the safe side, the milder the soap, the better. Wash new underwear before wearing. Fabric softeners and dryer sheets should not be used.

Rinse skin off with plain water frequently. Use tap water, distilled water, sitz baths, squirt bottles, or bidets. Additionally, hand held showers can be helpful for rinsing the vulva. After rinsing, pat the skin gently dry.

If the anus is irritated, consider cutting white flannel squares and placing the square in warm water. Wipe the anus with the wet flannel and discard or wash the flannel.

Use very mild soap for bathing. It is best not to use any soaps on the vulva. The vulva should be rinsed with warm water. Unscented soaps or soaps for sensitive skin are best to use on the body. Special soap products can be found at pharmacies or health food stores. Remember that frequent baths with soaps may increase the irritation.

A compress of oiled Aveeno (a powdered oatmeal bath treatment) has been recommended by some. It is placed over the vulva three to four times a day. Put two tablespoons of Aveeno in one quart of water. Mix in a jar and refrigerate. This is often helpful after intercourse or when symptoms of burning and itching are present.

Some patients find the use of cool gel packs on the vulva to be helpful.

Do not use products with benzocaine.

Consider using 100% cotton menstrual pads and tampons. Many women with vulvar pain experience a significant increase in irritation and pain every month when they use commercial paper pads or tampons. This monthly increase in pain can often be reduced by using 100% washable and reusable cotton menstrual pads. Pure cotton tampons are available.

Don't sit or remain in a wet bathing suit for prolonged periods.

Additionally, it is often recommended that the vulva is left uncovered at night (i.e. no underwear) to allow adequate exposure to the air.

Adapted From:

The Vulvar Pain Foundation, "Natural and Prophylactic Measures Suggested", Vulvar Pain Newsletter 1993: Spring: 5-6

The Interstitial Cystitis Association Vulvar Pain handout

VULVAR PAIN

A large proportion of the patients seen at the University of Michigan Center for Vulvar Diseases have vulvar pain. The following information is a comprehensive review of the different aspects of vulvar pain.

Definition: Throughout history many different terms have been used to describe vulvar pain. Vestibulodynia (previously called vulvar vestibulitis) consists of pain at the entranceway to the vagina. Vulvodynia (previously called dysesthetic vulvodynia) consists of a burning or pain on the vulva present in areas outside of the vestibule. Patients with vulvodynia may also have burning or pain at the vestibule. Symptoms consist of burning, stinging, irritation or rawness. Other terms used to describe the vulvar discomfort include stretching and throbbing.

Causes: Vulvar pain can be divided into two major categories: those with a known cause and those where a cause cannot be identified.

Pain with a known cause: Vulvar pain can be associated with simple chemical irritation, so-called contact dermatitis. Common irritants include soaps, shampoos, scented toilet paper, douches, fabric softeners and scented menstrual pads. It can also be caused by certain medications which have been used to treat vulvar problems. Various infections can also be causes of vulvodynia. Women with chronic vulvar and vaginal yeast infection can frequently have vulvar itching and burning. Often symptoms worsen before menses as the changes in ovarian hormone production and the local vaginal environment can favor yeast growth during that time. Recurrent herpes simplex virus infection can also cause vulvar pain. These infections wax and wane, often starting at stressful times and lasting anywhere from a couple of days to a week or more. Irritation of the nerves which supply the vulva can also cause vulvar pain. This type of vulvar pain may radiate from the vulva to the perineum and into the groin and

thigh. Some patients have lower back problems which may be associated with this pain also. Vulvar pain also results from injury (i.e. childbirth, vaginal/vulvar trauma).

Pain without a known cause: Physical examination of this group of patients does not demonstrate any visible abnormalities. It is important to understand that vulvar pain with a normal appearing vulva does not mean that there is not a cause of the vulvar discomfort, rather a cause cannot be identified. Despite the fact that a cause of vulvar pain cannot be established in all cases, two things are important to keep in mind: 1) frequently the discomfort associated with vulvar pain can be controlled, and 2) it is clear that there is generally no relationship between vulvar pain and the subsequent development of vulvar cancer.

Pain on the Vestibule of the Vulva: Some women present with distinct tenderness and at times erythema (redness) on the vestibule (entry to the vagina). Intercourse is painful and, in some cases, impossible due to the severe pain. Typically, women with pain on the vulvar vestibule present with a varying duration of symptoms from months to several years. Symptoms often begin after experiencing some type of infection or trauma followed by difficulty with intercourse. Burning, stinging, irritation or rawness at the vaginal opening with intercourse are the most common complaints. This same sensation may also be experienced when placing tampons or touching in the area of the vestibule. Women with severe symptoms may also feel this same sensation when riding a bicycle, horseback riding or jogging. In more extensive cases, some patients experience these symptoms while sitting, walking or even without any movement. Typically, these women have seen a number of health care practitioners and have had numerous attempts at therapy with topical or oral antifungals, topical steroids, and antibiotics. Often, these provide no long term relief.

The cause(s) of pain on the vestibule is not known. Early studies implicated the human papilloma virus as a cause, but this is no longer considered to be associated with vestibulodynia. There appears to be a small subset of women who have chronic yeast infection as a cause of their vestibular pain, and long-term yeast suppression has met with promising results in these women. There is also another group of women who appear to have both pain at the vulvar vestibule and interstitial cystitis (a condition of the bladder which causes urinary frequency and burning). Because the vestibule and a portion of the bladder are two tissues in the body derived from the same embryologic tissue, investigators have begun to look for an irritant which might affect both of these structures. To date, no one causative agent has been proven. Some patients relate the onset of their pain to a gynecological or obstetric event. It is important to recognize that there is absolutely no evidence that vestibular pain is a sexually transmitted disease, therefore, it cannot be contracted from or given to your sexual partner.

