



Women's Sexual Health Journal

Editorial

This issue is special. To my knowledge, this is the first time a journal has dedicated an entire issue to an emerging sexual health problem, Persistent Sexual Arousal Syndrome (PSAS). Two women afflicted with this syndrome have submitted their stories, an act of great courage. My dear friend and colleague Sandra Leiblum has allowed me to publish for the first time her chapter on PSAS from her textbook's 4th edition that is still in preparation. We have a Q & A section devoted entirely to PSAS issues from the health care professional's point of view. We have provided a link to an online support and education group for PSAS. These features result in making this the largest issue of this journal: fourteen pages.

Reading these women's stories and Dr. Leiblum's article, I was struck by certain recurring issues. These revolve around the patient/doctor interaction. The patients had great difficulty being heard. Doctors dismissed their complaints or made inappropriate jokes. What does it mean to be a patient? What does it mean to be a doctor? Both of these roles have been in a state of flux since the 1960s. The post-WWII era has often been hailed as the Golden Age of Medicine. Powerful antibiotics, anxiolytics, antipsychotics, chemotherapy, birth control pills, surgical techniques, and other "miracles of modern medicine" offered the promise of longer lives unmarred by health problems. Physicians appeared to be gods. Many physicians and many patients gladly accepted this state. My parents and most of their generation expected their doctors to know everything and accepted whatever their doctors said as Gospel.

The development of sophisticated laboratory tests and incredible imaging devices encouraged doctors to order more tests to ferret out their patient's medical problems. The ever-increasing reliance on third party payment systems, standardized diagnostic

algorithms, and governmental and legal oversight of the medical process depersonalized the patient/doctor relationship.

It is my observation that the public typically precedes the medical profession with regards to health issues and social change. A classic example is

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cholesterol. In the 1950s, Fleischman's Margarine was promoted to the public as a way of reducing cholesterol. Yet doctors did not routinely start measuring cholesterol until the 1970s. The public's demand for "cholesterol medicine" pressured doctors and the pharmaceutical industry to respond. Now we focus heavily on cholesterol, and a statin is the most lucrative drug in the world.

The mid-1960s were a time of great social upheaval with the Baby Boomers' distrust of the Establishment. With time, that affected the role of the patient. Now, patients must act as their own advocates, researching their conditions and possible treatments as an empowerment to overcome the poor health care promoted by cost-cutting third party payors. Doctors are no longer gods. Litigation intrudes incessantly on the medical process. Many doctors have not accepted that the "times, they are a changing."

William Hurt played a surgeon who learns he has cancer in the 1991 movie, *The Doctor*. Forced into the patient role, he discovered that the high technology, high efficiency medical system did nothing to comfort him or encourage his recovery. This epiphany totally altered his approach when he

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Articles, letters, and questions may be submitted to the Editor, David Ferguson, at info@twshf.org.

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returned to doctoring. Suddenly listening became important.

At the risk of self disclosure so eschewed by a certain FSD organization, I want to reveal that I have had an opportunity to be a patient. March 24, 2004, I fell on the driveway going out to my car. The head of the left humerus exploded against the shoulder socket destroying the rotator cuff. On March 25, a titanium prosthetic humeral head was installed. In June, more surgery was done to remove wandering bone fragments. Following that operation, a sinus formed from the joint capsule to the surface which allowed infection of the joint. A third operation in November revised the wound, removed the infectious nidus, and freed adhesions. Infections recurred throughout winter and spring. Function decreased and pain increased. In July, 2005, I saw an "expert" in Minneapolis who said he had nothing to offer and that I would lose the arm within one year.

Not accepting that prognosis, I made arrangements to go to Mayo Clinic in Rochester Minnesota. The surgeon at Mayo offered two options: a fusion or a reverse ball and socket prosthesis, but first all remaining infection must be removed. On August 24, 2005, the Mayo surgeon removed the titanium prosthetic head of the humerus and all of the cement that held it in place. Intra-operative cultures indicated I had osteomyelitis. Now after 42 days of intravenous antibiotic, I go back to Mayo for installation of a reverse ball and socket joint. This should allow my deltoid to abduct and flex the shoulder, but there will be little medial or lateral rotation. The major benefit should be a significant reduction in pain.

What have I learned as a patient? The first surgeon was not an "expert." He did the best he could for me given a very messy accident. He always discussed everything thoroughly with me; he never assumed I knew something just because I am a doctor too. He called me frequently. He always listened to my concerns. He even followed up after I had been referred to another doctor.

The "expert" did not listen and only spent 5 minutes examining me and reviewing my films. He was brusque and haughty. He made me angry. He said if he had nothing to offer nobody would. He offered no treatment, yet told me not to go back to my first doctor, but rather return in one year for an amputation. My impression of him is unprintable.

My experience at Mayo was totally different. Everyone there was caring, concerned, and empathetic. Although the Mayo system moved everything along very efficiently, I never felt like a number. People listened and tried to answer my

questions. When they did not have an answer, they said so.

How does this relate to patients and doctors confronting FSD? Patients need to do their homework. The internet offers amazing opportunities for researching medical conditions and also for finding support groups. Patients must realize that doctors do not know everything, but those doctors should be open to learning. Doctors need to truly listen to their patients. Validate their concerns. Be open and honest. Be their advocate. In many cases, neither of you has been down this path before. Join together to achieve the best outcome. *Editor—David Ferguson, Grand Marais, MN*

A Woman's Story: PSAS

I have a condition called persistent sexual arousal syndrome (PSAS), a sexual dysfunction that manifests as sexual arousal that occurs apart from any of the physical or psychological stimuli that trigger normal arousal. As its name suggests, the feeling is, for many women including myself, unrelenting. It fluctuates only in degree of intensity. Orgasm not only does *not* relieve the feeling, it actually exacerbates the sensation: after only a few moments or minutes of relief following orgasm, the sensation returns.

PSAS has, at various times, and depending on its intensity or my situation, interfered with my work, my marriage and my psychological wellbeing. I was in health care, in a profession where errors are unacceptable and could have dire consequences. When I was confronted with PSAS, I needed to learn how to focus on my work while all the time being distracted by a sensation over which I had no control and that wouldn't go away. I would come home from work exhausted. I felt as if I were working two jobs: one was my real job, the other was suppressing acknowledgement of this physical sensation in order to get on with my real work. Even my exercise and leisure activities hung under the cloud of PSAS.

