

**BATTEN DISEASE SUPPORT AND
RESEARCH ASSOCIATION**

**REPORT ON AUDIT OF
FINANCIAL STATEMENTS**

**FOR THE YEARS ENDED
APRIL 30, 2004 and 2003**

BATTEN DISEASE SUPPORT AND RESEARCH ASSOCIATION

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INDEPENDENT AUDITOR'S REPORT

The Board of Directors
Batten Disease Support and Research Association

We have audited the accompanying statements of financial position of Batten Disease Support and Research Association as of April 30, 2004 and 2003, and the related statements of activities and changes in net assets, cash flows and functional expenses for the years ended April 30, 2004 and 2003. These financial statements are the responsibility of the Association's management. Our responsibility is to express an opinion on these financial statements based on our audits.

We conducted our audits in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement representation. We believe that our audits provide a reasonable basis for our opinion.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of Batten Disease Support and Research Association as of April 30, 2004 and 2003, and the changes in its net assets and cash flows for the years ended April 30, 2004 and 2003, in conformity with accounting principles generally accepted in the United States of America.

Columbus, Ohio
June 4, 2003

Batten Disease Support and Research Association
Statement of Financial Position
As of April 30, 2004 and 2003

	<u>2004</u>			<u>2003</u>		
	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Total</u>	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Total</u>
Assets:						
Current Assets:						
Cash	\$ 57,172	\$ 95,163	\$ 152,335	\$ 159,627	\$ 22,043	\$ 181,670
Investments (Note 4)	28,919	55,310	84,229	32,535	37,962	70,497
Prepaid Expenses	-	-	-	1,748	-	1,748
Total Current Assets	<u>86,091</u>	<u>150,473</u>	<u>236,564</u>	<u>193,910</u>	<u>60,005</u>	<u>253,915</u>
Property and Equipment (Note 1):						
Equipment	9,145	-	9,145	5,461	-	5,461
Less: Accumulated Depreciation	(853)	-	(853)	(4,994)	-	(4,994)
	<u>8,292</u>	<u>-</u>	<u>8,292</u>	<u>467</u>	<u>-</u>	<u>467</u>
Deposits	350	-	350	350	-	350
Total Assets	<u>\$ 94,733</u>	<u>\$ 150,473</u>	<u>\$ 245,206</u>	<u>\$ 194,727</u>	<u>\$ 60,005</u>	<u>\$ 254,732</u>
Liabilities & Net Assets:						
Current Liabilities:						
Payroll and Associated Taxes	\$ 7,505	\$ -	\$ 7,505	\$ 6,731	\$ -	\$ 6,731
Accrued Expenses	828	-	828	463	-	463
Accounts Payable	-	-	-	8,000	-	8,000
Current Portion of Long-term Debt	2,001	-	2,001	-	-	-
Total Current Liabilities	<u>10,334</u>	<u>-</u>	<u>10,334</u>	<u>15,194</u>	<u>-</u>	<u>15,194</u>
Long-term Debt (Note 5):						
Note Payable	6,064	-	6,064	-	-	-
Total Liabilities	16,398	-	16,398	15,194	-	15,194
Net Assets	<u>78,335</u>	<u>150,473</u>	<u>228,808</u>	<u>179,533</u>	<u>60,005</u>	<u>239,538</u>
Total Liabilities & Net Assets	<u>\$ 94,733</u>	<u>\$ 150,473</u>	<u>\$ 245,206</u>	<u>\$ 194,727</u>	<u>\$ 60,005</u>	<u>\$ 254,732</u>

See Accompanying Notes to Financial Statements

Batten Disease Support and Research Association
Statement of Activities and Changes in Net Assets
For the Years Ended April 30, 2004 and 2003