Treatment: There is no standard treatment for patients with vulvar pain since there are likely multiple causes. Treatments suggested will depend on your individual case. Modifications of treatments and medication dosages may need to be altered if your symptoms vary. The health care providers at the Center for Vulvar Diseases will discuss your individual case with you and develop an individual treatment plan based on your history, prior treatments and severity of symptoms.

Vulvar pain can be a difficult process to treat. Improvement may take weeks to months (even years) of long-term treatment. Spontaneous remission of symptoms has occurred in some

women, while with others multiple attempts with medical management have proven unsuccessful in relieving 100% of symptoms.

Medical: Treatment of vulvar pain conditions is confounded by the fact that the cause is unknown in a great majority of cases, and the best treatment will likely come only when the cause has been identified. Where chronic yeast infection can be identified, suppression of yeast growth can be gratifying. Other topical therapies such as steroids and antibiotics have not met with success. Topical anesthetic agents (e.g., viscous or liquid Xylocaine® [lidocaine]) can sometimes help with temporary relief. Depending on the individual case, treatment may be with topical medications (such as xylocaine or a compounded medication) and/or oral medications. The general classes of oral medications that are used are tricyclic antidepressants (such as amitriptyline or nortriptyline) or anti-convulsants (such as gabapentin or pregabalin). These medications work by inhibiting certain pain fibers which supply (innervate) the vulva.

Tricyclic Anti-depressants are classically used to relieve depression and anxiety. Drugs that are in this category include, Elavil® (amitriptyline), Norpramin® (desipramine) and Pamelor® (nortriptyline). Tricyclic antidepressants may also be used for the treatment of a variety of pain conditions. They must be taken regularly to be effective. Do not skip doses, even if you feel that you do not need them. The drug must be taken regularly for three to six weeks before its full effect is felt. Do not stop taking these medications abruptly, especially if you have taken large dose for a long time. You will need to gradually decrease your dose per your health care provider's recommendations.

Anti-Convulsants such as gabapentin and pregabalin are used to help control some types of seizures in the treatment of epilepsy, but are also used by pain clinics to control various forms of pain. It helps control pain by decreasing the excessive impulses of nerves that transmit pain and by preventing the spread of increased excitation from abnormal to normal neurons.

Surgical: Vestibulectomy is a surgical excision of the vulvar vestibule that may be offered as treatment for pain on the vestibule if conservative measures have failed.

PHYSICAL THERAPY

Physical therapy (PT) and biofeedback has been important in the treatment of vulvar pain. Evaluation and treatment may include observation, palpation, use of topical vaginal or rectal sensors for biofeedback and/or electrical stimulation, vaginal probes for biofeedback, soft tissue mobilization, education, relaxation exercises, and ultrasound. Each physical therapy program is very individualized according to findings from the patient's initial evaluation and according to the patient's goals.

Various pain conditions can be aggravated or caused by muscle tension. When a person experiences pain, the body's natural response is to protect that body part by tightening the muscle. PT uses biofeedback to help educate patients on how to relax a contracted or tightened muscle. Biofeedback gives you immediate information on whether your pelvic floor musculature is relaxed or tensed and helps you to gain voluntary control of your muscles. It aids in developing self-regulation strategies for confronting and reducing pain. This allows you to become actively involved in your own treatment and learn how to relax the pelvic floor muscles in various positions. Sensitive detectors can be used on the vulva to tell you what is happening in your vulvar nerve environment. With the aid of an electronic measurement and amplification system or biofeedback machine, an individual can view a display of numbers on a meter, or colored lights to assess nerve and muscle tension. In this way it is possible to develop voluntary control over those biological systems involved in pain and discomfort.

The body has a protective muscle guarding mechanism to protect painful areas. The muscles react by tightening up. Patients are taught to isolate their pelvic floor muscles and learn how to strengthen them. After exercise therapy, the muscles return to a stronger, more relaxed and more stable state.

A health care provider's referral or prescription is necessary for evaluation and treatment in physical therapy. Pre-certification from your primary care health care provider may also be required. It is recommended that you contact your insurance company prior to scheduling your initial physical therapy visit to assure physical therapy is covered by your insurance program.

IMPORTANT THINGS TO REMEMBER ABOUT VULVAR PAIN

- Vulvar pain is not generally associated with malignancy
- Despite the fact that the cause of vulvar pain cannot be established in many cases, careful investigation has established that it is not a sexually transmitted disease and is not contagious to your partner.
- Vulvar pain is not due to poor hygiene, and the use of strong soaps and detergents can
 worsen the condition. Use gentle soaps to the skin and no soap on the vulva,
 allowing water alone to cleanse the perineum.
- Improvement often takes weeks to months.
- Although the cause of vulvar pain cannot always be determined, it has been characterized well enough to allow treatment of the pain with a reasonable expectation of significant improvement, if not complete alleviation of pain.
- Treatment setbacks may occur; they are not necessarily the fault of your health care provider or you.
- We understand that chronic pain is exhausting and can be demoralizing.
- There is nothing wrong with you as a person, the problem is your pain.

- Don't feel that because this is genital pain that you can't talk to other people. People
 with chronic problems need others for support. Family and friends can help.
- If you are in a relationship, both of you are affected by this problem. Appropriate couple counseling may be needed.
- It is OK to seek information on your own. The more you know about this disease, the more control you have over your situation.
- Sometimes patients become depressed if new treatments fail. Remember this as we work through this problem.

