Susan Westrom serves as state representative for Kentucky's 79th District, located in Lexington.

A Legislator's Mission

Educating fellow legislators and others about AD/HD is a priority on Rep. Susan Westrom's packed agenda

By Susan Buningh, MRE

WHEN SUSAN WESTROM WAS ELECTED to the Kentucky state legislature in 1998, she was confident that she was entering familiar territory. Westrom had worked as an advocate for children and as a lobbyist in Frankfort, the state capital, and Washington, DC. She understood the legislative process. She expected to tackle challenges.

Westrom's record reveals energetic representation of her district, which is in Lexington. She has sponsored legislation to benefit children and senior citizens, as well as on medical issues, consumer protection, and small businesses. She serves on a number of legislative committees, including Health and Welfare, Banking and Insurance, Licensing and Occupations, Agriculture, Natural Resources and Small Business; she currently chairs the Subcommittee on Horse Farming. She serves on the Child Support Commission, the Juvenile Justice Advisory Board, the Status Offender Workgroup, and the Blue Ribbon Task Force on Adoption.

Westrom serves on numerous national committees and task forces, including the National Conference of State Legislatures (NCSL) Women's Advisory Board, and the National Conference of Insurance Legislators (NCOIL); she co-chairs the NCSL Legislative Effectiveness Committee and chairs the NCOIL Health and Long Term Care Committee. She serves on the advisory boards of the University of Kentucky College of Social Work, and the Midway College Center for Women and Leadership, and is a member of many other organizations.

Clearly, Susan Westrom could be called a dynamo. Yet in the early days of her political career she faced an unexpected challenge that could have become a stumbling block. It impeded her commitment to serving her constituents and could possibly have derailed her career as a legislator.

Within months of taking office, piles of mail and phone messages accumulated on her desk. Each letter demanded a reply; each message, a phone call. Kentucky state legislators, like those in most states, do not have support staffs to field calls or answer letters. In Kentucky, there is one secretary for every ten legislators. And although the legislature meets for four months in even years, and three months in odd years, legislators can receive hundreds of letters, emails, and calls every day.

"I quickly realized I faced other challenges that my colleagues seemed immune to," Westrom says. "I could not answer letters in a timely manner and found the list of phone calls needing to be returned grew faster than my indoor plants. I became the Queen of Procrastination."

PHOTOS COURTESY OF SUSAN WESTROM

Diagnosis and treatment

About halfway through her very first legislative session, a friend of twenty years approached Westrom after church one Sunday. The gentleman asked, tentatively, whether he might ask her a personal question. After she assured him he could, "he proceeded to explain that after sitting behind me and observing my restlessness throughout the service, he recognized behaviors of ADD, with which he had recently been diagnosed, and wondered if I had the same malady. Knowing the pressures of my new position," she recalls, "he offered me the name of a specialist that would 'save my life.'"

While her son had been diagnosed with AD/HD previously, Westrom never thought she too might have the disorder. "Little did I know that within three weeks I would be so overwhelmed by the stacks of awaiting constituent letters and phone calls that I would be calling this professional, who worked with adults facing similar challenges," she says. "I was disconsolate; I couldn't concentrate, and I couldn't meet the expectations of my constituents."

Westrom consulted the specialist, who diagnosed her with AD/HD after four hours of testing and prescribed medication. "The first day I was medicated," Westrom says, "I went into my office and wrote letters for eight straight hours and felt that I had been part of a miracle." Medication, she found, enabled her to deal effectively with the sleep and organizational problems she was experiencing.

Westrom, who calls herself a "classic case," hadn't realized how the undiagnosed, untreated disorder had impacted her organizational skills. Research has demonstrated that multimodal treatment is the best treatment for AD/HD, so she knew she needed behavioral strategies in addition to the medication in order to cope with the disorder's effects.

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She needed additional practical skills that would keep her organized and effective—quickly. Although the legislature meets for only part of the year, Westrom says, "my calendar is always full. Since I always lose lists, I keep binders. I would miss events if I didn't keep everything together." Binders help her to keep in order the thousands of contacts and hundreds of events that come with a legislator's office. The binder system has proved to be her lifesaver, allowing her to organize information about all the "who, what, when, where, and why" aspects of her job.

While strategies such as binders have proven invaluable for her, Westrom remains positive about treating the disorder with medication. "I can do so much more when I'm able to focus and concentrate," she says. "As a legislator, this is a golden period—in ten years I've accomplished so much. I can juggle so many things. With medication, the juggling is more organized." Sculpting and gardening are two of her many hobbies, and in her experience, "medications don't diminish or challenge creativity, but allow it to be fully expressed." She found that medication helped in other areas of her life as well—such as the battles she once faced with writing monthly editorials or diminishing the height of the stacks of her "TTDs" or "things to do."