Because PSAS was made worse by orgasm, my interest in sex declined and my physical relationship with my husband suffered. To make matters worse, for a long time I could not even achieve orgasm despite the sensation of constantly feeling on the 'edge.' In depression, I began to pull away from my relationships with people, and at one point I told my husband that if I knew there were no possibility of getting better, I would consider suicide.

When the problem first occurred, in 2001, I

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had recently stopped taking an SSRI antidepressant. In my extensive search through the Internet at that time, I used every imaginable search term I could think of, but found nothing written that matched what I had. There was not even a name for it. In desperation, and at my husband's urging, I mustered the courage to talk with my gynecologist, being as careful as I could to describe to her exactly what I felt. She clearly had not heard of anything such as this, which I realized when she was dismissive of me, suggesting that, compared to her other patients, I was 'lucky' to have this problem. This was one of the most devastating encounters I'd ever had with a doctor, and yet she topped this at my next visit when she suggested I should see a psychiatrist because the problem was all in my head. I found another gynecologist instead.

Not long after this disappointing episode, my husband called me at work one morning, telling me he had news that I wouldn't believe. There was an article in our local paper about other women with this problem, and there was a name for it. Hallelujah! Sometimes, the luck of time and place opens up doors. In this case, the door that opened up for me led to an online support group specifically for women with PSAS.

Upon discovering this support group, I went from thinking I was a freak of nature to becoming part of a small community of women who have what I have and have had similar experiences as mine. This was a revelation for me and helped me to begin to cope with PSAS. Furthermore, because I was exchanging information about my PSAS history and reading posts from other women with the problem, the language of PSAS became easier to use. I became able to talk to other family and friends about my condition, getting the support I needed to cope further with PSAS. Significantly, belonging to this online community emboldened me to speak to all my doctors, not just my gynecologist. Orgasm and clitoris were no longer four-letter words.

If ever again I feel rebuffed or belittled by a physician, I know I can depend on the PSAS board members to be empathetic. Every member of the board has had at least one unfortunate experience with a physician. Most had a similar experience in that their doctor couldn't be bothered to deal with or even acknowledge a problem he or she had never heard of. I, myself, felt that one or two doctors were embarrassed by my description of my symptoms of PSAS (I only wish they knew how I felt, having to describe it). When I gave one doctor the newspaper article to read, he focused on the sensational bits and didn't read the article all the way through, drawing

conclusions about me that were unfounded. At the least, PSAS has certainly confounded all of the doctors I've told. Only one doctor, my 'replacement' gynecologist, questioned her colleagues and learned that one of them had had a patient with a condition that could be described as PSAS. My personal care physician latched onto information published in a journal article about PSAS in order to verify that PSAS was a bona fide medical condition.

Since my PSAS seems to have arisen in conjunction with stopping a neuropsychiatric drug, the underlying problem for me, I thought, might be neurological, not physical or hormonal. In other words, the cause of PSAS could very well be in my head, as the first gynecologist suggested, but not the psychiatric problem she implied. I had learned that the onset of PSAS in a significant number of other women on the board was also coincidental with stopping an SSRI (a class of antidepressants). This further knowledge made me feel justified in thinking that there was a strong connection in my case. Because of this likelihood, I was not compelled to try some of the therapies that other women on the board had tried. I felt that the best approach for me was to work with a neurologist. I was further convinced of this upon talking with my friend's husband, a psychiatrist who is extremely knowledgeable about neuropsychiatric drugs and who was able to give me several treatment suggestions. Without the PSAS board and the input of an expert, I may not have come to this conclusion.

My biggest frustration with the group is seeing how easy it is for some women, in their desperation, to be swayed by one person who thinks she has found the answer to PSAS. Nearly everyone will jump on the bandwagon if someone thinks she has the answer, and other voices get drowned out. For most of us, the underlying cause of PSAS is unknown. Despite this, there have been women who rushed right into undergoing a treatment as extreme as surgery or other invasive therapy, only to be disappointed because the treatment failed. This was compounded by some physicians who specialize in a particular procedure and who will make the same diagnosis of everyone who comes to see them, a diagnosis that they swear their treatment or procedure will help. This also sets the stage for treatment failure, because, clearly, not everyone with PSAS has the same cause. Much has been written in TWSHF about getting second opinions, especially for surgery or other invasive procedures.

As on all online support groups, there are times when arguments start and the fur begins to fly, or when members use the board to send personal

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communications back and forth and the posts become very chatty. On the other hand, much of the information I've gotten from the board has been invaluable and has helped me make a case for myself with my doctors. I've read about all the many therapies that have been offered to women with PSAS and have seen what has or hasn't worked. The links are posted on this site, including members' experiences, doctors' names, and suggested treatments for the various physiological or neurological problems thought to be at the root of PSAS. We have been fortunate to have had physicians log onto the group and give us further ideas and insights into the possible causes and treatments of PSAS. Finally, and perhaps most importantly, there is the real support one feels in a community of people with the same interest.
Anonymous

Another Woman's Story

It was six years ago to be exact. I remember lying on my couch watching TV when I felt an odd fluttery feeling in my vagina. That day was the beginning of my slow descent into misery. Prior to that day, however, life was fairly good. Although my days were spent mostly in bathrooms, considering I had to (and still have to) pee every hour, sometimes 4-6 times in an hour, the pain was minimal. And if there was ever pain, it was when I had to hold off going to the bathroom. Like going out for drinks with friends, the boyfriend/husband, and then the drive home! Why do we women (and I'm sure some men too), always have to pee right after we have peed, as soon as we get in a car to drive home from wherever we had that forsaken alcohol? The pain would be a burning, stabbing feeling inside my pelvic floor. I always thought it was normal....until the fluttery feeling in my vagina.

As time went on I noticed the fluttery feeling in my vagina happening more and more. It was so uncomfortable. I was not sure what it was and where it was coming from. Considering it was something I never experienced before, I was not sure how to approach getting help for it, especially considering I recently had been laid off and so did not have health insurance. For over a year I endured this odd feeling getting worse and worse, until I finally got benefits and made a doctor appointment.