OTHER VULVAR CONDITIONS

Yeast Infections

Yeast infections are a common vulvar infection. Diabetes, pregnancy, antibiotic use, a suppressed immune system and zinc deficiencies are factors that predispose women to yeast infections. Candida albicans is the most frequent cause. The vagina, as well as the vulva, may be infected also. Many women in the reproductive age group have yeast present in the vagina or vulva without symptoms. Yeast infections generally are not sexually transmitted, but there are exceptions and you may want to address whether or not your partner should be treated. Symptoms of yeast infections can include redness, itching and a whitish, clumpy discharge. For women with recurrent yeast infection, the symptoms tend to flare at the same time during each menstrual cycle. Sometimes women have burning with urination. Intercourse may be painful. Some women complain of vaginal dryness.

Many times patients with symptoms thought to be from yeast do not have the fungus. To diagnose this infection, the discharge on the skin of the vulva or in the vagina may be taken and examined under a microscope. A culture may be sent to the laboratory. If a culture is sent, it can take up one week to determine if yeast are present. If a yeast culture is taken, you will be contacted if it is positive, otherwise, assume it is negative. If an infection is present, antifungal drugs are the usual treatment. A cream or tablet (or both) can be inserted into the vagina and applied to the vulvar skin. Occasionally, powders are used to treat yeast. Oral medications can also be used to treat yeast infections (such as fluconazole). Many women with recurrent vaginal candidiasis can be effectively treated with intravaginal boric acid If you have recurrent yeast, at times twice weekly intravaginal boric acid is used (for example, on Monday night and on Thursday night) to prevent recurrences. Many resistant candida strains will respond to boric acid. It is important to keep this medication (as well as all medications discussed) away from children. It is important to treat the yeast with the appropriate medication to insure that the infection will resolve. It is also important to complete your course of treatment.

Patients with recurrent infections may benefit from limiting large amounts of sugars (sucrose and lactose) from their diets. Such sources would include candies, syrup, milk, cottage cheese and artificial sweeteners containing lactose.

Itch Scratch Syndrome

Itch-Scratch is vulvar condition categorized by a significant amount of itching causing the patient to scratch the vulva. This leads to a cycle of itching and scratching that can be severe, disruptive, and difficult to treat. This condition is treated most effectively by breaking the cycle of itch-scratch. Vulvar care measures as reviewed above are extremely important in treatment. Additionally, if the underlying cause can be identified, this should be treated. Treatment is accomplished in several steps. First, any underlying infection must be treated. Sometimes there is a superimposed bacterial infection. This is best treated with a broad spectrum antibiotic such as a cephalosporin. Also, if yeast can be identified it should be treated. Furthermore, steroids are very useful. Topical steroids such as clobetasol ointment 0.05% or triamcinolone ointment 0.1% are prescribed. Depending on the severity, the patient may also benefit by a course of oral steroids (prednisone) or intramuscular steroids (Kenalog). Lastly, if a patient is scratching at night, they must be given a medication to help them sleep more soundly. Many sleep medications can be useful, including hydroxyzine, amitriptyline, and zolpidem. If scratching during the day is a concern a medication such as citalogram can be useful in controlling the urge to scratch. Occasionally patients get initial relief but the itch-scratch recurs. This can be treated with a longer course of an oral steroid taper.

Condyloma Acuminatum

Genital warts (condyloma acuminata), like warts on other parts of the body, are caused by the human papilloma virus (HPV). This is the same kind of virus that causes warts on the hands and feet. They are usually spread to the vulva through sexual contact but can in some instances be spread by other means. Women of childbearing age are the most susceptible to infection with HPV. The growths are occasionally seen before puberty or after menopause. The vulva, particularly at the opening of the vagina (vestibule) and the labial folds, is the most common site of this disease. Lesions can also arise on the skin near the anus, vagina, cervix and urethra. They usually appear first as a small thickened area of skin with definite edges. The wart may become surrounded by seedlings (smaller warts) that may grow to involve other areas. Occasionally, they spread and enlarge, forming a large cluster of warts that look like tiny cauliflower. The warts appear on the vulva as raised and sometimes reddened patches that may hurt or itch.

There are several ways to treat genital warts:

One topical therapy is the application of trichloroacetic acid (TCA) to the warts. Treatments occur weekly (by the health care provider) until the warts are gone. Burning may temporarily follow its application. Imiquimod (Aldara®) is another topical drug for warts. Patients place it onto the warts three times a week. It needs to stay on for 6-10 hours then it is washed off with a wet wash cloth. Another topical medication is Condylox® (also applied by patients). Interferon, a drug that is injected into the warts or into a muscle, may be used for recurrent lesions or for immunosuppressed patients. Laser treatment or Loop electroexcision are used to treat condylomata at times. Excision with a scalpel under local or general anesthesia is sometimes necessary.

These treatments are not always successful; the warts may come back. It is important to watch for recurrences.

Lichen Sclerosus

Lichen sclerosus is a skin disorder that affects the vulva. It may occur in any age group. The exact cause of lichen sclerosus is unknown. The condition resembles the appearance of lichens (mixture of fungi and algae) found in nature but is not caused by fungi or algae. It is not an infection that you caught from anyone, and you cannot transmit it to others. There have been reports of family members with lichen sclerosus, thus it may have a genetic link. There is also the possibility that it has an autoimmune component.

It is characterized by small white patches that are thin and have a crinkled appearance, looking like cigarette paper at times. It may involve the entire vulvar area (from the clitoris to the anus). Often, changes of the clitoral foreskin hide the clitoris. The labia minora almost completely disappear at times. Not uncommonly, splitting of the skin in the midline is seen. Tears may also develop in the natural folds of the vulva. The vaginal opening may become smaller, interfering with intercourse. Occasionally the tissue breaks down, forming an ulcerative lesion. It may be a chronic process which at times is not curable. The disease does not spread into the vagina. Itching is the primary symptom.