Perhaps there were signs along the way that might be recognized by parents and educators today. Westrom is, after all, a member of the "undiagnosed generation," many of whom were diagnosed with AD/HD following their children's diagnoses. "I move very quickly, and it's a challenge for someone to keep up with me," she shares. Too impatient, and often distracted, she couldn't go to movies or select greeting cards. Still, she says, "even as a child I could read a book cover to cover at one sitting." She describes herself as somewhat of a "late bloomer" academically. A freshman in college at 35, she went on to earn a master's degree in social work. While she was employed as a social worker, before entering state politics, Westrom says her challenges were not apparent because life as a child advocate and lobbyist provided vast diversions and a support staff was available.

Rep. Susan Westrom and former CHADD president Mary Robertson, RN, discussed raising awareness of AD/HD among lawmakers during a CHADD meeting in Lexington, Kentucky, in February 2007.

Viewing her diagnosis in a positive light, she says, "I finally comprehended why I had difficulty finding people to keep up with me!" Westrom gradually realized she had developed certain strategies on her own. "Over time I had honed some coping skills to overcome barriers to success which I feel gave me a tremendous advantage," she says.

Westrom is convinced that one of the "gifts" of AD/HD is the ability to see things that others don't. For example, ten years ago, the Agriculture Committee commiserated on the impending demise of the tobacco industry in Kentucky. "Our leaders had not come to the point that they could recognize the value of our horse industry," Westrom says. "I had been

frustrated for years that our signature industry had not been recognized in our state capitol and became determined to rectify that omission by pushing for a committee to educate legislators on the vast value this industry has been providing for years, yet had been so overlooked." As a result, the Subcommittee on Horse Farms was created, of which Westrom is the co-chair. State leaders now anticipate Kentucky being the first non-European host of the World Equestrian Games, which will be held at the Kentucky Horse Park in 2010 and are expected to draw over 600,000 attendees. "All members of the general assembly now have a basic knowledge of this fabulous industry," Westrom says, "and know the impact will be shared statewide." The equine industry has indeed replaced tobacco as Kentucky's premier industry.

The family's journey

Westrom's adult son and daughter have also been diagnosed with AD/HD. Neither was diagnosed as a child, however.

"My son wasn't diagnosed until his senior year in high school," Westrom says, "he was one who fell between the cracks [in school]. He forgot his homework often, but he didn't stand out since he was not an academician or an athlete." Although he was very intelligent, with an "incredible memory," his teachers didn't identify his forgetfulness about turning in homework as a red flag. Neither did his mother, although at one point in her career she had been a therapist for children and adolescents. "I knew he was having academic challenges, but even though I have a master's degree in social work, I didn't see that it was AD/HD," she says. "Someone else, a good friend, identified it and suggested that I get him evaluated." He was diagnosed and prescribed medication, which helped.

Rep. Susan Westrom and her children during a family vacation.

She quickly discovered that in Kentucky only psychiatrists seemed to have the courage to prescribe the medications, and for a single mother, the frequent psychiatrist visits were cost-prohibitive. Westrom found the family doctor reluctant to prescribe medications to treat AD/HD, fearful that the Kentucky Board of Medical Licensure would place his name on a list of doctors prescribing Schedule III medications. And, as often happens with independent-minded older children, her son stopped taking the medications, which he had never liked anyway. Some challenging years followed.

"During his first semester of college, my son acted like he was on vacation and turned into a party animal, so I brought him home until he was ready to take school seriously," Westrom says. "For a time he self-medicated, and started bouncing checks because he could not pay attention to adult details such as balancing a checkbook." An encounter with the judicial system brought him into contact with an attorney who recognized the poor impulse control symptom so often seen with AD/HD. For years he had observed the court system "churn out and recycle" young people who forgot to pay court costs or ignored court dates, their irresponsibility keeping their lives in turmoil.

Westrom says she will be forever grateful for the attorney's recommendation that her son return to the medication regimen and therapy to get him back on his feet. That cycle of her son's life has now ended, and although he is still unmedicated, "he lives independently and understands that his learned behavioral and coping skills have helped him achieve success." He recently completed culinary school at the Atlanta Art Institute and was a Hell's Kitchen semifinalist; he now works as an executive chef and has a second job in catering. "He is very funny, smart, and intense," says Westrom, "and demonstrates why we should not give up on our sons with this disorder."

Westrom's daughter was a different story; she had a 3.5 grade point average in high school. Artistic and very social, she often worked on group projects, which helped disguise learning difficulties. Teachers never expressed concerns about her; she had great "people skills" and was well-behaved. "However, during her first month of college, she realized she was very different from the other students," Westrom recalls. "She called me, crying, saying she thought there was something wrong with her brain. She had compared her grades to nonacademic athletes—who did not study, while she prepared for hours for tests—only to find she received lower grades. This was about a year after my son's diagnosis. I took her to my adult specialist, who diagnosed her AD/HD and also a co-occurring reading disorder—things that I, as a therapist, hadn't recognized in her."