	<u>Year Ended April 30, 2004</u>			<u>Year Ended April 30, 2003</u>		
	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Total</u>	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Total</u>
Operating Revenue & Support:						
Donations	\$ 145,560	\$ 23,747	\$ 169,307	\$ 77,514	\$ 78,367	\$ 155,881
Dues	3,964	-	3,964	4,570	-	4,570
Grants	270	-	270	1,270	-	1,270
Fundraising	190,159	114,966	305,125	46,972	264,496	311,468
Interest/Dividend Income	1,033	341	1,374	668	1,465	2,133
Other	23	3,289	3,312	131	3,404	3,535
Unrealized Gain (Loss) on Investments	13,731	-	13,731	(14,620)	(14,527)	(29,147)
Net Assets Released from Restrictions	51,875	(51,875)	-	429,489	(429,489)	-
Total Operating Support Revenue	<u>406,615</u>	<u>90,468</u>	<u>497,083</u>	<u>545,994</u>	<u>(96,284)</u>	<u>449,710</u>
Operating Expenses:						
Support Services						
Administration	35,653	-	35,653	48,628	-	48,628
Fund Raising	1,510	-	1,510	5,671	-	5,671
Total Support Services	<u>37,163</u>	<u>-</u>	<u>37,163</u>	<u>54,299</u>	<u>-</u>	<u>54,299</u>
Program Services						
Grants	352,463	-	352,463	343,186	-	343,186
Programs	118,187	-	118,187	99,335	-	99,335
Total Program Services	<u>470,650</u>	<u>-</u>	<u>470,650</u>	<u>442,521</u>	<u>-</u>	<u>442,521</u>
Total Operating Expenses	<u>507,813</u>	<u>-</u>	<u>507,813</u>	<u>496,820</u>	<u>-</u>	<u>496,820</u>
Changes in Net Assets	(101,198)	90,468	(10,730)	49,174	(96,284)	(47,110)
Net Assets, Beginning of the Year	179,533	60,005	239,538	130,359	156,289	286,648
Net Assets, End of the Year	<u><u>\$ 78,335</u></u>	<u><u>\$ 150,473</u></u>	<u><u>\$ 228,808</u></u>	<u><u>\$ 179,533</u></u>	<u><u>\$ 60,005</u></u>	<u><u>\$ 239,538</u></u>

See Accompanying Notes to Financial Statements

Batten Disease Support and Research Association
Statement of Cash Flows
For the Years Ended April 30, 2004 and 2003

	2004	2003
Cash Flows From Operating Activities:		
Change in Net Assets	\$ (10,730)	\$ (47,110)
Adjustments To Reconcile Change In Net Assets		
To Cash (Used) Provided By Operating Activities:		
Depreciation Expense	819	612
Increase In Prepaid Expenses	1,748	(1,748)
(Decrease)/Increase In Accrued Liabilities	1,139	(231)
Increase In Accounts Payable	(8,000)	8,000
Unrealized (Gain) Losses on Investments	(13,731)	16,921
Net Cash Used By Operating Activities	(28,755)	(23,556)
Cash Flow Used By Investing Activities:		
Purchase of Equipment	-	(501)
Net Cash Used By Investing Activities	-	(501)
Cash Flows From Financing Activity:		
Payments on Long-term Debt	(580)	-
Net Cash Used By Financing Activity	(580)	-
Net Increase (Decrease) in Cash	(29,335)	(24,057)
Cash and Cash Equivalents, Beginning of the Year	181,670	205,727
Cash and Cash Equivalents, End of the Year	\$ 152,335	\$ 181,670
CASH FLOWS SUPPLEMENTAL INFORMATION		
Interest Paid	\$ 188	\$ -
Property Acquired Through Note Payable	\$ 8,645	\$ -

See Accompanying Notes to Financial Statements

**Batten Disease Support and Research Association
Statement of Functional Expenses
For the Year Ended April 30, 2004**

	<u>Research</u>	<u>Conference</u>	<u>Sibling</u>	<u>Bereavement</u>	<u>Parent Mentor</u>	<u>Education</u>	<u>Member Services</u>	<u>Total Program Services</u>	<u>Fund Raising</u>	<u>Management and General</u>	<u>Total Expenses</u>
Payroll and Related Taxes	\$ -	\$ 962	\$ 69	\$ 1,849	\$ 2,420	\$ 493	\$ 70,277	\$ 76,070	\$ 1,497	\$ 17,608	\$ 95,175
Conference Stipend	-	8,091	-	-	-	-	5,000	13,091	-	-	13,091
Board Travel	-	-	-	-	-	-	-	-	-	427	427
Travel Expenses	1,185	504	182	-	-	706	2,511	5,088	-	1,862	6,950
Fees/Dues	177	-	-	-	-	-	-	177	-	423	600
Rent	-	-	-	-	-	-	3,564	3,564	-	1,836	5,400
Office Supplies	-	50	-	-	-	27	1,320	1,397	-	1,021	2,418
Depreciation	-	-	-	-	-	-	-	-	-	819	819
Telephone	62	56	-	95	1,215	37	1,993	3,458	-	665	4,123
Equipment	-	-	-	65	-	-	1,568	1,633	-	1,010	2,643
Printing	-	-	-	876	-	-	136	1,012	-	300	1,312
Postage	23	7	-	-	-	352	1,279	1,661	11	1,663	3,335
Professional Fees	1,374	-	-	-	-	500	1,046	2,920	-	7,580	10,500
Special Projects	-	-	-	336	-	-	2,049	2,385	-	-	2,385
Insurance	-	-	-	-	-	-	-	-	-	1,899	1,899
Reimbursements	-	-	258	-	11	-	-	269	-	-	269
Other Conferences	-	-	790	-	-	466	-	1,256	-	-	1,256
Research Awards	352,367	-	-	-	-	-	96	352,463	-	-	352,463
Fund Raising Expense	838	-	-	-	-	-	-	838	-	-	838
Memorial	-	-	-	-	-	-	1,640	1,640	-	-	1,640
Contingent Liability	-	-	-	-	-	-	-	-	-	(2,000)	(2,000)
Miscellaneous	215	188	329	679	-	2	315	1,728	2	540	2,270
Total Expenses	\$ 356,241	\$ 9,858	\$ 1,628	\$ 3,900	\$ 3,646	\$ 2,583	\$ 92,794	\$ 470,650	\$ 1,510	\$ 35,653	\$ 507,813