A biopsy (a minor surgical procedure to remove a small piece of tissue that is then examined under a microscope), is performed to make the diagnosis.

The goal of treatment is to eliminate itching and protect the skin from damage. Occasionally, complete resolution of the abnormal vulvar appearance may occur. More commonly, the skin changes of lichen sclerosus will not completely resolve. This does not mean the treatments are not helping. Various medications are used to improve the skin condition. Although testosterone had been used frequently in the past for treatment, the current therapy is potent topical steroids in ointment form. Ointments tend to be gentler than creams on vulvar skin. Temovate® (clobetasol propionate 0.05%) is a frequently prescribed topical treatment. Following the initial use of clobetasol propionate 0.05% ointment, the steroid content of the ointment is decreased gradually. Long term topical steroid use is often required. During early treatment, avoidance of tight clothing will prevent further tissue damage. Several follow-up appointments will be necessary to evaluate response to treatment.

Many people have wondered if lichen sclerosus can turn into cancer. Lichen sclerosus scars the skin, and in theory, could increase the risk for a local skin cancer (this happens in 3% to 5% of patients). You will need to be followed closely to have the vulva examined at regular intervals. A sore or ulcer that doesn't heal in a few weeks, a lesion that bleeds easily, or bumps or raised lesions that are becoming larger are signs of a skin cancer. In some cases, an additional biopsy may be indicated. You should examine the vulva monthly and have regular visits with your health care provider to follow the skin appearance.)

Lichen Planus

Lichen planus is a skin condition characterized by itchy bumps on the shins, the inner wrist, and the hands. A particular type of lichen planus affects the mucous membranes of the mouth and external genitalia. It often involves the vagina as well as the vulva. It can resemble other vulvar skin conditions. It is diagnosed by biopsy. This is a minor procedure often done in the office under local anesthesia. Small areas of skin are removed and sent for analysis. At times the

biopsy does not reveal lichen planus yet the mouth and vulvar appearance are consistent with this diagnosis.

The exact cause of lichen planus is unknown. It is not believed to be an infectious disease. The lesions consist of inflamed skin, but what causes the inflammation is unknown. In erosive lichen planus, the thin mucous membranes inside the mouth and vagina lose their top layer when they become involved with lichen planus, so red erosions rather than bumps develop in these areas.

Erosive lichen planus may be painful in the mouth and vagina and secondary infection may occur. If the areas touch one another, scarring may occur resulting in a narrowing or complete closure of the vagina.

Lichen planus is often improved with various creams and ointments. Several drugs are used to treat this condition. Vaginal dilators may be used to prevent scarring. If scarring has occurred, vaginal dilators may be used to help prevent further scar formation. Vaginal dilators may also be recommended prior to surgery. Surgical separation of the vaginal scar tissue is sometimes necessary.

You should pay close attention to any changes in the vaginal discharge. If vaginal discharge occurs, it may indicate an erosion or secondary infection. Medication is most often used on a regular basis to maintain optimal tissue status, rather than only with flares in disease. There is a slightly increased risk of squamous cell carcinoma of the vulva developing in patients with vulvovaginal lichen planus. Regular visits with your health care provider and monthly vulvar self examinations will be necessary.

Squamous Cell Hyperplasia

Squamous cell hyperplasia (formerly termed hyperplastic dystrophy) is an abnormal growth of the skin of the vulva. It has a variety of appearances. It may present as a pink or red vulva. It frequently appears as elevated white patches. Moisture, scratching, scrubbing and medications may cause variations in the appearance of the lesions. The size of the lesions ranges from small to extensive. The areas most frequently involved are the hood of the clitoris, labia majora, outer aspect of the labia minora and the posterior commissure. Lesions may also extend to the lateral surface of the labia majora and even to the thighs. When the skin becomes too thick, hardened patches on the vulvar area may appear. This is related to chronic irritation. A biopsy (a minor surgical procedure to remove a small piece of tissue that is then examined under a microscope) is often performed to diagnose this problem.

Many things can trigger itching on the vulva. The itching generally stops when the skin heals. Remember that it took a long time for the squamous cell hyperplasia to develop, so don't expect it to improve overnight. It is often chronic and may require long-term treatment with steroid ointments. These are rubbed into the vulvar tissue. Squamous cell hyperplasia is sometimes observed next to lesions of invasive squamous cell cancer. You will need to be followed closely while you have squamous cell hyperplasia. Patients with a combination of lichen sclerosus and squamous cell hyperplasia are at an increased risk for development of vulvar cancer.

Vulvar Intraepithelial Neoplasia

Vulvar intraepithelial neoplasia (VIN) is a type of precancerous vulvar tissue abnormality. It is caused by changes in the cells of the vulvar tissue that allow them to grow abnormally. The human papilloma virus (HPV) has been linked to VIN. VIN can progress to invasive cancer of the vulva. This happens in only a small portion of cases and usually progresses slowly.

Patients may be without symptoms or complain of pruritus (itching) or burning. Raised brown, red, pink, white, or gray lesions of various colors may be present. Tests to diagnose VIN include colposcopy (viewing of the cervix, vulva or vagina under magnification with a special instrument) and biopsy (a minor surgical procedure to remove a small piece of tissue that is then examined under a microscope).

Treatment depends on the degree of the disease. VIN 3 can usually be treated successfully with surgical or laser removal. VIN may reoccur. For this reason, and because VIN may not produce any symptoms, it is important to have regular checkups by your health care provider. This is especially true if you smoke, as this contributes to the recurrence and progression of the disease.

