

CHADD Annual Report 2003-2004

**Mary Durham
President**

CHADD, the leading non-profit organization serving individuals with attention-deficit/hyperactivity disorder (AD/HD) and their families marked its 17th year of providing information, education and support to individuals, families, and professionals. With more than 16,000 members and 212 volunteer grassroots units in 45 states, as well as Puerto Rico, CHADD continues to grow in the services it provides to those dealing with AD/HD on a daily basis. CHADD constantly works to improve the lives of people affected by AD/HD through: collaborative leadership, advocacy, research, education and support – CHADD CARES!

CHADD – Children and Adults with Attention-Deficit/Hyperactivity Disorder STATEMENT OF ACTIVITIES Year Ended June 30, 2004

| PUBLIC SUPPORT AND REVENUE | <u>Unrestricted</u> | <u>Temporarily Restricted</u> | <u>Total</u> |
|--|---------------------|-----------------------------------|--------------|
| Total public support and revenue | \$ 3,724,087 | \$ 33,321 | \$ 3,757,408 |
| | | | |
| EXPENSES | | | |
| Program services | | | |
| Public Education and Outreach | 2,496,632 | -- | 2,496,632 |
| Membership and Chapter Services | 468,173 | -- | 468,173 |
| Public Advocacy | 51,974 | -- | 51,974 |
| Total program services expenses | 3,016,779 | -- | 3,016,779 |
| | | | |
| Supporting services | | | |
| Management and general | 423,606 | -- | 423,606 |
| Fundraising | 173,684 | -- | 173,684 |
| Total expenses | 3,614,069 | -- | 3,614,069 |
| Change in net assets | 110,018 | 33,321 | 143,339 |
| NET ASSETS AT BEGINNING OF YEAR, as restated | 446,532 | 255,187 | 701,719 |
| NET ASSETS AT END OF YEAR | \$ 556,550 | \$ 288,508 | \$ 845,058 |

Strategic Objectives

Using CHADD's strategic plan as the foundation of our organizational work in 2003-2004, we continue to build upon the positive achievements of our past as well as looking toward the challenges of the future. In undertaking our daily work and in keeping with CHADD's mission, the CHADD Strategic Plan involves 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) broaden overall communications strategies and outreach efforts, including the National AD/HD Education Initiative, and (c) continually improve upon the quality and comprehensiveness of CHADD's annual conference.
- Support the growth and diversity of the CHADD membership by clearly identifying targeted audience needs, developing initiatives to meet their specific needs, improving communication between the national organization and the grassroots membership, and improving customer service for both members and chapters.
- Enhance CHADD's influence on national and state public policies, legislation and regulations impacting AD/HD, including an emphasis on the protection of rights for children and adults with AD/HD.
- Maintain financial solvency. Attempt to build cash reserves by \$200,000 in 2004 through targeted reserve set-asides.
- Support the efforts of employees, enrich their employment, invest in their personal growth and involve them, both individually and collectively, in the continuous improvements of CHADD.
- Improve the functionality and navigability of the CHADD website, ensuring that the CHADD and NRC websites are differentiated yet complementary.

In meeting our mission and implementing our strategic plan, CHADD again celebrated several major milestones during the 2003-2004 fiscal year and this annual report highlights the key accomplishments, developments, and challenges for the organization.

The Financial Picture:

Every organization is reliant on a positive financial accounting in order for its strategic objectives and core mission to become a reality. Our financial status impacts every decision made and implemented by the organization. As of June 30, 2004, the composition of the budget was: members dues and contributions - 28%; annual conference revenue - 9%; revenue from publications and related educational products and information - 16%; federal government support - 24% and non-governmental and non-pharmaceutical grants and donations - 1%. Total pharmaceutical donation support of CHADD through unrestricted educational grants totaled 23% of the total revenue, including substantial conference grants and donations. Pharmaceutical donations received by CHADD as of June 30, 2004 included support from Cell Tech, Cephalon, Janssen, Eli Lilly, McNeil, Novartis, Pfizer, and Shire.

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.