My first doctor appointment was five years ago. I walked into her office unsure on how to talk to her about this, what was I going to say, "Hi doctor, the area around my clitoris flutters all the time and I

don't know why." To me, that was the embarrassing route and the route I wanted to avoid. I instead had a plan to talk to her first about what was going on in my life, then slowly ask her about the fluttery feeling in my 'pelvic floor' (the technical definition). When the doctor finally came in she had an intern with her; a girl my age. I was horrified. I couldn't talk with her around. I had asked friends if they had similar feelings before and I always just got ghastly looks. I already thought of myself as a freak, and I didn't need any more people agreeing with me.

Immediately I asked the doctor if I could speak to her alone. Although I felt bad for the intern, the doctor adhered to my request and gave me the chance to talk to her alone. I was embarrassed, distraught, scared...I didn't know how to approach this. I started to tell her how I recently started a new job and school again, etc, and then how I got a fluttering feeling in my vagina on and off all day and that I wasn't sure what it was, oh, and that it was worse when I was nervous or had anxiety. I felt better saying that (and it wasn't entirely untrue), because I felt like my problem needed some sort of excuse. The doctor was so nice about everything, I was so relieved! And she had an answer for me! After a year of waiting, I found out that I had a lot of stress in my life which was causing a lot of blood flow in the area, and, thus, I was getting the ever so wonderful 'flutters'. So my doctor prescribed me Zolofl and sent me on my way.

First of all, I was a psychology student at the time and knew I didn't need Zolofl (I have since gotten my degree). Sure, I might have had some recent changes in my life that may have led to certain anxiety now and then, but I didn't have a disorder; or at least I thought I didn't have a disorder. Regardless, after only a week of taking the Zolofl, my body rejected it by my fluttering feeling in my vagina getting worse rather than better. A few weeks after I quit taking Zolofl, my fluttering feeling began metamorphosing itself to more of a throbbing feeling. It was horrifying! I made another doctor appointment.

I was so humiliated by this problem. I didn't know what it was. So along with peeing constantly (which wasn't popular for the desk jobs I had often), I now had a throbbing feeling constantly (just simply a replacement of the flutters) in my vagina. The throbbing was everywhere in my vagina, not just clitoral. It felt similar to the throbbing I felt after an orgasm, but I wasn't nearly going to tell my doctor that. However, I had to tell her something. When I went back, she had me do a questionnaire; mainly on incontinence. She (my doctor) came to the conclusion that this fluttery/throbbing feeling was probably

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coming from my bladder. I was referred to a urologist.

Having been referred to now a male doctor, I had even a harder time talking about the problem that I had; that kept changing and getting worse over time. However, he was very nice and suspected I suffered from Interstitial Cystitis (IC), which was a chronic bladder disease that has been known to cause odd symptoms with the pelvic floor. Did I have another answer!? I was very excited, but not about the number of tests I had to go through first to get the diagnosis. It would not have been so bad if I didn't lose yet another job two tests away from my diagnosis, thus my insurance once again.

Two years went by and still no diagnosis. I worked temp jobs in the administrative field while I went to school, and so did not have insurance. It was also hard keeping a job due to sitting all day. It seemed the longer I sat, the worse my problem got. After a year, it got to the point to where I could barely sit through class. Along with going to the bathroom often during class, I also was often fidgety in my chair in class causing others to look at me as if I was odd, annoying, or else the worst case of ADHD they had known. It's not like I could look at them and say; " sorry I'm annoying you, but I'm getting a constant throbbing sensation down there that makes me want to jam my pencil into my vagina or even my temple, at least that would make the problem go away". And, yes, I often had thoughts like this. I knew I had to wait to see a doctor until I had insurance, so in order to cope until then I tried talking to friends and family. I first confided in my best friend. Although she was one of the one's before that gave me those ghastly looks, but I thought it would be different this time. Yes, she listened. Yes, she seemed like she deeply cared. But, no, she had no idea what it was doing to me emotionally. I thought I explained it clear enough to her just how debilitating this was becoming, but often she would call and ask how my 'orgasm' problem was doing. That made me so angry that I didn't bother talking to her anymore about it and refrained from telling others.

Three years went by and still no diagnosis. The problem was worse. I needed to find a job with insurance. Now I was beginning to feel that burning, stabbing feeling in my pelvic floor even when I didn't have to use the bathroom. It was most often either right after I went (if I didn't get it all), or after I ate. It was so odd. But it was getting worse, to where I would sit on the toilet for almost an hour every night to make sure I would pee it all out so I wouldn't get that feeling when I went to bed. I did what I could and found a full time job with benefits, and so I went

back for my diagnosis.

It was the cystoscopy with hydrodistension that finally gave me my diagnosis. So up to that point I had been given anti-anxiety pills, poked, prodded, and surgically reviewed. It was final, I had Interstitial Cystitis, and I was chronic meaning there was no cure for what I had. I sank into a deep, deep depression.

With no one to talk to, and knowing I was going to live with this burning, stabbing, throbbing feeling in my vagina forever, I thought it was all over. I started to do poorly in school, at my new job, and started withering away from friends and family. I had no one to talk to! If my back hurt, or my head, or something normal, things would have been different. It was this point I felt I was being punished by God for not settling down for one man. You might say I dated a lot, but I always thought that was normal for a college girl. But I felt I was seen differently in God's eyes, I mean I must have been to have been struck with this humiliating, weird, horribly painful and embarrassing problem.

Four years went by and I had my diagnosis. I was chronic. I was never going to sit normal in a chair again. I was never going to be able to enjoy time alone with my mom having coffee and chatting about the weather without feeling burning, stabbing, and the throbbing feelings in my vagina. That was worse of all. Those were and are the times I have thoughts I would never repeat to another soul. I thought things were just getting worse. I was at my end, then I met my husband.

He became my everything. He was the nicest, most caring and wonderful man in the world, and did I mention absolutely stunning? I didn't get it. I was cursed with this horribly humiliating and painful disease, and yet I was given the most wonderful man in the world. After seven months we were married. All was wonderful, even after I told him everything...most of the time.

My husband became the only person (except for the few friends I told initially who thought of me as a hypochondriac) who really knew what I went through. Every day was a struggle. The poor guy became my sole confidant. The only person I could talk to, and that was a huge responsibility and even more so, a burden (in my eyes). I knew and still know at times it is hard for him to handle my problem. Living with a chronic disease is not only physically exhausting, but emotionally draining. One can only take so much.

