A Passionate Advocate

First lady launches inaugural CHADD support groups in the Virgin Islands

by Karen Sampson, MA

Two of the newest CHADD support groups have an unusual, but passionate, founder. Cecile deJongh, first lady of the U.S. Virgin Islands, decided with her husband’s election as governor that she would help improve the lives of Virgin Islanders affected by attention-deficit/hyperactivity disorder.

“When I was first interviewed after my husband’s inauguration I said this was my goal,” deJongh said, “to raise awareness through a CHADD support group.”

Nine months later, she accomplished that goal. CHADD President Anne Teeter Ellison, EdD, joined deJongh, Governor John deJongh Jr., and the territory’s commissioners of health, education and human services on September 26 and 27, 2007, for the first meetings of CHADD support groups on the islands of St. Croix and St. Thomas.

“It was such a powerful meeting because you have the governor and first lady making a commitment to their citizens that they were going to address the problem of AD/HD and do it in a coordinated fashion,” Ellison said. “I kept telling the audience and the first lady that this is remarkable.”
A family’s journey

The deJongh family’s journey with AD/HD began fifteen years ago, when their oldest son was diagnosed with the disorder. Before long, their second son was also diagnosed. There was little public information available at that time as she and her husband began the “crash course” into AD/HD that many parents are familiar with. That’s when she happened upon a copy of Attention magazine. The science-based information and the techniques to help her family were what she had been looking for. DeJongh’s interest in CHADD was solidified.

“We found it very helpful to get e-mail and updates,” she said, “just to keep up with all the information. We found that CHADD was a lifeline. Through CHADD, I’ve been able to glom onto some of the important things. I thought, as first lady, I could bring some attention to this disorder.”

“Mrs. deJongh reminds me of all the CHADD leaders and coordinators I’ve met in the past who have had to carve a path on their own, and now she’s ready to reach out to others,” Ellison said. “She is looking forward to working with CHADD. She’s really into empowering people and getting them to get the government to meet their needs.”

Each of the first meetings drew more than a hundred people and local media coverage. Ellison and deJongh were featured on local television news reports and on a radio talk show.

Ellison told deJongh that issues raised at the meetings were remarkably similar those brought up stateside, noting during the first meetings people were interested in the disorder, how to get help, how to receive an assessment and where to find medical professionals who could help. “There was just a lot of genuine interest in AD/HD. It was pretty obvious people had some clues as to what
AD/HD is all about. I think, not unlike parents on the mainland, they noticed something was wrong with their child, so they were coming to hear what the Virgin Islands has to offer.”

**Expanding the social movement**

Now the social movement aspect has attracted deJongh; she has a deep interest in motivating people to work together to address the concerns of those affected by AD/HD. She wants to mobilize the people, the resources, and the government ministries better able to assist individuals and their families who are dealing with AD/HD on a daily basis.

“One of the things I hope through parent involvement is to get together all these individuals who have been fighting their own fights,” deJongh said. “Almost like an army, to effect change...
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in education, health and human services here. My hope is to create a resource manual of the departments of health, education and human services where you can get help, so it’s almost a road map. The other thing to do is get those three departments to treat each case as single case, not as three separate cases.”

In addition to the hard work to bring CHADD to the Virgin Islands, deJongh and her husband have worked with Special Olympics to open two summer camps for athletes, both children and adults, with intellectual disabilities. “Children with disabilities, both intellectual and physical, are extremely important to us,” deJongh said. “It certainly has been rewarding to be part of this movement.”

DeJongh is also a Parent to Parent Certified Teacher, Ellison pointed out. The two spoke for some time about bringing CHADD’s innovative Parent to Parent program to the Virgin Islands. “Mrs. deJongh is really interested in getting parent and teacher training on evidence-based practices to the Virgin Islands,” Ellison said. “There’s a big interest in P2P classes,” deJongh said, adding that many teachers want information too. “They’re ordering education guides on their own. The teachers at the meetings seemed very hungry for information on how to handle classroom situations, especially with inclusion.”

Ellison, who spent two days as a guest of the deJonghs, said she was glad to have had the time to get to know the first lady. “She’s really dedicated,” Ellison said. “I think she can be a major spokesperson.”

DeJongh, who attended the 20th Annual International Conference on AD/HD in Washington, DC, and served as a captain for the Morning on the Hill visit to members of Congress, said she isn’t looking to be the leader of the two new CHADD support groups. Instead, she is looking for the natural leadership of members to come forward.

“My hope isn’t to be a leader, but that there will be some people to step up and lead these groups,” she said. “From what I felt [at the first meetings] there will be many, many people who step up and go from here.”