

**CHADD Annual Report
2004-2005**

**Mary Durheim
President**

CHADD, the leading non-profit organization serving individuals with attention-deficit/hyperactivity disorder (AD/HD) and their families, marked its 18th year of providing information, education and support to individuals, families, and professionals. With 15,000 members and 200 affiliates nationwide, CHADD continues to grow in the services it provides to those dealing with AD/HD on a daily basis. Through collaborative leadership, advocacy, research, education and support, CHADD provides science-based, evidence-based information about AD/HD to parents, educators, professionals, the media and the general public. Our mission statement - CHADD CARES! - reflects these priorities.

**CHADD – Children and Adults with Attention-Deficit/Hyperactivity Disorder
STATEMENT OF ACTIVITIES
Year Ended June 30, 2005**

PUBLIC SUPPORT AND REVENUE	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Total</u>
Total public support and revenue	\$ 4,436,601	\$ 197,255	\$ 4,633,856
EXPENSES			
Program services			
Public Education and Outreach	\$ 2,608,753	--	\$ 2,608,753
Membership and Chapter Services	658,705	--	658,705
Public Advocacy	<u>50,321</u>	--	<u>50,321</u>
Total program services expenses	\$ 3,317,779	--	\$ 3,317,779
Supporting services			
Management and general	\$ 517,965	--	\$ 517,965
Fundraising	<u>203,486</u>	--	<u>203,486</u>
Total expenses	<u>\$ 4,039,230</u>	--	<u>\$ 4,039,230</u>
Change in net assets	\$ 397,371	197,255	\$ 594,626
NET ASSETS AT BEGINNING/YEAR as restated	\$ 556,550	\$ 288,508	\$ 845,058
NET ASSETS AT END OF YEAR	<u>\$ 953,921</u>	<u>\$ 485,763</u>	<u>\$ 1,439,684</u>

Using CHADD's strategic plan as the foundation of our organizational work in 2004-2005, the organization built upon the positive achievements of our past and looked toward meeting the increasing challenges of the future. In addressing our daily work and in keeping with CHADD's stated mission, the CHADD Strategic Plan focuses on the following six priority strategic objectives:

- Increase the public's understanding of AD/HD by:
 - (a) continuing to build the National Resource Center to become the national clearinghouse for science-based and evidence-based information on AD/HD;
 - (b) broadening overall communications strategies and outreach efforts, including the National AD/HD Education Initiative; and
 - (c) continually improving the quality and comprehensiveness of CHADD's annual international conference.

- Support the growth and diversity of the CHADD membership by
 - (a) clearly identifying targeted audience needs,
 - (b) developing initiatives to meet those specific needs,
 - (c) improving national and grass roots membership communication and
 - (d) improving customer service for both members and chapters.

- Enhance CHADD's influence on public policy,
 - a) focusing on national and state policies, legislation and regulations impacting AD/HD and,
 - b) emphasizing the protection of rights for children and adults with AD/HD.

- Maintain financial solvency by
 - a) attempting to build cash reserves by \$200,000 in FY 04-05 through targeted reserve set-asides.
 - b) implementing unbudgeted initiatives only upon receipt of written commitment of funds, or through budget reallocation.

- Support the efforts of employees by
 - a) enriching their employment,
 - b) investing in their personal growth and

- c) involving them, individually and collectively, in the continuous improvements of CHADD.
- Improve the functionality and navigability of the CHADD website
 - a) strengthening functionality and navigability and
 - b) ensuring CHADD and NRC websites are differentiated yet complimentary.

In addressing our mission and implementing our strategic plan, CHADD celebrates and recognizes the efforts of our dedicated and talented staff and volunteers. This annual report highlights the key accomplishments, developments and challenges of the organization in meeting various milestones during the 2004-2005 fiscal year.

THE FINANCIAL PICTURE

Every organization relies on a positive financial accounting in order to realize its strategic objectives and core mission. Our financial status dictates every decision made and implemented by the organization. As of June 30, 2005, the composition of the budget was:

- membership and contributions – 27%;
- annual conference revenue – 9.6%;
- revenue from publications and related educational products and information – 18.3%;
- federal government support – 20.3%; and
- non-governmental and on-pharmaceutical grants and donations - 1%

Total pharmaceutical donation support of CHADD through unrestricted educational grants comprised 22% of the total revenue, including substantial conference grants and donations. Pharmaceutical donations received by CHADD as of June 30, 2005 included support from Cephalon, Eli Lilly, McNeil, Novartis, Pfizer, Shire and UCB Pharma.