Approaching our one year wedding anniversary, I saw just how draining my problem became on our marriage and on my husband who was my everything. I had been taking Elmiron for my

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Interstitial Cystitis, but it wasn't helping. I was getting worse still. Now instead of just the throbbing in the vaginal area with the burning, stabbing feeling, I started to get a pulling, pushing feeling in my vagina right before I would get the throbbing. So now every time I sat down, layed down, took a bath, walked to class, everything but swimming or sitting on a toilet (it was weird), I would feel a horrible pulling/pushing feeling following a throb, then the burning/stabbing sensation. I was a mess. I went for more help, more answers. After all, both my husband and I agreed that a chronic problem shouldn't keep getting worse. I had already quit smoking, watched what I ate and drank, took this 'Elmiron', and began taking Prelief to help with me eating acidic foods, and I was getting worse. At this point, if it wasn't for my husband, I really don't know if I would be here now.

Five years went by and I still had no real answer. What was this throbbing feeling? Where did the burning come from? Nothing made sense. I was beginning to scare myself because I was changing into a different person, a person I didn't like at all. I cried often, had violent outbursts, and, yes, all of this around and to my husband....poor guy. Also, sex began to become painful, putting even a worse burden on our new marriage. But I started feeling a new pain on top of everything else. That's when I went to see my gynecologist only to find out I had a 5.5 cm cyst on my left ovary.

The first thought that came into my head was this ovary was pushing against either a nerve or artery and was the cause of all my problems. Did I find another answer? I needed to know, and I needed to get it removed. To my dismay, however, my gynecologist wouldn't remove it. She said it wasn't the cause of my problems and would probably go away on its own. Unfortunately, she was right. By the next month, it had shrunk. What a disappointment. I was even more depressed than before. The depression was different this time, however. I was losing hope, and hope had always been my true sense of security aside my husband.

Being in her office and hearing this bad news caused me to burst into tears. I think I caught her off guard, but I was slightly relieved she could see just how detrimental my problem was. The doctor said the only thing she could do for me was refer to me to the Incontinence Center of America (ICA) in town. They are specialists with the pelvic floor and specialize in bio-feedback. Although I had no clue what that was, I took their number. But I didn't have any intention on calling. I felt doomed. Nothing was the answer, nothing worked, no one believed in me,

no one wanted to help me. I felt helpless, abandoned, and lonely. I went home and cuddled with my husband.

The next week I had a seminar to go to for work. I had my immediate boss sitting next to me and the owner of the organization on the other side. What a nightmare! I had tears in my eyes after only a half hour of trying to sit still. All I felt was throbbing and pulling, then burning and stabbing, constantly. I got up to use the bathroom multiple occasions using different excuses; I have to wash my hands, oh, I spilled something on my skirt, I don't feel well....the excuses were endless, the embarrassment infinite. Then the next week I started classes again for my graduate program in counseling. I got up the first day in the middle of the class to use the bathroom, and the teacher had the nerve to announce to the class that we just had a break and he didn't understand why I had to go again. Luckily, he pushed my buttons the wrong way and I had the right words to say, because I gave him my two cents after class on just the surface of my problems (my excuse was always just my bladder disease). Although it felt good to tell someone off, I didn't feel better inside. I still hurt....more than ever.

After a few weeks since my gynecologist appointment, I decided to give this ICA a try. I called and made an appointment. Wow, what an amazing organization! In their office, they had information all over regarding IC and how these women with this bladder condition (as I had) lived with such pain all the time. Although I was grateful, it didn't explain the other pains I had; the pains directly on my vagina. A pain that no doctor had been able to identify for me. The ICA wanted to try biofeedback.

This biofeedback included sticking a stick like object in the you know where, and having the pelvic floor muscles read for spasms while registering those spasms on a machine. Supposedly, I was off the charts. The nurse at the ICA said I had the worst muscle spasms she had seen, but didn't know what to do for me except assign me pelvic floor exercises to do at home. Those didn't go well at all. If anything, the exercises made it worse.

Five and ½ years had gone by and I was as depressed as ever. This problem was getting in the way of work, school, friends, family, and most importantly my marriage. I was at a dead end. During these times I often would get online and do research about what I had, symptoms, etc (which would often come up with porn sites), but something different happened one day. I came across a support group online called PSAS (Persistent Sexual Arousal Syndrome). To my astonishment, the majority of the women (and there were men too) on this website had

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symptoms similar to what I had. It was at this support group where I learned of a little thing called Pudendal Nerve Entrapment (PNE) where people often get burning, stabbing, pulling, throbbing feelings in and around the pudendal nerve which was located throughout the pelvic region. I was overjoyed, but anxious and scared at the same time!

The next week I called the ICA (I was done with regular doctors), and told them about this nerve and of PNE. The nurse said that made sense and that this PNE could be a cause of a lot of their patients' problems. They never even heard of it, imagine that! And after years and years of searching, the nurse gave me a name and number to a doctor less than 25 miles away who specialized in pudendal nerve problems. I felt like I was finally there, that I finally had an answer. I was so scared however.

After a month of waiting (the doctor was quite popular), I made it in. She was so wonderful, caring, and listened attentively. After only a brief description from me of my symptoms, she knew immediately what I had. I had nerve damage to my pudendal nerve. It wasn't exactly pudendal nerve entrapment, but it was the nerve. After all these years of searching, it was as simple as a nerve problem. This particular part of the pudendal nerve was sent messages by the brain to pull, push, stab, and burn along with telling my vulva muscle to throb. However, she was not sure exactly what caused the nerve damage. She had three theories. First, either there was something wrong in my brain, possibly due to scar tissue from a serious car accident I had 10 years ago, the trauma from my IC caused the nerve damage, or else, strangely enough, I had the chicken pox (better known as shingles) still dormant in that nerve and thus irritating the nerve. Speaking of the chicken pox, I have had re-occurring shingles on my face since I was a child due to the same problem from a nerve in my face.