Paget's Disease of the Vulva

Vulvar Paget's disease appears as a red velvety area with white islands of tissue on the vulva. At times it may be pink. Occasionally there are moist oozing ulcerations that bleed easily. Itching is present in over half of the patients. Soreness may also be present. Almost all patients are postmenopausal, Caucasian women. The cause of Paget's disease is unknown. It is diagnosed by biopsy (a minor surgical procedure to remove a small piece of tissue that is then examined under a microscope) and is usually treated with surgery. It is rarely associated with an underlying cancer on the vulva. Genital Paget's disease may however be related to a primary carcinoma of the rectum, urethra or bladder.

Hidradenitis Suppurtiva

This is a chronic, inflammatory skin disease that usually begins after puberty. It is characterized by painful, deep, inflamed lesions (pus-containing bumps, also called abscesses). These areas can expand and break open, draining blood or pus and leaving behind scars as the disease advances. The lesions tend to occur in certain areas of the skin containing sweat glands. These areas commonly include the armpits, anus, and genital areas, as well as under the breasts and on the buttocks.

The goal of treatment for hidradenitis suppurtiva is to slow the disease progression and to help reduce the severity of its symptoms. Depending on the stage of illness, treatment can include specific self-care procedures, prescription medications, and surgery. For patients who have early disease limited to small, single lesions without scarring (Stage I), treatment includes topical antibiotic creams. For patients with more extensive disease consisting of more widely separated, recurring lesions with scarring (Stage II), treatments include oral antibiotics in addition to the topical cream, as well as other oral medications. Finally, for patients with diffuse disease made up of many interconnected lesions (Stage III), surgery is the definitive treatment with medical therapy used both pre-operatively for preparation and after the operation for prevention of future outbreaks. Regardless of the stage, care may also include preventative

treatments like zinc gluconate, and medications that work against testosterone. These medications include anti-androgens such as Yasmin (Ocella), Yaz, and spironolactone.

Along with medical and surgical management, care often includes general guidelines that may help reduce the physical impact associated with hidradenitis suppurtiva. These include avoiding irritants, wearing loose closing, losing weight, and not smoking.

Desquamative Inflammatory Vaginitis (DIV)

Desquamative inflammatory vaginitis (DIV) is a cause of persistent vaginitis. It is often associated with painful intercourse and can occur at any age of reproductive life and during menopause. Women often have had significant vaginal discharge for years or suddenly develop discharge with irritation of the vulva and vagina. The inflammation may cause the vaginal wall to peel or shed, called desquamation. DIV is not a common cause of vaginitis. Women will have an excessive discharge that may have been present for yeasts (often yellow-green but may be bloody). The discharge may be associated with vulvar burning, irritation, and itching. Diagnosis is made my physical examination and wet prep. Exam shows copious yellow-green discharge and can show redness in the vaginal wall. Wet prep shows elevated pH, many white blood cells, lack of lactobacilli, and parabasal cells. Treatment is with hydrocortisone and antibiotics intravaginally.

Additional Patient Education Information is available on these conditions as well as other conditions at:

www.issvd.org

http://libbyedwardsmd.com/

Vulvar Conditions and Sexual Health

Practitioners at The Center for Vulvar Diseases believe that sexual health is an integral part of overall physical and emotional health. For this reason, all new patients (and their partners) to the Center are strongly encouraged to meet with one of the Certified Sex Therapists as part of their medical appointment.

Pain and medical conditions of the vulva and vagina can often affect sexual feelings and sexual functioning for both the patient and her partner in ways that other medical conditions do not. Medical conditions affecting the vulva and vagina can be much more emotionally "loaded" than, for instance, pain located in the shoulder or neck. For this reason, we believe that an important part of healing process of the "whole person" includes addressing issues related to sexuality.

Sexual functioning and sexual health

Sexual health can be very different for different people. There is no "normal"- there is only what is relevant and comfortable for each individual and couple. Many couples and individuals stop or even give up on continuing a sexual relationship when pain occurs. Sexual interest (libido), arousal, lubrication, orgasm, and ability to allow or tolerate vaginal penetration can be affected

by pain. Often these changes can cause misunderstandings and even conflict in couples which can build and remain over a long period of time. Pain can also bring up body memories of past trauma or other painful times in one's personal history for some women. These changes and concerns can be experienced as permanent when indeed they can be quite temporary and changeable.

Low libido is a very normal response to vulvar pain and is the sexual complaint we hear most from our patients. Low libido is one way that the body teams up with the mind to protect you. It's normal to move away from things that hurt! A pattern can be created over time that makes it difficult to return to sexual desire and resume sexual intimacy. If low libido or other sexual difficulties were present even before the pain, these can combine to create a powerful pattern. Negative interactions in a couple due to misunderstandings can also further exacerbate the problem. However, all of these things can be addressed, corrected and even healed with time, patience and a bit of determination. Following are some suggestions to try:

Listen to your body and consider avoiding activity causing significant discomfort or pain. You can rate the discomfort on a scale of 0 (no discomfort at all) to 10 (excruciating pain). Avoid activities that rate more than a 2 on this scale.

Communicate with your partner extensively if you are in a relationship. A partner needs to know what hurts you, what feels good, and how to approach sex with you in order to move forward. This is a team endeavor, and you can't play on a team if your teammate is in the dark. Sometimes a partner is not, or seems not to be, as understanding as you desire them to be. Often this comes from frustration, lack of real understanding of your experience and a sense of helplessness. Open communication, even if scary, can help a great deal. Sometimes a couple needs to consult a counselor or therapist if it is particularly difficult to open this conversation. A Certified Sex Therapist is almost always present at our clinic and can also recommend professionals in your area. Later on in this document you will find resources to help you find a Certified Sex Therapist as well. (See resources on pg. 25).