See Accompanying Notes to Financial Statements

Batten Disease Support and Research Association
Statement of Functional Expenses
For the Year Ended April 30, 2003

	<u>Research</u>	<u>Conference</u>	<u>Sibling</u>	<u>Bereavement</u>	<u>Parent Mentor</u>	<u>Education</u>	<u>Member Services</u>	<u>Total Program Services</u>	<u>Fund Raising</u>	<u>Management and General</u>	<u>Total Expenses</u>
Payroll and Related Taxes	\$ -	\$ 2,663	\$ 711	\$ 2,170	\$ 1,170	\$ 325	\$ 36,158	\$ 43,197	\$ 2,233	\$ 15,664	\$ 61,094
Conference Stipend	-	7,900	-	-	-	-	-	7,900	-	-	7,900
Conference Expense	-	175	-	-	-	-	-	175	-	-	175
Board Travel	-	-	-	-	-	-	-	-	-	237	237
Travel Expenses	-	-	184	-	-	-	1,006	1,190	156	550	1,896
Fees/Dues	-	-	-	-	-	75	150	225	-	273	498
Rent	-	-	-	-	-	-	2,828	2,828	-	1,122	3,950
Office Supplies	-	50	218	88	-	-	1,450	1,806	-	586	2,392
Printing	-	-	-	775	-	1,274	330	2,379	94	483	2,956
Depreciation	-	-	-	-	-	-	-	-	-	612	612
Telephone	-	27	-	22	1,194	7	477	1,727	-	2,619	4,346
Equipment	-	-	-	-	-	-	796	796	-	1,243	2,039
Postage	-	8	7	238	-	357	1,004	1,614	11	2,167	3,792
Professional Fees	751	-	-	-	-	10,000	-	10,751	-	7,580	18,331
Insurance	-	-	-	-	-	-	-	-	-	6,746	6,746
Other Conferences	-	-	-	-	-	-	618	618	-	-	618
Flowers/Cards	-	-	-	1,931	-	-	-	1,931	-	-	1,931
Meal & Entertainment	-	-	379	-	-	-	-	379	-	515	894
Research Awards	343,186	-	-	-	-	-	-	343,186	-	-	343,186
Equipment Exchange	-	-	-	-	-	-	105	105	-	-	105
Nurse on Staff	-	-	-	-	-	-	21,501	21,501	-	-	21,501
Contingent Liability	-	-	-	-	-	-	-	-	2,500	8,000	10,500
Promotional Supplies	-	-	-	-	-	-	-	-	675	-	675
Miscellaneous	-	-	-	2	-	103	108	213	2	231	446
Total Expenses	\$ 343,937	\$ 10,823	\$ 1,499	\$ 5,226	\$ 2,364	\$ 12,141	\$ 66,531	\$ 442,521	\$ 5,671	\$ 48,628	\$ 496,820

See Accompanying Notes to Financial Statements

BATTEN DISEASE SUPPORT AND RESEARCH ASSOCIATION
Notes to Financial Statements

NOTE 1 - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES
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A. Operations

The Association was created on July 15, 1987 in Spanaway, Washington. Currently, the Association is based in Columbus, Ohio, the home of the current Executive Director. The Executive Director manages the day-to-day activities and is paid a salary. A Board of Directors and sub-committees assist the Executive Director and provides leadership and direction to the Association. In addition, a network of volunteers assists the Executive Director in maintaining the operations of the Association.

B. Basis of Accounting

The Association accounts are maintained on the accrual basis of accounting. Capital expenditures in excess of \$500 are capitalized and depreciated over their useful life using tax methods of depreciation.

C. Estimates

The preparation of financial statements in conformity with generally accepted accounting principles requires management to make estimates and assumptions that affect certain reported amounts and disclosures. Accordingly, actual results may differ from these estimates.

D. Cash Equivalents

The Association considers all highly liquid investments with maturities of three months or less when purchased, including certificates of deposit, to be cash equivalents. The Association's cash is held at one financial institution. At April 30, 2004 and 2003, the cash balance in the Association's accounts exceeded federally insured limits by \$56,681 and \$82,748, respectively.