So after six years of waiting, I finally have an answer. What a relief. I still have my negative thoughts when I feel the burning, stabbing, pulling, pushing...and, oh, throbbing feeling in my vagina, but I force myself to think of the future, the future that now carries hope. I had my first nerve block not long ago, in the nerve branch that is damaged, and for the first time I could sit without pain. I never appreciated something so much in my life. Unfortunately, the first nerve block didn't work, the pain is back to normal. But I have recently had an MRI done, and have scheduled another nerve block in the near future. I am optimistic everything will work out...finally. I'm just so thankful I never 'threw in the towel' and gave up. Although at times I wish I

would have just came right up front and told the doctors the details of what was wrong, but our society is based around sex, mostly dysfunctional. I was embarrassed because of the area that was being affected in my body, and my embarrassment led me to 6 years of total and complete agony. I am writing my story today to share with the many women who might have these symptoms or other symptoms, to tell all of you to go to your doctors and share your stories! Doctors need to be introduced and made aware of problems such as these that are affecting women across the globe. We shouldn't have to live in pain anymore. I never gave up, and I'm finally getting the answers that I hope will one day make me pain free. *Rebecca Tamboli, (author's name printed with permission)*

Questions and Answers

Q: If my patient tells me that she thinks she has persistent sexual arousal syndrome (PSAS), how should I respond?

A: Here are some general tips.

Keep Communication Open: Be careful of your body language. Wincing, looking shocked or horrified will shut down communication instantly. Your patient may never come back to you, and she may relate to her friends that you are not an empathetic listener. She will need to feel validated and believe that you are there to help her. In general, most women with PSAS have told us that their first experience explaining PSAS to their provider was not positive. This is also not a time to joke to break the ice. Comments such as I wish my wife was like you are inappropriate.

Be Supportive: It is very difficult for many women to raise the topic of PSAS with their provider. There is little information available to women and healthcare providers concerning PSAS. This syndrome can be devastating and so distressing that thoughts of suicide are not unusual. Many women feel as if they are alone in their journey to find a caring provider.

Be Honest: It is OK to admit you have never heard of PSAS. Most healthcare providers are unaware of the syndrome. Be willing to help find a referral for another provider. If your patient brings in the limited journal articles on the topic, educate yourself. It

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won't take that long, because there is very little information available.

Don't Tell Her It is All In Head: The etiology at this time is unknown. To state that PSAS is all in your head can be offensive to your patient. There may be physical causes and/or psychological components. However, both should be explored. Even if there is a physical cause, psychological support may be helpful to deal with the pain, burning, and distress of PSAS.

Provide The Following Solutions and Resources

SOLUTIONS SUGGESTED BY WOMEN TO MINIMIZE SYMPTOMS

- **Ice packs to the genital area**
- **Massage and stretch techniques**
- **Avoiding triggers**
- **Omega 3 (fish oil)**
- **Omega 6 (evening primrose)**
- **Mind-body therapy for Tension Myositis Syndrome**
- **20% Benzocaine in over the counter creams (Vagisil or Vagigard)**
- **Kegels may or may not help**
- **Applying pressure to the pelvic floor by sitting on one foot helps to reduce the intensity of sensation**
- **Lidocaine ointment 5 %**
- **Lidocaine 2.5% and Prilocaine 2.5%**
- **Masturbation**
- **Rolling up a small pillow and positioning it lengthwise on the lower back and buttocks while lying down may help with sleep**
- **While riding in a car, place an empty travel coffee cup between the legs to keep pressure on the area**

RECOMMENDED RESOURCES

PSAS support group such as:

http://health.groups.yahoo.com/group/psas_group/

The Women's Sexual Health Foundation will assist in getting your patient in touch with a support group at www.TWSHF.org

Give her a copy of this issue of the Women's Sexual Health Journal.

Sexual Medicine Article: *Persistent Sexual Arousal Disorder: An Update of Theory and Treatment*, Sandra R. Leiblum. Chapter in *Principles and Practice of Sex Therapy: 4th Edition*. Edited by Sandra Leiblum. New York: Guilford Press, in press.

Most female sexual complaints involve a deficiency or absence of some sexual response – a lack of sexual desire, too little vaginal moistness or lubrication, too few genital sensations, an inability to experience orgasm or too muted orgasms, too little sexual pleasure. But there also exists a perplexing condition in which the woman's major complaint centers on "too much" response, and the response is unremitting genital arousal in the absence of conscious feelings of sexual desire. This condition has been called persistent sexual arousal syndrome (Leiblum and Nathan, 2001), although it may more accurately be termed *persistent genital arousal disorder*.

Women who complain of persistent genital arousal are quite diverse in presentation, but they are alike in that their major complaint centers on the sensations of insistent and persistent vaginal congestion and other physical signs of sexual arousal in the absence of any initial or deliberate attempt to invoke either desire or arousal. Their sensations of genital arousal usually lead to attempts to satisfy or quell the arousal – either alone or via partner stimulation. However, despite deliberate genital stimulation and the experience of one or more orgasms, the feelings of arousal persist – sometimes for hours, sometimes for days, sometimes for years. It is this aspect of the condition that makes it so mysterious, distracting, and, ultimately, distressing. In some cases, women report feeling suicidal because of their inability to experience relief. For instance, one 71 year old woman said "It's just a horror; it bothers me more than breast cancer because it never stops, it never lets up, and it ruins everything, including riding in a car, seeing friends or simply sitting still. It colors your whole life." Another younger woman said "This is an unimaginably miserable affliction and the total lack of success in treatments despite time, effort, money, and misery only adds to the feelings of fear, anger, and frustration."

Compounding the injury is the anticipation of embarrassment or humiliation that women feel about admitting their condition to physicians or even to partners. The embarrassment and fear of ridicule that women feel about disclosing this problem is,

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perhaps, the reason that the phenomenon of persistent genital arousal has gone unrecognized for so long, and very likely remains under-reported. At present, there are no reliable figures concerning prevalence, but it is notable that with increased media attention and internet support groups, more women are consulting physicians with this complaint.

Distinguishing Features of Persistent Genital Arousal: Leiblum and Nathan (2001, 2002) were the first to name and describe the condition after having encountered several women presenting with bothersome persistent and unprovoked genital sensations that appeared without obvious provocation and would not cease.