CHADD operates under a statement of “Ethical Principles for Acceptance of Support.” An excerpt from that statement reads:

“While CHADD is committed to achieving a diversified base of corporate support and actively seeks contributions from businesses and corporations with no direct financial interest in AD/HD, CHADD believes it is ethically sound to request business concerns that profit from AD/HD to devote a portion of those profits to support

charitable endeavors that will benefit people with AD/HD. At the same time, CHADD is committed to avoiding a conflict of interest or even its appearance in accepting financial support from corporations with vested interests in how consumers, the health care community, and education professionals regard their products. To assure that conflicts of interest do not occur, CHADD's Board of Directors has determined that acceptance of substantial restricted or unrestricted gifts from commercial enterprises and foundations, and CHADD's subsequent relationship with these donors, shall be governed by a strict set of ethical principles that requires mutual agreement by CHADD and its donors."

A member of the National Health Council, CHADD is in "full compliance" with the NHC Good Operating Practices standards for the entire voluntary health agency movement. Information on the National Health Council is available from www.nationalhealthcouncil.org.

For the fiscal year July 1, 2004 through June 30, 2005, 84.1% of CHADD's expenditures (\$3,564,339) went to program services with 11.1% (\$469,968) going to management and general, including internal board activities, and 4.8% (\$203,486) going to fundraising. Only 1.2% of CHADD's budget (\$48,807) is spent on "lobbying" activities as defined by the Internal Revenue Service.

PROGRAM SERVICES

Public Education and Outreach

Centers for Disease Control and Prevention – National Resource Center on AD/HD

CHADD continues to recognize the outstanding accomplishments of the NRC in the area of public education and outreach. Given the strategic priority of increasing the public's understanding of AD/HD, we were pleased to receive continuation funding of the National Resource Center from the Centers for Disease Control and Prevention. In August of 2004, CHADD was notified that our funding for the NRC had been increased to \$1,000,000 up from \$735,000 for the previous year. In addition, the NRC-AD/HD parent CDC agency, the National Center on Birth Defects and Developmental Disabilities (NCBDDD), through a CDC-wide

reorganization, is now part of the Coordinating Center on Health Promotion (CoCHP). The NRC library continues to grow with library online holdings as of June 30, 2005 totaling 1,848. The NRC library contains subscriptions to scientific journals and information from the fields of developmental psychology, special education, social work, mental health and psychopharmacology. The collection of scholarly and popular books has increased to 240. Our NRC librarian continues to update the controlled vocabulary, adding several new terms keeping up to date with the latest research terms. We continue to add new staff to the NRC in order to meet the increasing requests for information on AD/HD. Staff of the NRC is multilingual and constantly works to meet the needs of our diverse culture with a focus on increasing the number of print and online resources available in a variety of languages. The NRC, in cooperation with the National Alliance for Hispanic Health, has recently completed a bilingual brochure on educational rights. NRC staff also continues to exhibit at prioritized conferences throughout the U.S. to reach target audiences. The NRC has also initiated a redesign and expansion of CHADD's fact sheets on AD/HD. .

Through the continued efforts of our Professional Advisory Board, volunteers and staff, the NRC has updated and added new information and resource sheets on AD/HD. Over the past year, the NRC has produced the following new fact sheets: "*Self-Esteem*" (for adult issues); "*Inattentive Type AD/HD;*" "*Sleeping Disorders & AD/HD;*" and "*Tics, Tourettes Syndrome & AD/HD.*" Updated information and resource sheets include: "*The Disorder Named AD/HD;*" "*Assessing Complementary & Controversial Interventions;*" "*Educational Rights for Children with AD/HD;*" and "*Parenting a Child with AD/HD.*" These have also been published in Spanish and are posted on the NRC website: www.help4adhd.org. CHADD's focus on having materials available in Spanish has also resulted in the translation of one article for each issue of *Attention!* ® magazine.

The combined websites of the NRC and CHADD receive an average of over 8900 unique visits per day. Over the last year, statistics gathered on the NRC website indicates that over 91, 817 unique visitors visited the site – an increase of 30,000 visits from last year. For the CHADD website, this number totals 2,175,426. CHADD's core constituencies of parents of individuals with AD/HD and adults with AD/HD continue to account for the bulk of inquiries and accounted for well over half of the total inquiries received by the websites. The most popular areas of information requested include child and adult information, diagnostic information, educational

resources, legal rights under special education, Section 504 of the Rehabilitation Act and the Americans with Disabilities Act and medication information.