Expand your sexual repertoire and experiment with sexually stimulating activity that does not involve penetration. Oral sex, manual sex, sex using a vibrator, massage, kissing, fondling, breast touching, and light caress have all been found to be pleasurable alternatives to intercourse. If some of these ideas are objectionable to one or both partners, this should be frankly discussed. We have found that many couples have gradually become interested in alternative activities by slow exposure and experimentation. Again, clear communication is important, including paying attention to what is experienced as unpleasant.

Avoid sex that hurts. This may seem obvious, but we have found that some women may grit their teeth through uncomfortable sex because they feel that they are unfairly depriving their partner of the partner's satisfaction. We have noted, however, that partners are distressed when they sense that the woman is not being straightforward about the fact that she is in pain. They don't want to cause hurt or harm, and generally do not find sex pleasurable that causes pain to their partner.

Focus on sensual as well as sexual. When sex begins to be associated with pain, the experience of sensual pleasure can be lost as well. Sensuality can be re-introduced with "non-demand" (meaning sex is not expected) massage, cuddling, backrubs or other activities. Some couples become touch-avoidant when they have experienced the cycle of pain. Continuing pleasurable touch and affection is an important part of sustaining intimacy in a relationship, even when sex is (at least temporarily) not an option.

Sexual activity - not orgasm oriented. Our culture tends to reduce sex to the pursuit of orgasm. Incorporating sexual and sensual play where the goal is simply to experience the moment, have fun, and enjoy each other has been liberating to many couples. Couples tell us that—if anything can be considered positive about vulvar pain—they have greatly expanded their definition of sex by concentrating on the pleasure of the moment and to greatly de-emphasize the need for orgasm only.

Lubrication- The female body will produce its own lubricant with pleasurable mental and physical sexual stimulation. It is extremely common for people not to spend enough time in arousal activity and shortcut the natural lubrication process. However, with menopause, vulvar disease, vaginal skin changes, etc., natural self-lubrication may not be enough even when plenty of time is taken for arousal. Commercial lubricants should be used liberally in addition to adequate stimulation to decrease painful friction. Lubricant can be applied to the vaginal opening, the vulva, inside the vagina and also on the penis or on a sexual toy. Later in this document is a section explaining different types of lubricants that are available. (See next section).

Muscle tightening (vaginismus). Sometimes muscles tighten involuntarily as a response to fear of pain. This is an involuntary, protective mechanism the body uses, much like blinking if something is flying straight for your eye. Sometimes it is difficult to sort out the origin of the pain. We will work with you to carefully determine whether you may be experiencing a muscle tightening within the vagina in addition to vulvar pain. Fortunately, there are techniques, such as dilator therapy or pelvic floor physical therapy, which work to overcome this symptom. You will work with your clinician or team to determine a treatment.

LUBRICANTS 101

Use lubricants to make vaginal penetration more comfortable. The list of lubricants below does not attempt to be complete, but rather describes several commonly used lubricants. This is not a list of official recommendations, but a resource for options. These products are available at grocery, pharmacy and health food stores or online via a search engine such as Google.

Some lubes have glycerin and some are 'glycerin free.' Although not well researched, glycerin has been shown to increase the production of yeast and irritation in the vagina for some women. Propylene Glycol is another ingredient used in some lubricants that can cause irritation for some women. Remember most lubes impair sperm's motility, so if trying to conceive, a brand called Pre-Seed is considered the best option.

Silicone lubricants last longer than water-based varieties because they are not absorbed into the skin, but often need to be rinsed off with water. Water-based lubricants are easier to wash off but may need to be reapplied during sexual activity. **Don't mix silicone lubes with other silicone products** such as contraceptive diaphragms or "sex toys," as doing this can cause the silicone in such products to deteriorate. Try to avoid lubricants or products that claim to cause "warming," "cooling," "tingling" or otherwise enhance sensation. Some patients have told us these products have caused them irritation or a burning sensation. **Do NOT use oil-based lubricants with condoms**, as the oils can break down the condom material and render them less effective in

preventing pregnancy or STD/STI transmission. Flavored lubricants can contain sugars, which may promote yeast overgrowth.

LUBRICANTS

Many drug stores only carry one or two lubricant brands. You may have better luck finding more lubricants online at such sites as Amazon.com, S3safesexstore.com, or DrugStore.com. The following is only a partial list of available lubricants to get you started. We do not officially recommend or endorse any of these resources over any others.

Silicone Lubricants

- <u>Sliquid</u> Sliquid Silver is a high-quality silicone lubricant. Paraben and glycerinfree.
- UberLube glycerin and paraben-free.
- <u>ID Millenium</u> non-glycerin, latex compatible.
- System JO thicker in consistency than other lubricants.

Water-Based Lubricants

- Sliquid Organics Paraben and glycerin-free.
- <u>Astroglide</u> water-soluble, contains glycerin and propylene glycol, latex compatible
- Glycerin & Paraben Free Astroglide water-soluble, latex compatible, glycerin free, paraben free contains propylene glycol
- Astroglide Natural- Free from glycerin, parabens, fragrance, flavor, alcohol.
- <u>Sylk-</u> Made of Kiwi fruit vine and purified water. From New Zealand. Marketed through Whole Foods. Mimics natural secretions, contains glycerin.
- <u>Swiss Navy</u> Paraben-free, thinner consistency than other brands

"Fertility Friendly" Lubricants

<u>Pre-Seed</u> -will not affect sperm motility, water soluble

Hypoallergenic Lubricants- Organic and chemical free:

- <u>Pink Women's Hypoallergenic Silicone Lubricant</u>- made with silicone, vitamin E, and aloe vera.
- Just Like Me- made by Pure Romance, pH balanced, water-based
- Good Clean Love 95% organic materials, water-based, paraben and glycerinfree

Other Lubricants

- <u>Surgilube</u> Surgical lubricant which may be used with dilators, water soluble, contains propylene glycol, latex compatible.
- Vitamin E oil Available in health food stores, natural, non-irritating qualities.
- Saliva can be used for lubrication.