When conferring about their cases, Leiblum and Nathan were surprised to find a similar set of descriptive features. A priori, they identified five features of the complaint based on the description of the women whom they had seen (Leiblum & Nathan, 2001):

1. The physiological responses characteristic of sexual arousal (genital and breast vasocongestion and sensitivity) persist for an extended period (hours to days), and do not subside completely on their own.
2. The signs of physiologic arousal do not resolve with ordinary orgasmic experience, and may require multiple orgasms over hours or days to remit.
3. These physiologic signs of arousal are usually experienced as unrelated to any subjective sense of sexual excitement or desire.
4. The persistent sexual arousal may be triggered not only by sexual activity, but also by seemingly nonsexual stimuli or no apparent stimulus at all.
5. The physiologic signs of persistent arousal are experienced as uninvited, intrusive, and unwanted.

To date, there have been few research studies on persistent sexual arousal, although recently, an internet survey was conducted to determine whether the original descriptive features would receive empirical support (Leiblum, Brown & Wan, 2005). A 46 item questionnaire was posted on three internet sites related to women's sexual health. The survey included demographic questions, medical and sexual history, questions related to the experience of persistent genital arousal, triggers of arousal, treatment attempts and their success, and advice received from physicians. The published study was based on responses from 103 women from all over the world although at this time, questionnaires have been received from more than 300 women. The majority of respondents were all in relatively good health, well educated, and in long-term relationships.

Some women described their sexual orientation as heterosexual while a distinct minority self-identified as bisexual or homosexual.

The results supported several of the initial observations about the condition. For example, although the original description of five features identifying persistent sexual arousal was based on a small handful of cases, results from the internet survey revealed that 98% of the women who took the survey endorsed at least one feature of the syndrome and 53% endorsed all five criteria suggesting that the original description of the condition was replicable. Involuntary genital and clitoral arousal persisting for extended time periods, genital arousal unrelated to subjective feelings of sexual desire, and genital arousal not relieved with orgasms were the most frequently endorsed features.

When asked what stimulated the sensations of genital arousal, women described a host of varying triggers, some physical, some psychological:

“Persistent sexual arousal began a few weeks after my cesarean section.”

“I alternated between Zyban (bupropion) and Paxil and believe my PSAS started while on Zyban as a rebound effect.”

“Beginning of PSAS coincided with cessation of periods.”

“Originally started following ectopic pregnancy and subsequent pregnancy with second child.”

“Persistent yeast infections”

“The original cause, I think, was the accident and injury to my pelvis that I suffered in the summer of 2002. The first time I experienced PSAS was after masturbation a couple of weeks after my injury, which was also the first time I had done anything sexual.”

“Switching to different anti-depressants.”

“Possible original trigger- receiving many enemas as a child for years?”

Overall, the respondents identified the following major groups of triggers: terminating or beginning a particular medication or hormonal regimen, intense sexual stimulation by self or partner, and emotional stress and anxiety. Sixty-three percent of respondents reported at least moderate distress as a result of their persistent feelings of genital congestion while 19% reported extreme distress. The strongest predictors of distress were intrusive and unwanted feelings of genital arousal ($P < .0001$), continuous symptoms ($P < .001$), feelings of unhappiness ($P < .03$), shame ($P = .0001$) and worry ($P = .01$),

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reduced sexual satisfaction ($P < .004$), enjoyment of symptoms some of the time ($P = .01$), and relationship status ($P < .004$).

More recent research (Brown, Leiblum, Wan, 2005) examined the sexual functioning of 45 women with PSAS compared to 152 women with female sexual arousal disorder and 244 healthy control women using the Female Sexual Function Inventory. PSAS women scored significantly *lower* on the total FSFI scale and on the desire, arousal, lubrication, and orgasm subscales suggesting *reduced overall sexual functioning and less satisfaction than the normal controls*. They obtained higher scores on the desire, arousal, lubrication, and orgasm subscales than women with FSAD.

Current Etiological Theories: At present, there is no consensus about etiology. Goldstein (2004) has suggested the following major etiological possibilities: 1) central neurological changes (e.g., post-injury, specific brain lesion anomaly); 2) peripheral neurological changes (e.g., pelvic nerve hypersensitivity or entrapment); 3) vascular changes (e.g., pelvic congestion); 4) mechanical pressure against genital structures; 5) medication-induced changes; and 6) psychological changes (e.g., stress), or some combination of all. Many cases appear to be idiopathic, and no definite etiology can be determined even after a thorough and comprehensive history.

It is likely that there are at least two subtypes of persistent genital arousal: one which is more related to neurovascular or neurochemical causes, and the other more related to a psychological etiology. For instance, certain sexually-related words acted as a trigger for one 23 year old woman. She reported that her arousal "operates at a subliminal level at times so that while there seems to be no cause, there actually is." She went on to say that once when she was listening to a lecture about the social behavior of monkeys, "a strong feeling of arousal intruded and interfered with my concentration. I realized on reflection that the arousal started when the lecturer made a passing remark about the sex of the monkeys. It was just that word that triggered it." She also noted that anxiety could trigger her arousal and that the ensuing pelvic tension would become unbearable. For this young woman, the feelings of arousal were "constant and waves of orgasm-like (without the contractions) feelings would flood me. ...I would feel physically hot; my knees would sometimes go weak and it seemed to interfere with my consciousness of what was going on around me for the duration of the feeling."

For other women, the condition clearly seems pharmacologically induced. For instance, in

men, there have been case reports of trazadone being implicated with prolonged penile erections, especially nocturnal erections. While the exact mechanism is unknown, it is speculated that the effect is related to trazadone's alpha-adrenergic and serotonergic blocking activity resulting in the persistence of smooth muscle relaxation (Medina, 2004; Pescatori, et. Al., 1993). If the trazadone is used for extended periods of time, it is conceivable that it may foster a condition of persistent sexual arousal in women although there are no published data to support this speculation. Goldstein, et al, (2005) reported that two women experienced symptomatic relief when the use of trazadone for sleep difficulties was discontinued.

SSRIs and PSAS: Several writers have wondered whether there might be a relationship between PSAS symptoms and the use of selective serotonin reuptake inhibitors such as paroxetine (Paxil), sertraline (Zoloft), venlafazine (Effexor) or fluoxetine (Prozac). There have been isolated case reports or private communication noting that the symptoms of PSAS seemed to be associated with the start of one of these anti-depressant medications and that discontinuation of the medication seemed to relieve the condition.