For the first time ever, the NRC held a Children's Mental Health Summit in April of 2005. The meeting included representatives from the CDC, SAMSHA, and private sector organizations and focused on developing a public health approach to identify social/emotional/behavioral issues in children and youth through developmental screening.

Education Initiative

The National Education Initiative on AD/HD, "*Just A.S.K. – AD/HD. Science. Knowledge.*" continued to be a major priority for CHADD. This initiative, now in its third year, is a multi-year campaign to dispel the myths and misperceptions about AD/HD and is directed by the CHADD Communications Department. CHADD collaborated with the National Mental Health Association (NMHA) on the development of a booklet for parents about AD/HD with a focus on parents of color. CHADD hosted a Congressional Black Caucus briefing with over 30 organizations signing on as partners and in August of 2004 hosted a successful dinner for the National Medical Association. This meeting resulted in a first-ever consensus statement, which was presented and passed by the Psychiatry and Behavioral Science Section of the NMA. This milestone is highly significant in CHADD's cultural competence efforts and Education Initiative.

In May of 2005, CHADD hosted a Congressional Hispanic Caucus briefing on Capitol Hill With speakers highlighting the challenges of seeking and obtaining mental health services in the Hispanic/Latino community. The August issue of *Attention!*® included a summary of the Congressional Hispanic Caucus briefing and articles on the Education Initiative and related advocacy efforts were included in the October issue. Conscious efforts to feature ethnically diverse photos continue as an organizational priority

Promoting AD/HD Awareness Day, held in September the last two years, CHADD collaborated with the Attention Deficit Disorder Association (ADDA) and NMHA on activities. Efforts included mention of Awareness Day in the August issue of *Attention!*®, preparing and promoting Awareness Day tips and ideas for coordinators to share with their chapters, linking ADDA's Awareness Day tool kit to the CHADD website, working with ADDA and NMHA to write and circulate a press release, circulating the press release via "*News from CHADD,*" partnering on any Capitol Hill or legislative efforts to acknowledge the day, and other related activities.

Activities mentioned above demonstrate CHADD's overall commitment to the Just A.S.K program. During the last year, the Communications Department worked closely with *U.S. News and World Report* on a cover story entitled "*Adults with AD/HD.*" Using the U.S. News and World Report article as a springboard for additional focus on the topic of adults with AD/HD, CHADD conducted a radio media tour featuring Patricia Quinn and Stephen Spector. This tour generated a combined total of 892 broadcasts, reaching more than 10.6 million listeners.

Attention!® Magazine

During the 2004-2005 fiscal year, *Attention!®* magazine added two new columns – "Ask the Experts Q & A" and Chapters in Action. In July of 2004, CHADD obtained an international standard serial number (ISSN) for *Attention!®* magazine from the Library of Congress. All issues of the magazine now display the ISSN in the masthead. Additionally, the magazine has expanded to 56 pages to accommodate an increase in advertising. Editorial content has also been increased resulting in providing our readers with the most current, up to date information on issues important to those dealing with AD/HD. Each issue also contains one article translated into Spanish.

Efforts to obtain reader feedback on the magazine have been increased through a comprehensive and extensive reader survey. The April issue of *Attention!®* featured an advertisement inviting readers of the magazine to fill out an online version of the survey. The Chief Development Officer negotiated an agreement with UCB Pharma for bulk delivery of the magazine to physicians' offices; we continued our previous arrangement with Shire, as well. CHADD's print run now totals 141, 000 for each issue produced. Over the last year, CHADD advertising revenue has doubled, due in large part to the acceptance of branded advertising.

Other

Anti-psychiatry threats continue to take a great deal of CHADD's time and efforts. In response to the Tom Cruise appearance on NBC's "Today," CHADD developed and circulated a statement via "*News from CHADD*" expressing concern about his anti-psychiatry views. The American Psychiatric Association, National Alliance for the Mental Illness, and the National Mental Health Association collaborated with CHADD and permission was granted to circulate their joint statement with endorsement from CHADD. Readers were referred to CHADD's

Education Initiative Website information for an overview of recent outreach efforts to dispel myths and misunderstandings about AD/HD.