BATTEN DISEASE SUPPORT AND RESEARCH ASSOCIATION
Notes to Financial Statements

NOTE 1 - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (continued)
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E. Financial Statement Presentation

The Association has adopted Statement of Financial Accounting Standards (SFAS) No. 117, "Financial Statements for Not-for-Profit Organizations." Under SFAS No. 117, the Association is required to report information regarding its financial position and activities according to three classes of net assets: unrestricted, temporarily restricted, and permanently restricted net assets. There were no permanently restricted net assets at April 20, 2004 and 2003.

Donor-restricted funds are used to differentiate the resources whose use is restricted by donors or grantors from resources on which donors or grantors have placed no restrictions and the resources that arise as a result of the operations of the entity for its stated purpose. Restricted funds received in a year and completely expended before the end of the year are classified as unrestricted revenues and expenses.

F. Association Mission

The Association's mission is to 1) promote the civil and human rights of persons with Batten Disease, 2) maximize the opportunities of persons with Batten Disease through medical, educational, vocational, habitational, and financial means in order to ensure these persons lead lives as normal as possible, 3) educate lay persons and professionals as to the special needs of persons with Batten Disease, as well as their families, 4) assist by providing information and referral services to secure benefits available by law, 5) provide technical assistance and emotional support to families with Batten Disease and to provide research information as it is developed, and 6) promote research on Batten Disease.

G. Association Vision

The Association pioneers concepts designed to improve the health of persons with Batten Disease through investing in programs and services that will achieve measurable results.

H. Expense Allocation

Directly identifiable expenses are charged to programs and supporting services. Expenses related to more than one function are charged to programs and supporting services on the basis of time and expense studies. Management and general expenses include those expenses that are not directly identifiable with any other specific function but provide for the overall support and direction of the Organization.

BATTEN DISEASE SUPPORT AND RESEARCH ASSOCIATION
Notes to Financial Statements

NOTE 1 - SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES (continued)

I. Income Taxes

The Association is exempt from federal income tax under Section 501(c)(3) of the Internal Revenue Code, and therefore has made no provisions for Federal income taxes in the accompanying financial statements.

NOTE 2 - OPERATING LEASE

The Association leases office space on a month-to-month basis. The lease calls for payments of \$450 each month.

NOTE 3 – RESTRICTIONS ON NET ASSETS

The April 30, 2004 restricted cash balance of \$95,163 is comprised of donations received by the Association for specific uses. The Association has cash in the amount of \$15,568 restricted for the siblings of persons with Batten Disease and \$79,595 restricted for stipends for participants to attend the Association's annual conference.

The April 30, 2003 restricted cash balance of \$22,043 is comprised of donations received by the Association for specific uses. The Association has cash in the amount of \$12,043 restricted for the siblings of persons with Batten Disease and \$10,000 restricted for stipends for participants to attend the Association's annual conference.

The Association has received donations that have been restricted, by the donors, as to how the Association may expend these funds. Currently the majority of the cash funds held by the Association are to be spent on research relative to Batten Disease. The Association has developed a system to control and expend restricted funds. The restricted investments were derived to generate income to be used for general and administrative purposes. The Association may liquidate the investments as deemed necessary by the Board of Directors.

The Association sends notifications to the medical and research communities as to the availability of these funds. Interested parties submit grant requests detailing the research they are focusing on and how they would utilize the grant if it were awarded to them. A committee reviews each of the grant requests and funds are disbursed based on this review. The Association receives updates as to the progress of the research to ensure that the granted funds were utilized as the recipient indicated that they would.

BATTEN DISEASE SUPPORT AND RESEARCH ASSOCIATION
Notes to Financial Statements

NOTE 4 - INVESTMENTS

The Association has adopted SFAS No. 124, Accounting for Certain Investments Held by Not-for-Profit Organizations. Under SFAS No. 124, investments in marketable securities with readily determinable fair values and all investments in debt securities are reported at their fair values in the statement of financial position. Unrealized gains and losses are included in the change in net assets. Investment income and gains restricted by a donor are reported as increases in unrestricted net assets if the restrictions are met (either by passage of time or by use) in the reporting period in which the income and gains are recognized.

The fair market value of the Association's investments is based on quoted market prices as of April 30, 2004 and 2003.

NOTE 5 – LONG-TERM DEBT

The Association entered into a note agreement with a financial institution on December 8, 2003, for \$8,720 to purchase a copier for the Association. The note is repayable in forty-seven (47) payments of principal and interest of \$120 monthly. Interest is accrued at a fixed rate of 7.34%.

Scheduled debt maturities are as follows for the year ending December 31:

2005	\$2,001
2006	2,153
2007	2,317
2008	<u>1,594</u>
Total	8,065
Less: Current Portion	<u>(2,001)</u>
Total Long-term Portion	<u>\$6,064</u>