Sexual response is certainly influenced by serotonin although data are conflicting as to whether it serves primarily as an inhibitory, excitatory or mixed agent. It may depend on which receptor subtype is stimulated. Although the incidence of sexual side effects associated with the use of SSRI's is quite high (30-40%), delayed rather than enhanced arousal and orgasms is typically reported. This is not surprising since SSRIs block nitric oxide (NO), decreasing smooth muscle relaxation and inhibiting genital blood flow (as opposed to a PDE5 inhibitor, like sildenafil (Viagra) which increases NO levels by inhibiting phosphodiesterase-type 5 enzyme [PDE-5]), thereby enhancing arousal and the likelihood of orgasm. However, some psychiatrists have suggested that if pudendal nerve irritation is the cause of the persistent genital arousal, the use of SNRIs such as venlafazine (Effexor) or duloxetine (Cymbalta) or anti-seizure medications such as valproic acid (Depakote) may be helpful (Saks, 2005).

Given that the role of medications in both the genesis and treatment of persistent genital arousal is poorly understood, a careful drug history- both past and current- should be taken with all patients complaining of PSAS. Careful specification of the order of events, e.g., did the onset of genital arousal precede or follow the termination of a new medication, is obviously of critical importance.

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Pudendal Nerve Entrapment and PSAS:

While medications may trigger genital arousal in some women, for others the condition appears related to pelvic muscular changes or pelvic nerve hypersensitivity. These conditions may cause blood to become "entrapped" in the pelvic region. The pudendal nerve as well as the other nerves innervating the female pelvis (the ilioinguinal nerve, the genitofemoral nerve, and the iliohypogastric nerve) may be implicated. When blood becomes trapped in the genital area and/or there is a resulting condition of hypertonicity of the pelvic muscles, tremors or feelings of pressure in the genital area may result which may contribute to, or cause, feelings of sexual arousal.

The feelings of arousal may not dissipate with masturbation or partner stimulation because the fascia surrounding the nerves trap the blood thereby maintaining high levels of arousal despite one or many orgasms. *In fact, the more insistent the attempts to relieve the congestion by either self or with a partner, the more insistent or more continuous are the feelings of genital arousal.*

In summary, at this time, it appears that PSAS is a multi-factorial disorder due to two major classes of factors: (1) neurovascular or neurochemical causes or (2) psychological/stress-related causes. For different women, each of these factors may interact in different ways and exist to varying degrees. Moreover, it is possible that the factors currently maintaining the condition may be quite different from the factors initially giving rise to it.

Treatment: The most sensible approach to treatment is one that emphasizes self-management along with an initial use of anesthetizing agents to numb the area and provide some relaxation of the pelvic floor musculature. Treatment should focus on control rather than elimination of the complaint since it may re-occur. Psycho-educational interventions, cognitive-behavioral therapy, and physiotherapy/stretching exercises all comprise aspects of this approach. Each component is discussed below:

Psychoeducational: Women complaining of PSAS report extreme relief when they discover that they are not alone in having this condition—that the problem has a name and that there exists a support group which can provide sympathy and suggestions (http://health.groups.yahoo.com/group/psas_group/).

Physical Therapy: Pelvic massage or stretching exercises may reduce or eliminate pelvic floor tension and break up whatever connective tissue strictures contribute to the PSAS. Consultation with an experienced pelvic therapist may be

helpful as well.

Medication: As we have seen, certain medications may alleviate (or paradoxically, worsen) feelings of genital tension. Mood stabilizing, anti-seizure medications such as valproic acid (Depakote) have helped some women, while others report relieve with some of the SNRIs (Serotonin/Norepinephrine Reuptake Inhibitors). Determining which, if any medication, may alleviate the sensation of genital vasocongestion is often a question of trial and error.

Cognitive-Behavioral Interventions: Helping women identify and challenge their self-defeating, self-blaming or pessimistic thoughts and replacing them with more adaptive and positive cognitions may enhance "coping behaviors." This is especially crucial when women report feeling suicidal or despairing because of the chronic, incessant, and distracting nature of their genital sensations.

A plea for caution: It must be emphasized that the majority of women who experience PSAS suffer considerably and hence are vulnerable to any treatment that promises relief. Regrettably, although many novel treatments have been described and discussed by women in a PSAS support group, none have provided long-lasting relief. While psychotherapy, from virtually any theoretical orientation, can be helpful in promoting insight, providing possible explanations, encouraging cathartic expression, and contributing to stress reduction and self-soothing exercises, it has not resulted in any "cure". At the same time, to be pragmatic, it must be emphasized that any treatment that helps reduce emotional stress or physical tension, is to be encouraged.

At this time, it is unlikely that there is a single intervention for the varied presentations of this condition. Rather, self-management strategies, both physical and psychological, are recommended along with the realization that for some sufferers, the condition may be more chronic but one that can be tamed and controlled.

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Sandra R. Leiblum, Ph.D. is Professor of Psychiatry and Obstetrics/Gynecology and Director of the *Center for Sexual and Relationship Health* at UMDNJ-Robert Wood Johnson Medical School, Piscataway, NJ. A leading authority in sex therapy, she has edited or co-edited ten books, including *Principles and Practice of Sex Therapy* (now in its third edition), *Sexual Desire Disorders*, *Erectile Disorders: Assessment and Treatment*, and *Case Studies in Sex Therapy*, as well as more than 100 clinical and research articles. Her popular book on female sexuality entitled *Getting the Sex You Want: A Woman's Guide to Becoming Proud, Passionate, and Pleasured in Bed* (Crown Publishing), written with Judith Sachs, is available in most bookstores and online. The book explains how women come to either love or hate sex. It offers practical, medical, surgical, recreational, and spiritual innovations that can boost sexual desire and make sex rewarding.

Her professional interests center on female sexuality, infertility and menopause, and the impact of the internet on couple relationships. In recent

years, she has been increasingly involved in research on female sexual function and dysfunction, including pharmacological enhancement of female sexuality as well as the impact of couple relationships on sexual satisfaction.



Dr. Leiblum is nationally known for her leadership activities in the field of human sexuality. In October, 2000, she was elected to be the first president of the International Society for the Study of Women's Sexual Health. She is past president of the Society for Sex Therapy and Research and she is a fellow of the Society for the Scientific Study of Sexuality.