<u>Vaginal Moisturizer – Used regularly to enhance overall vaginal moisture, rather than "as</u> needed," like a lubricant

• <u>Replens</u> - Long lasting, inserted by applicator into the vagina. Can be used on a regular basis for vaginal moisturizing. Contains glycerin, water soluble.

The following brands can be inserted deeper into the vagina with needleless syringes:

- <u>Liquid Silk</u> silky to the touch, does not get sticky, moisturizes skin. Hybrid (silicone and water based) and glycerin-free.
- <u>Pink Indulgence Lube</u> Similar to Liquid Silk but lasts longer. Hybrid (silicone and water based).
- <u>Sliquid Organics Silk</u> glycerin and paraben-free. Moisturizing. Contains botanical extracts.

DILATORS

HOW TO USE VAGINAL DILATORS

At times, the use of vaginal dilators for your vulvar condition may be recommended by your medical team. The following is a discussion on the use of vaginal dilators.

Pain with sexual activity can cause some reflexive tension in pelvic muscles. Anticipating that an activity may be painful can cause muscles to tense voluntarily or involuntarily, as a way to be self-protective. This tension is called "vaginismus." Sometimes a woman can benefit from learning how to gain voluntary control over the pelvic muscles. At times, **vaginal dilators** may be recommended by your health care provider. Vaginal dilators are smooth cylinders, rounded at the end, which come in various sizes. The dilator is inserted by you, slowly and gently into the vagina in the privacy of your home – to help stretch and relax the vaginal muscles. The smallest dilator in some kits is about the diameter of a small tampon, while other kits include even smaller dilators. Dilators will be recommended for you in the appropriate size, with discussion about how to use them. These instructions can be used for reference in between clinic visits. You may want to keep this handout with you when you are first using dilators. Various types of dilators are available, and there is more information later in this document.

Getting ready to use dilators. Select a time and place when you can have privacy and will not feel rushed. Many women elect to use their bedroom, and to use dilators while lying down. Plan for about 10 to 20 minutes a day, four to five times a week. If this seems like too often or too long, start with what you feel comfortable with. But do start! We want you to be successful, and this will require repetition and consistency.

What you'll need: At first you may benefit from using a hand mirror in order to see the vulva and vaginal opening. Locate the labia and clitoris as well as the opening to your vagina (See page 7 for information on Vulvar Self-Exam). You will need the dilator and some lubricant. Lubricant can be purchased in any drug store or online (See previous section on lubricants to determine which brand or type may be right for you). You may want to use a silicone-based lubricant, as these tend to last longer because they are not absorbed the way water-based

lubricants are. In most stores, lubricants are located in the same area as birth control items and condoms.

Beginning with dilators. Use a small amount of lubricant on the dilator (you will likely want to begin with the smallest size, and eventually work your way to the largest). Tense and relax the pelvic floor muscles a few times (See Kegel Exercises later in this section). When you are in the "relax" phase of the exercise, gently touch the dilator to the opening of the vagina and begin to massage in a circular motion. As you massage the vaginal opening with the dilator, slowly begin to push the dilator in. Be gentle and take your time. At first, you may only be comfortable placing the dilator at the vaginal entrance and doing no more. That is okay! Some women find that a very gradual progression of dilator use works best for them. Challenge yourself, but don't overwhelm yourself. While inserting the dilator, some women find it helpful to use their pelvic muscles to push against the dilator, as if they were attempting to expel it. Notice your breathing. If you are tense and breathing is shallow, stop and attend to the tension before you proceed. Make sure to exhale fully. When you are ready, try inserting the dilator about two inches or so. You may be able to insert the dilator further. The larger dilators do not need to be inserted all the way. In their unaroused state, most women's vaginas are not long enough to accommodate the full length of a large dilator anyway. The pelvic muscles which tend to tense up are about an inch or so inside the vaginal opening, so the goal of this therapy is not how far you can insert the dilator, but what is happening to the muscles when you insert.

If you have pain, stop. Dilator therapy won't be effective if you are in pain. Check with the medical provider who prescribed your dilator therapy. If you are feeling a physical tension, feel free to try and proceed with the dilator as you work on relaxing your mind and body. However, stop if you feel pain.

Leave the dilator in place for 10 minutes to 20 minutes. You may have to hold the dilator in place during this time. Some women will watch TV or read during this time; others will meditate or visualize the dilator relaxing the vaginal muscles. Do what feels comfortable for you. Once time is up, remove the dilator. Later on this page you will find instructions for caring for your dilators after use.

Changing dilator sizes. When you can insert a dilator with very little effort, it may be time to move to a larger size. Follow the steps above with the next largest size. At first use your most recent dilator. Then after a few minutes remove this dilator and use the next size up. This will allow you to gradually transition between sizes. Remember, the larger dilator will be more difficult to insert at first, so it may take some time before you can place it into your vagina without much resistance. The dilating process starts over, only with a larger size, each time you move from one dilator to the next. Again, stop if you have pain. If you find that the smallest dilator in your set feels too large to begin with, try using the applicator of a "junior" size tampon as a dilator.

Care of dilators. Dilators do not need any special treatment. They can be cleaned with soap and water, making sure they are rinsed thoroughly. Let them air dry or pat them dry with a clean towel.