MEMBERSHIP AND CHAPTER SERVICES

CHADD continues to work to support the growth and diversity of the CHADD membership. CHADD's local affiliate structures remain both our greatest strength and our greatest challenge. Efforts have been initiated to reinvent chapters as fundraising, membership development and more visible community education resources. Support Group Toolkits have been developed for chapter leadership and helpful guides have been included on the coordinator website. Revisions of the coordinator's manual have been initiated. In analyzing data to date, it is clear that proactive steps must be taken to identify struggling chapters early and provide technical assistance aggressively.

In order to better respond to state issues, CHADD added a staff position for Deputy CEO for Public Policy and Community Resources. By combining chapter and public policy management in a single position, CHADD's ability to respond to state issues is enhanced. In 2005, CHADD staff assisted CHADD of Utah in combating a bill that would have severely limited the ability of school personnel to discuss the need for evaluation and treatment of any psychiatric or psychological disorder, including AD/HD. Work was also initiated in Florida to combat a similar bill.

As we continue to struggle with the current chapter model, work has been initiated on chapter infrastructure issues. The process of auditing chapter files and chapter websites has begun and will ultimately result in a number of inactive chapters being closed. Overall, this process will result in stronger chapter organizations and has already resulted in a greater number of requests to establish new support groups under a simplified process.

In February 2005 a new, separate membership committee was formed. The first meeting resulted in a proposed two-year work plan that focuses on the five stages of membership recruitment and retention: (1) Prospecting; (2) Recruiting; (3) Orienting; (4) Involving; and (5) Renewing. In the following months, redesign of CHADD's membership brochure was initiated. The brochure updates include an introduction to the Professional Plus and Organizational Plus membership categories, and the current environment and knowledge base about AD/HD. While

membership numbers are somewhat stagnant, the Membership and Chapter Services Committees have developed a cooperative agreement on how to process inquiries and complaints. Overall the number of active members is lower due to previously counting 14 months worth of memberships instead of 12.

It has been noted that customer service must be incorporated in every aspect of CHADD's operations. Since August of 2004, customer service within the membership and chapter services departments has significantly increased. To that degree, CHADD has significantly reduced the amount of time it takes to process a new member application. In addition to utilizing the work of a new mail house, welcome materials are now processed and sent out within two weeks.

With the hiring of a new director for membership, fresh innovative ideas have been generated by the committee. As data is gathered and studied, new approaches for marketing will be piloted.

PUBLIC POLICY

CHADD continues to participate with many national organizations to better advocate for the needs of people with AD/HD and co-occurring disorders. Collaborations include, but are not limited to, the Campaign for Mental Health Reform, Consortium for Citizens with Disabilities Education and Employment and Training Task Forces, National Alliance for the Mentally Ill – School-based Mental Health Program., Mental Health Liaison Group, the American Academy of Pediatrics and the American Academy of Child and Adolescent Psychiatry.

CHADD's CEO, Dr. E. Clarke Ross, helped develop the Campaign for Mental Health Reform statement, "Why Representative Paul is Wrong" (on mental health screening) and circulated it to CHADD lists. The stated role of the Campaign: "To enable the enactment of progressive legislation that transforms mental health and other public systems so that individuals can live, work, and thrive in the community, as articulated in the President's New Freedom Mental Health Commission report."

The Education Task Force has been one of the most active groups in which CHADD participates. The co-chairs, including CHADD's Director of Public Policy, met with leaders in

both the House and Senate and held multiple meetings with Administration officials of both the Department of Education and the White House. CHADD's CBA paper, "In the Best Interests of All," has been distributed at many of these meetings and was frequently used to defuse the desire to change the IDEA discipline provisions.

Because of the increased emphasis on developing local participation at the IDEA regulatory meetings and the emphasis on state legislative activities and capacity, work on juvenile justice issues has been curtailed. Staff worked tirelessly on the reauthorization of IDEA and provided intensive technical assistance in preparing individuals for testifying at regional meetings.

The Outcomes Roundtable has produced a core of performance measures focused on children with mental health needs and their families. CHADD's representative to the American Academy of Child and Adolescent Psychiatry continues to address the ethical and policy issues regarding the safety and effectiveness of psychotropic medications in children. CHADD's CEO also serves as a resource for the AAP on health insurance reform advocacy and served on the teen and adolescent work group that produced two brochures for teens on AD/HD and drafted an article summarizing the research for *Pediatrics*.

CHADD's Professional Advisory Board has worked to develop an action agenda as a follow-up to the AD/HD chapter in *Mental Health, United States, 2002*. In addition, several BOD members participated in the NAMI School-based Mental Health Program design.