Program Services:

Public Education and Outreach:

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

CHADD's most exciting area of accomplishment continues to be in the area of public education and outreach. Given the strategic priority of increasing the public's understanding AD/HD, we were pleased to receive continuation funding of the National Resource Center on AD/HD from the Centers for Disease Control and Prevention. The NRC library continues to grow with library online holdings as of June 30, 2004 at 1,237. Through our subscriptions to scientific journals, the NRC has added information in the fields of developmental psychology, special education, social work, mental health, and psychopharmacology. The collection of scholarly and popular books housed in the NRC continues to grow and staff are developing procedures for a lending library for individuals who do not have the ability to access books and literature on AD/HD. Staff of the NRC are multilingual and constantly work to meet the needs of our diverse culture with a focus on increasing the number of print and online resources available in Spanish. The NRC has begun a working relationship with the National Alliance for Hispanic Health to produce new bilingual products addressing AD/HD and continues to work with professionals in the African American community to develop long range strategies for reaching African-American families with science-based information on AD/HD.

Through the combined efforts of our Professional Advisory Board, volunteers and staff, the NRC has added a new series of adult information fact sheets. Over the past year, the NRC has produced the following new

fact sheets: *"Medical Treatment of Adult AD/HD;" "AD/HD in Women;" "Coaching Adults with AD/HD"* and *"Evidence-based Psychosocial Treatment of Children and Adolescents with AD/HD."* In addition, updates reflecting the most current information have been made on existing fact sheets entitled *"Evidence-based Medication Management of Children and Adolescents with AD/HD,"* and *"The Disorder Named AD/HD."* In collaboration with the American Academy of Pediatricians, the NRC worked on two brochures aimed at adolescents with AD/HD: *"What is AD/HD Anyway? Questions for Teens,"* and *"What About Medicines for AD/HD Questions from Teens who Have AD/HD."*

The combined Web sites of the NRC and CHADD received an average of over 8,000 visits per day. The first full year of statistics gathered on the NRC Web site indicate that the site received 867,783 visits. For the CHADD Web site, this number totals 2,088,712 visits. 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 and the Americans with Disabilities Act and medication information.

Raising awareness of the NRC among the public, medical providers and educators resulted in the NRC exhibiting at many prestigious conferences this past year including the National Council for Community Behavioral Health and the Association of Maternal & Child Health Programs. These two conferences alone resulted in distribution and/or requests for information on AD/HD to well over 1,900 administrators and clinicians.

Education Initiative

The Education Initiative, *"Just A.S.K. – AD/HD. Science. Knowledge."* continued as a major priority for CHADD during the 2003-2004 year and is directed by the CHADD Communications Department. In its second year of a multi-year campaign to dispel the common myths and misperceptions surrounding AD/HD, this initiative continues to make a dramatic impact for those with AD/HD. Just four brief months after hosting a U.S. House briefing on AD/HD, a similar Senate briefing was held to a packed room with increased participation of mental health and education partners. In another highly successful briefing, the Congressional Black Caucus was attended by over 100 participants in Washington D.C. and resulted in an exciting first for CHADD. In May of 2004, CHADD hosted a Consensus Conference to explore the controversies, truths, fallacies, perceptions and impact of AD/HD in African American communities. This conference resulted in the development of a consensus statement which was presented to the National Medical Association Section on Psychiatry and Behavioral Science.

In recognition of Mental Health Awareness Month and in collaboration with United Behavioral Health and Tennessee Radio Network, the Education Initiative funded a week of radio spots focused on AD/HD. Another first for CHADD, these *"Mental Health Minutes"* were broadcast two times each day for a week, focused exclusively on AD/HD and was broadcast to 78 radio stations throughout the state reaching over one million people. Through promotion of *"Just A.S.K.,"* the Communications Department worked closely with U.S. News and World Report on the cover story *"Adults with AD/HD."* As a result of this article, a radio

media tour followed generating a combined total of 892 broadcasts, reaching more than 10.6 million listeners.