Dr. Leiblum has received awards and acknowledgements for her excellence in teaching at the Robert Wood Johnson Medical School where she has been on the faculty for 28 years. In addition to her awards for medical school teaching, she has received the "Woman Of Distinction" Award from the Middlesex County Commission on Women, the AASECT Award for professional contributions to the field of sex therapy, and the Masters and Johnson Lifetime Achievement Award from the Society of Sex Therapy and Research. She is the North American Editor of the journal *Sexual and*

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Relationship Therapy and serves on the editorial boards of 4 other journals.

In The News

Uterine Fibroid Legislation: Three in every four American women suffer from uterine fibroids. African American women are affected in even greater numbers. Very little is known about fibroids and treatment options are limited.

There are two very prominent advocates for this particular women's health issue on Capitol Hill. Senator Barbara A. Mikulski (D-MD) recently re-introduced legislation in the United States Senate that would increase funding for research and education on uterine fibroids. Identical legislation was re-introduced in the U.S. House of Representatives by Representative Stephanie Tubbs Jones (D-OH).

Senator Mikulski introduced the Uterine Fibroid Research and Education Act in June 2005 with the hope that new and better treatments or possibly a cure for uterine fibroids are found. Senator Mikulski has been on the front line fighting for women's issues for many, many years. She wants to ensure that women get the health treatment they need and deserve.

The \$30 million in federal funding being sought would be used to research the cause of uterine fibroids, determine why African American women are affected in such higher numbers, and find ways to prevent and treat fibroids. In addition, a portion of the funding would be allocated to creating an educational program for doctors and their patients. The mission of the educational program would be to provide information so doctors and patients are better informed when making health-related decisions.

The Uterine Fibroid Research and Education Act is one of many pieces of legislation focused on health issues affecting women waiting for enactment. Progress is being made, albeit slowly.

Please contact your US Senator and Congressional Representative asking that they support S 1289 and HR 3034 The Uterine Fibroid Research and Education Act of 2005. Go to http://www.senate.gov/general/contact_information/senators_cfm.cfm for contact information on your senator and www.house.gov/writerep for contact information on your representative.

Also please take The Women's Sexual Health Survey if you have had a hysterectomy. Go to http://www.twshf.org/hysterectomy_survey.html.

TWSHF On the Air: The Women's Sexual Health Foundation will be live on radio on "Let's Just Talk," Saturday, Dec 3 on WBOB AM 1160, Cincinnati, Ohio. Women seeking information about their sexual health and well-being can turn to AM 1160 or <http://www.wbob.com/> and click on *listen live* on the internet Saturday, Dec 3 at 11:00 a.m. EST when Lisa Martinez RN/JD, Executive Director of The Women's Sexual Health Foundation and Dr. Susan Kellogg of the foundation's professional advisory board are the featured guests on "Let's Just Talk" with host Kathryn Raaker.

Resources

Persistent Sexual Arousal Syndrome: Support group

http://health.groups.yahoo.com/group/psas_group/

Uterine Fibroids:

The National Uterine Fibroids Foundation
www.nuff.org

Meetings

Columbia University College of Physicians & Surgeons, Department of Urology and The Women's Sexual Health Foundation **PRESENT: Female Sexual Dysfunction 2006, A Multidisciplinary Update**, Saturday, April 22, 2006 at Columbia University Medical Center, New York, New York.

International Society for the Study of Women's Sexual Health, **2005 Annual Meeting**, October 27-30, 2005, Las Vegas, Nevada.

Donations

As a nonprofit organization, The Women's Sexual Health Foundation is supported through individual donations, memberships, and in a small measure, by the bulk sales of TWSHF brochures and the Journal. We are currently seeking to finance research projects

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through grants from government agencies and non-federal sources such as corporations, women's groups, and medical organizations. However, private gifts will always be the mainstay of the Foundation.

All donations are tax deductible. The Women's Sexual Health Foundation will send you an acknowledgement receipt for your tax records.

If you would like to make a donation, please send your contribution to:

TWSHF
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Information

See www.twshf.org for information on membership, donations, instructions for authors, volunteering, and additional resources.

Editor's Note

The January 2006 issue of the Journal is in preparation. The Editor welcomes articles, letters, meeting notices, pertinent internet websites, breaking news, information on support groups, and publications that may be of interest to the readers.

We are all inundated with news articles about drugs, vitamins, and health. Many of these stories are written by journalists or TV reporters trying to sensationalize articles published in medical journals. Frequently, the reported results or conclusions do not stand up to scrutiny. Retractions and corrections usually get no attention from the media. I am appalled by the number of my scientific colleagues who do not have a clear understanding of basic statistics. The public too are deficient in this knowledge. Yet, everyday we are confronted with statistics and "medical studies." It is essential that all of us have the means to properly assess these reports. Therefore, I will prepare a brief course in statistics to be published in future issues of the Journal.

Abbreviated Instructions for Authors

Manuscripts, guest editorials, questions, stories, and letters to the editor may be submitted by e-mail to David Ferguson at info@twshf.org. Manuscripts should be 3,000 words or less. All authors must be listed with first and last names and affiliations. Sponsorship (if any) should be indicated. Format should follow standard scientific style for an original piece of research or a review article.

Questions may be submitted by anyone and may be directed to a member of the Advisory Board or simply to the editor. The Editor may need to clarify the question prior to publication, so the author must provide contact information. Authorship of a question will be published unless a specific request for anonymity is made.

Personal stories should be 1,000 words or less. The Editor may need to edit the story prior to publication, so the author must provide contact information. Each story will be published anonymously unless a specific request by the author is made.

Letters to the editor should be 500 words or less with full contact information and affiliation provided. The Editor may work with the author to refine the letter prior to publication. The Editor will decide whether a letter will be published. Authorship of a letter will be published unless a specific request is made. Authors of all material to be published will be required to complete a Transfer of Copyright form available from info@twshf.org.

The Editor welcomes suggestions for content, meeting notices, pertinent internet websites, breaking news, information on support groups, and publications that may be of interest to the readers.

Disclaimer

TWSHF recommends that you consult with your health care provider to determine appropriate treatment. TWSHF is not responsible for any consequences that occur based on information contained in this publication.