State legislative actions have been monitored when brought to the attention of the CHADD staff. Through advocacy activities, CHADD was able to have a representative included on the New Hampshire AD/HD Governor's Commission. During regional meetings on the reauthorization of the IDEA, CHADD was able to identify a volunteer base to provide testimony. In June of 2005, CHADD offered free advocacy training for members from Virginia to Maine. Presenters included CHADD members and associates who have been successful in local and state advocacy efforts. Advocacy training continues to be provided at the international CHADD conference.

SUPPORT SERVICES

Fundraising:

None of our strategic objectives and core mission statement components can become a reality without adequate funding. Our Development Department continues to do an outstanding job of supplementing CHADD's financial base. CHADD receives federal funding from the Centers for Disease Control and Prevention to establish and operate the National Resource Center on AD/HD. Our largest fundraising activity is our annual international conference, which through the leadership of our Conference Director, has continued to grow at a steady pace with the net income increasing each of the last three years. Through the management and oversight of the CHADD exhibit hall at the annual conference, the number of exhibitors is at an all time high.

CHADD's fifth annual charity Golf Tournament in May again brought out a large crowd of participants and supporters. Income from the golf tournament again increased and is becoming a major fundraising event for CHADD as well as providing popular venue for meeting and renewing industry friends. The President's Council has again added new members including two lifetime members. Revenue from the President's Council exceeded budget expectations. A major influx of President's Council funds was received in the summer 2004 from a benefit dinner hosted by the Center for the Advancement of Children's Mental Health at Columbia University through the assistance of Dr. Peter Jensen. This year also initiated the Professional Circle category for doctors and others who may support several charitable institutions and causes. Donations of \$1000 to \$2,500 annually will place an individual into the Professional Circle. Money available from the President's Council funds the Parent to Parent: Family Training on AD/HD project. This project trained two classes of teachers during its inaugural year. This interactive training session provides information on AD/HD through the lifespan to parents and others over a seven week series of classes. Monies generated by the President's Council has also allowed for the rewriting of the Educator's Manual, due out by summer of 2006.

Corporate donations through unrestricted educational grants continue to grow. CHADD policy caps the amount of dollars that can be generated from pharmaceutical funding. As a result, CHADD continues its work to create foundation partnerships and has hired staff to develop grant applications and assist with the search for foundation funding. CHADD's participation in the Combined Federal Campaign, United Way, and other employee giving programs is ongoing. CHADD continues to research and invest in higher profile promotion of affinity programs; however, during the 2004-2005 FY, monies from both the medical assistance cards and the car donation program have been substantially reduced. As the organization collaboratively identifies new member benefit opportunities, the result should be increased member retention

and increased income for CHADD. In looking at untapped opportunities, CHADD is beginning to focus on planned giving and estate planning.

Fundraising efforts for the Matt Cohen Membership Support Fund and the Young Scientist Research Fund also continue to grow. Through the Matt Cohen Membership Support Fund, individuals of limited means are given the opportunity to join CHADD and participate in meaningful membership and chapter programs. Through the efforts of various members of the Professional Advisory Board, standards for the awarding of the Young Scientist Research Fund have been developed and approved.

MANAGEMENT AND GENERAL

The management of CHADD is responsible for establishing and maintaining effective internal controls over compliance with requirements of laws, regulations, contracts, and grants applicable to federal programs. CHADD adheres to the guidelines established by the National Health Council and met the compliance standards to be recognized with the National Health Council's Standards of Excellence. In receiving this recognition, CHADD has established that it has maintained the highest levels of efficiency, accountability and public stewardship. The standards cover the areas of governance, personnel policies, programs, fundraising, finance, accounting and reporting and evaluation.

SUMMARY

Through the expert leadership of CHADD throughout the entire organization, we have been able to accomplish many outstanding activities in 2004-2005. Our Board of Directors has reduced its number of directors in response to industry standards while maintaining its quality and dedication. The efforts and commitment of a well qualified and talented staff as well as our many volunteers throughout the nation allow CHADD to meet its strategic objectives. By remaining true to the values reflected in our core mission statement of providing collaborative leadership, advocacy, research, education and support to improve the lives of all individuals with AD/HD, CHADD is truly creating a social movement on AD/HD. As CHADD continues to make progress in becoming a more inclusive, professional organization, we also are becoming a major stakeholder in the mental health and advocacy arenas.

Thanks to all of you who continue to contribute to the growth and success of CHADD. The CHADD organization looks forward to many continued years of providing our members and the general public with quality information on the disorder of AD/HD.