ATTENTION!® Magazine

ATTENTION!® Magazine continues to garner praise for its insightful articles, special features and regular columns from parents, professionals and others. Two new columns have been added to the magazine – book reviews and research briefs. Requests for reprint permission of articles increase with each day and points to the quality and professional information contained within each publication. With an incredible group of talented staff, the magazine continues to offer the very latest information on current trends, breaking scientific reports and basic parent information to its readers. Distributed to over 85,000 readers six times per year, *ATTENTION!®* Magazine is growing not only in size but also in its reputation. In a first and major policy change for CHADD, the BOD approved publication of non-branded pharmaceutical ads in *ATTENTION!®* Magazine. CHADD has increased its focus on cultural diversity and the number of articles published in Spanish. The magazine is focused on promoting CHADD's accomplishments and services via one "Inside CHADD" article in every issue to demonstrate what CHADD provides its members.

Membership and Chapter Services:

As CHADD works to support the growth and diversity of the CHADD membership, the CHADD local affiliate structures remain both our greatest strength and our great challenge. Providing needed support, information and advocacy to its members and others interested in issues related to AD/HD, these groups are lead by a total volunteer base. With limited national resources, only minimal support can be provided to the local volunteer leaders. Over the last year, CHADD has made a concerted effort to identify targeted audience needs, develop initiatives to meet their specific needs and improve communication between the national organization and the grass roots membership, and improve customer service for both members and chapters.

For the third consecutive year through support from the Center for Mental Health Services, CHADD conducted five community forums to educate the public about AD/HD and other childhood mental disorders. These forums also worked to build community partnerships with sister associations of families and advocates and to outreach to culturally diverse populations including the African-American community and the Hispanic/Latino community. Forums were held in Baltimore, Dallas, Denver, Detroit and New Orleans. Approximately 729 individuals attended these forums, most of who were new visitors to CHADD. While the actual forums were not completed by June 30, 2004, they have resulted in either organizational change or enhancement of efforts to outreach and serve the targeted previously under-served communities. While not receiving funding to continue this initiative in 2004-2005, CHADD has its highest priority to hold a collaborative forum with the Black Psychiatrists Association of America.

As we continue to struggle with the current chapter model, consistent with the recommendations from an outside consultant, CHADD completed the drafting of policies for the development of incorporated affiliates

and announced these opportunities to the chapters. Under this model, chapters would have the ability to become an independent state or local organization and be registered as an IRS 501(c)(3) not for profit organization. Transition to an incorporated affiliate does present challenges and concerns have been noted that the additional obligations outweigh any advantage of flexibility and more independent action. CHADD remains vested in further exploring possible options to make our chapters more independent.

To support our chapter coordinators, several helpful guides have been placed on the coordinator's web site. In addition, plans are in place to totally renovate the web site, making it more user friendly and functional. After many years, the coordinator's manual has been completely updated along with the required "critical elements", and is now posted on the coordinator's site. With both a new chapter services director and a new membership director, CHADD is looking forward to even greater improvements in this area and much needed support for our coordinators.

Maintaining our membership as well as getting new members continues to be our area of most challenge. With a renewed focus on customer services and coordination with our national call center, plans are underway to address many of these concerns. To encourage professional and organizational memberships, CHADD launched a Professional and Organizational Membership Directory of Products and Services as a key new member service for those market segments. The upgraded membership benefits package was launched in May 2004 and by June 30, 2004 had generated \$14,166. For its professional members, we launched "Hot off the Press", a quarterly newsletter of new research findings. CHADD also initiated its first Chapter Membership Incentive Program this past year. For chapters exceeding their goals, a financial incentive was provided. While showing only modest gains, 17 chapters were successful in raising memberships. CHADD is committed to developing a chapter-driven recruitment effort based on equitable and fair-share responsibilities.

Public Advocacy:

CHADD participates 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, Juvenile Justice and Delinquency Prevention Coalition, Mental Health Liaison Group, the American Academy of Pediatrics, and the American Academy of Child and Adolescent Psychiatry.