After treatment for AD/HD, her daughter "thrived in college," Westrom says. "Her diagnosis made a huge impact. Her academic challenges that first semester were a life-changing struggle. But after diagnosis and beginning to take medications, she was an A student." Westrom points out how easily a child falls through the cracks because "they do not cause trouble in the classroom."

Still, after graduating, her daughter found she "couldn't sit at a desk, or do that kind of job." Mother and daughter are now partners as real estate agents. They find their individual skills balance out what the other lacks. Westrom's daughter tracks business appointments for her using the same binder system that has been so successful in keeping her political career organized.

Mother and daughter are partner artists as well, creating a stunning art form they call "wall jewelry." Westrom's daughter invented the medium while working on her senior

A detail of one of the sculpted "wall jewelry" flowers Susan Westrom creates with her daughter. Originally undertaken as a creative outlet to reduce the stress of her long workdays as a legislator, the artworks were recently exhibited in a Lexington art gallery.

"I have no difficulty acknowledging something that I consider to be a curse and a blessing publicly," Westrom says. "When I look back on my many accomplishments, I must attribute some measure of success to a mind that continually churns at different levels while my body is used to a pace that has been conditioned to a different level of endurance than most people can understand."

thesis as an art major, combining drywall and beads to form three-dimensional flowers. To reduce the stress of working 14-hour days during legislative sessions, Westrom began to dabble with the flowers, using Austrian crystals instead of beads. Originally the team's artworks adorned their home, but not long ago, a Lexington gallery owner saw their dramatic sculpted flowers and offered her entire gallery for a two-month show. "We have found art therapy to be invaluable to us," Westrom says, "and we had no idea it would end up being another vocational outlet!"

Messages to parents

Parents must understand, Westrom says, that children can easily get through school without anyone detecting their attention issues. Particularly when children are highly intelligent and well-behaved, it is necessary to pay closer attention if they consistently fail to turn in work.

Often mothers are the first to recognize the red flags of AD/HD behavior, if they are familiar with the diagnosis. In most cases, a teacher or someone familiar with the symptoms will be the first to suggest there may be something awry. Westrom encourages parents to find answers quickly so their child will be provided early intervention. "Many parents have the fear their child will be labeled, but avoiding the issue can forever change outcomes of a child with untapped potential. Ignoring the problem will not make it go away," Westrom says.

Westrom cautions parents of teens with AD/HD to be realistic about the possibility that their teenager may self-medicate. "Weed and alcohol slow the brain. They'll find things that make the brain feel better and won't know why." Parents, she thinks, have to take responsibility and become vigilant about possible addictive behaviors, beginning with smoking cigarettes. She further counsels parents to "stop and reflect—is it genetic? Does anyone else in the family—including aunts, uncles, or grandparents—have similar challenges?"

Educating others

Today Susan Westrom is committed to turning around public perceptions of AD/HD. She considers it a mission to fight the stigma and to educate—but not scare—the public about the consequences of undiagnosed, untreated AD/HD.

Westrom is forthcoming about her AD/HD with constituents. "I have no difficulty acknowledging something that I consider to be a curse and a blessing publicly," she says. "When I look back on my many accomplishments, I must attribute some measure of success to a mind that continually churns at different levels while my body is used to a pace that has been conditioned to a different level of endurance than most people can understand."

"I consider myself the poster child for AD/HD but still find it a challenge to educate people who do not share the diagnosis," says Westrom. "When sharing my symptoms, I am astounded to find many other adults who realize they have been living with similar symptoms or have children diagnosed with AD/HD. I always ask which parent they inherited it from, and then they are enticed to learn more."

Her characteristic openness extends to her colleagues as well. "I actually referred two other legislators to my specialist after noticing immense disorganized stacks on their desks and the difficulty each had sitting though long committee meetings. Both ended up being diagnosed, appropriately medicated, and now are as grateful as I was to learn why some challenges seemed insurmountable," she says.

Westrom's goal is to see adult AD/HD become a topic for National Conference of State Legislatures annual meeting attendees. She has worked tirelessly to inform leaders of that organization and others about adults who unknowingly battle the disorder. Educating legislators about AD/HD is the key, she believes, to getting legislation passed that will help those affected by the disorder. Educating judges about AD/HD is also critical. "Our court systems lack understanding of individuals who are unable to break the cycle of poor decision making, due to lack of treatment," she says. "Our overcrowded jails are filled with people who have untapped potential because their gifts and talents have been lost to a frustrating disorder that limits achievement without professional intervention."

"I have always been sensitive about health care issues and mental health parity," Westrom says. "My mission is to get legislators and judges educated about AD/HD so policy decisions impacting schools and courts are realistic," she says. "We have no idea of the collective creative and academic accomplishments lost by vast numbers of undiagnosed adults."

"I hope that my life demonstrates people with AD/HD are not destined to a life of low achievement, broken promises, and zero potential," Westrom says. "AD/HD can be a curse or a blessing, depending on how it is harnessed."

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