

The New Face of AD/HD Goes to Capitol Hill

By Cindy Smith, MS, JD, and Nadine Taylor Barnes

TO MARK THE FOURTH ANNUAL NATIONAL CHILDREN'S MENTAL HEALTH AWARENESS DAY, members of CHADD and the American Academy of Child & Adolescent Psychiatry gathered on Capitol Hill on May 8, 2009, to meet with their senators and representatives.

Among the volunteers were Blake Taylor, the youngest author of a memoir on AD/HD, and Courtney Gifford, the reigning Miss Wyoming. Blake and Courtney both have AD/HD, but they are part of a new generation who, because of the enhanced education and treatment options, are managing their AD/HD better than many generations who have come before them.

Their message was threefold: support the Child Health Care Crisis Relief Act (HR 1932/S. 999), support an increase in funding for the National Resource Center on AD/HD, and ensure that children are adequately taken into account in any healthcare reform package. This year CHADD and AACAP are seeking a \$600,000 increase for the CDC's National Center on Birth Defects and Developmental Disabilities AD/HD line item, of which \$300,000 would fund technical assistance on employment benefits and supports as well as outreach to underserved populations.

As actress Goldie Hawn reminded attendees at a briefing in honor of Awareness Day, children may be a small percentage of the current population of the United States, but their health is 100 percent of the United States' future.

When resources are scarce

During meetings with members of Congress representing her home state of Wyoming, Courtney Gifford was accompanied by AACAP president Robert Hendren, DO, and the parent of an adult child with a mental illness, among others. The story seems to tell itself, as both Courtney and the parent spoke of trying to find and access treatment in Wyoming—a state with only three child and adolescent psychiatrists.

Courtney relayed her good fortune in being diagnosed and treated at a young age because her mother worked in special education and her general practitioner had some knowledge of AD/HD. Now she is a 4.0 college student who is working hard and succeeding, visiting Capitol Hill for the first time, and speaking out to remove the stigma of disability.



Blake Taylor and Courtney Gifford pause on the steps in front of the U.S. Capitol building following their visit to the office of House Speaker Nancy Pelosi.

Cynthia Smith, MS, JD, CHADD's public policy specialist, and **Nadine Taylor-Barnes**, Blake Taylor's mother, contributed to this report.

Courtney emphasized the importance of family and consumer-based organizations like CHADD and the NRC, which provide families with a wealth of information when they do not have resources in their local communities. Dr. Hendren pointed to the importance of examining options such as telemedicine to ensure that every child not only has coverage but access to the medical treatment he or she needs in a setting where primary care and mental health are integrated.

As Congress looks to passing healthcare reform legislation this year, it is important to remember Courtney and others like her. As Senator John Barrasso mentioned during their meeting with him, in Wyoming, monetary resources do not guarantee access because doctors frequently practice for a few years, and then move away for other reasons.



PHOTO: NADINE TAYLOR-BARNES

Blake and Courtney study for finals in between Capitol Hill visits and media interviews.

Importance of early intervention and access

Nineteen-year-old Blake Taylor, a University of California-Berkeley sophomore and the author of *ADHD & Me*, addressed the audience at the Thursday evening reception for lawmakers and members of AACAP and CHADD, as did Courtney. Blake called himself one of the “fortunate ones” because of how many elements came together to make profound changes in his life. He has a mother who had learned about AD/HD, had him diagnosed early and then learned herself how to parent him properly, using CHADD’s resources. He had access to a good child psychiatrist in Connecticut and teachers who had been instructed in how to deal with children with AD/HD. He benefited directly from legislation that gave him the rights under IDEA, and he is fortunate to be at UC-Berkeley, a university that is at the forefront of AD/HD research. Blake talked about how if one follows treatment and manages the troublesome side of AD/HD, its good qualities—high energy, creativity, and hyperfocus—can enable young people to thrive in life. He ended by saying he hoped that after hearing his story, “lawmakers would do what was necessary for the four million others like me.”

The group that met with Speaker of the House Nancy Pelosi’s health policy fellow included Blake, his mother Nadine Taylor-Barnes, Courtney Gifford, John Sikorski, MD, and Basil Bernstein, MD. Blake made the point that “early intervention and access to a child psychiatrist made all the difference” in his life and gave examples of how many people still disbelieve AD/HD exists. Nadine Taylor-Barnes cited the statistic that only 50 percent of children affected by AD/HD receive treatment. Sikorski and Bernstein, both psychiatrists, talked about the scarcity of child psychiatrists throughout the country and the lack of enough new ones to backfill those retiring. Taylor-Barnes talked about treatment requiring a partnership among parents, doctors, and teachers, a point echoed by the health policy fellow, who



FOR MORE INFO

Visit chadd.org to read further coverage as well as the op-ed by Blake Taylor and Courtney Gifford that appeared in various publications to coincide with their visit to Capitol Hill.



From left: CHADD president Marie Paxson, James Carville, CHADD director of communications Bryan Goodman, and Mary Matalin.

MARIE PAXSON HONORED

On May 7, 2009, Commonwealth Academy honored Marie Paxson, president of CHADD's board of directors, with one of its annual CARE Awards in recognition of her advocacy work on behalf of people with AD/HD. The event was hosted by political pundits James Carville and Mary Matalin, parents of a former Commonwealth student. Carville presented the award to Paxson, who was the evening's keynote speaker.

Commonwealth Academy is an independent coeducational college preparatory day school in Alexandria, Virginia. The school serves middle and high school students of average to superior abilities who benefit from small classes and instruction designed to address various learning styles, including students with organizational, attention, or learning differences.

commented that Speaker Pelosi believes such a partnership is important. Understanding the Speaker's focus on children and their health issues, the health policy fellow stated, "We need to continue to advocate for these reforms because they are very important for the next generation."

Along with the AACAP delegation of psychiatrists and families, Blake visited California Senator Barbara Boxer's office and asked her to support HR 1932/S.999 along with more funds for the NRC and AD/HD research. Blake emphasized the positive

qualities of AD/HD that can only be realized when young people are diagnosed and follow their treatment plans. "Influencing a child's life early," he said, "has all the more impact than doing it later." Another mother in the group then recounted her struggles in finding a child psychiatrist "who would spend the time and really get to know my ten-year-old child." But unfortunately, her son attempted suicide by trying to jump out of the car on the freeway, before finding the right doctor. "And this was in Los Angeles," she said. "We desperately need child psychiatrists." ●