Within the CHADD Public Policy Committee, priority areas are established each year through the development of a Public Policy Agenda which aligns to CHADD's overall strategic plan. With emphasis on the reauthorization of the nation's special education law (Individuals with Disabilities Education Act, IDEA) - great time and effort has been extended in educating our membership about the issues being addressed in the reauthorization as it impacts children with AD/HD in particular and children with disabilities in general, including the protection and enhancement of current eligibility rules, procedural safeguards, requirements regarding positive behavioral intervention and disciplinary procedures. Our "News from CHADD", an electronic newsletter to any requesting this service, continues to provide our readers with the most current information available on reauthorization and encourages readers to write their stories. CHADD attempts to

monitor state legislative actions and has been able to have a representative included on the New Hampshire AD/HD Governor's Commission.

Although the Children's Behavioral Alliance has not met during 2003-2004, the policy paper *"In the Best Interests of All"* continues to be circulated and additional organizations have asked to join the Alliance. The provisions of the paper advocated by Senators Clinton and Sessions as Subpart IV of Part D, IDEA Reauthorization Act, were adopted by the Senate. The CCD Education Task Force has been one of the most active. The co-chairs, including CHADD's Public Policy Director, have met with leaders in the House and the Senate, as well as multiple meetings with Administration officials. Through the use of the CBA paper, efforts to defuse the desire to change the discipline provisions of the IDEA have been greatly successful.

The purpose of the Campaign for Mental Health Reform, composed of sixteen organizations including CHADD, is to bring public policy maker support for the implementation of the President's New Freedom Commission on Mental Health report, "Achieving the Promise: Transforming Mental Health Care in America."

In an effort to better assist our membership in public advocacy, the Volunteer Action Network has been reorganized and is now called the CHADD Advocacy Network. Work has been initiated in revising and updating the advocacy manual to give our chapters and their membership better tools to meet the growing need for a more involved advocacy organization. The Web-based legislative action center continues to assist our limited staff and resources in helping members to respond quickly and effectively to threats and opportunities at both the state and national level. CHADD is dedicated to creating a social movement in addressing the issues of AD/HD and its impact on individuals and their family members throughout the lifespan.

Support Services

Fundraising:

None of our strategic objectives and core mission statement components can become a reality without funding. Our Finance and Development Department continues to do an outstanding job of supplementing CHADD's membership and citizen donor 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 since the devastating effects of 9-11. Through the management and oversight of the CHADD exhibit hall at the annual conference, exhibitors are at an all time high.

Our 4th annual charity Golf Tournament in May brought out the largest crowd of participants and supporters. Numbering over a 100 participants this year, the golf tournament has quickly become a popular as well as a major fundraising event for CHADD. The President's Council continues to add new members and with each new member, the amount of money available for special projects is directly impacted. The President's Council sponsored the development of Parent to Parent: Family Training on AD/HD, a seven-week training program on the lifespan issues of AD/HD. Additional money generated by the President's Council is also allowing for the rewriting of the previously published Educator's Manual with plans of distribution to every school in the United States.

Corporate donations through unrestricted educational grants grew this last year from 17.3% to 23%. CHADD has begun work to create foundation partnerships and grants. Work has been initiated to research and apply to foundations for grant support. Our 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, including Prescription and Vision Med Ass Assist and the CHADD Elan VISA[®] Credit Card. As the organization collaboratively identifies new member benefit opportunities, the result will be increased member retention and increased income for CHADD.

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. Plans are currently underway to develop standards for the awarding of the Young Scientist Research Fund.

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 activities of many volunteers and staff, CHADD has been able to accomplish many things in 2003-2004. Our Board of Directors has reduced its number of directors in response to industry standards. But without the efforts and dedication of a well-qualified staff and our many volunteers throughout the nation, CHADD would not be able 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, we ARE creating a social movement on AD/HD. As CHADD continues to make progress in becoming a more inclusive and more professional organization, we also are becoming a major stakeholder in the mental health arena. Achievements are due to the hard work and dedication of the CHADD staff, our volunteers across the nation, our chapter volunteer leaders, and our membership. Thanks to all of you who have contributed to our continued growth.

December 2004