Kegel exercises. Kegel exercises can help you gain voluntary control over pelvic muscles. How to figure out which muscles to use during Kegel exercises: when you are urinating, contract your pelvic muscles to start and stop the stream of urine. Those are the muscles you will learn to control better through Kegels. **The goal of Kegel exercises is not to tense the**

muscles, but to learn to relax them. When you are contracting the pelvic muscles, you are tensing them. When you stop the contracting, push slightly, as if you were attempting to expel urine or a tampon. This is part of the relaxation of the pelvic muscles. Pay particular attention to this relaxation aspect. These exercises should be repeated several times a day, and they can be helpful to strengthen the pelvic floor. Since the pelvic floor muscles are also involved in orgasmic pleasure, you may also be able to enhance orgasm. Try different speeds of Kegel exercises, tensing and relaxing once every second or faster, or try holding for up to 10 seconds and then relaxing for another 10.

Where to Find Dilators:

- <u>www.vaginismus.com</u> offers a reasonably priced set of five hard plastic dilators in graduating sizes with an attachable handle for ease of insertion.
- Pure Romance Dilator Set can be found through a Google search.
- Dr. Laura Berman Dilator Set vibrating dilators available in various sizes on Amazon.com, s3safesexstore.com, or AdamEve.com. Vibration helps to increase blood flow and lubrication, so some women who experience dryness or lack of sensation prefer to use these instead of dilators that do not vibrate. The smallest Berman dilator is 2.75 inches in circumference, which is larger than the first dilators in other sets.
- Doc Johnson Velvet Touch Vibrators an alternative to the Berman set, though only available in middle-ranged sizes. Could be used in addition to vaginismus.com set.
- Syracuse Medical Devices vaginal dilators, medical grade non-latex rigid plastic, seven graduated sizes from very small to very large. Can be ordered online or available from some gynecologists or a physical therapist.

RESOURCES FOR WOMEN WITH VULVAR CONDITIONS AND FOR THEIR PARTNERS

The following is only a partial list of available resources to get you started. We do not officially recommend or endorse any of these resources over any others. However, these are common resources that have been helpful to many women diagnosed with vulvodynia, vaginismus, and other conditions. If you have questions, concerns, or want further information or clarification on anything listed below, please consult your health care team.

· Reading:

- The V Book: A Doctor's Guide to Complete Vulvovaginal Health by Elizabeth G. Stewart and Paula Spencer
- Sex Matters For Women (2nd Edition) by Sallie Foley, Sally Kope, Dennis Sugrue
- The Vulvodynia Survival Guide: How to Overcome Painful Vaginal Symptoms and Enjoy an Active Lifestyle by Howard I., Ph.D. Glazer, Gae, M.D. Rodke
- Completely Overcome Vaginismus: The Practical Approach to Pain-Free Intercourse by Mark and Lisa Carter (available at www.vaginismus.com)
- Completely Overcome Vaginismus Personal Journal and Workbook by Mark and Lisa Carter (available at <u>www.vaginismus.com</u>)
- The Vulvodynia Guideline, Haefner HK, Collins ME, Davis GD et al., Journal of Lower Genital Tract Disease. 2005; 9.40-51. (available at http://vulvodynia.pl/wp-content/upload/materialy/2009-07-14-the-vulvodynia-guideline.pdf)
- Websites for educational resources, information and patient support:
 - National Vulvodynia Association- www.nva.org

- o Vaginismus and dilator information www.Vaginismus.com
- o International Society for the Study of Vulvovaginal Diseases- www.issvd.org
- University of Michigan Center for Vulvar Diseases
 http://www.uofmhealth.org/medical-services/vulvar-diseases
- U of M center for sexual health- http://www.uofmhealth.org/medical-services/sexual-health
- Websites to research and purchase lubricants, dilators and sexual aids:
 - o <u>www.drugstore.com</u> (lubricants)
 - o <u>www.amazon.com</u> (all products)
 - www.pureromance.com (various products)
 - o <u>www.vaginsimus.com</u> (dilators)
 - o www.babeland.com (sexual aids)
 - www.goodvibes.com (sexual aids)
 - o www.s3safesexstore.com (sexual aids)
 - o www.a-womans-touch.com (various products)
- The Safe Sex Store, located in Ann Arbor, MI: offers a wide variety of sexual aids, including vibrators and other adult toys, condoms, lubricants, novelties, etc. The store's owner, BethAnn Karmeisool has a Master's degree in public health. She can offer sexual health education to customers who have questions about the store's products and how they may benefit couples and individuals. You may want to call in advance if you would like to speak to Beth in person. Visit www.s3safesexstore.com for more information.
- Finding a counselor, therapist or sex therapist:

Your vulvar medical team, primary care physician, or local hospital may have helpful referral information for mental health care. In addition you may want to consult the following:

- American Association of Sexuality Educators, Counselors and Therapists (AASECT) www.aasect.org
 - Listings of Certified Sex Therapists and Counselors across the U.S. as well as internationally. Certified Sex Therapists are licensed mental health professionals who have special additional training in treatment of sexuality concerns.
- Michigan Mental Health Networker- lists psychotherapists throughout Michigan by name, specialty and location with descriptive information- www.mhweb.org
- CDs for muscle relaxation and stress reduction
 - Theta Sailing II and Dialing Down Anxiety (Audio CDs) by Carolyn Daitch, Ph.D. www.self-hypnosisprograms.com/Carolyn_Daitch.htm
 - Mindfulness Meditation for Pain Relief: Guided Practices for Reclaiming Your Body and Your Life
 [Audio CD] by Jon Kabat-Zinn
 - Mindfulness Meditation Cultivating the Wisdom of Your Body and Mind [Audio CD]
 - by Jon Kabat-Zinn