

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Financial Statements
December 31, 2012**

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March 15, 2013

INDEPENDENT AUDITORS' REPORT

To The Board of Directors
Dystrophic Epidermolysis Bullosa
Research Association of America, Inc.

We have audited the accompanying financial statements of Dystrophic Epidermolysis Bullosa Research Association of America, Inc. (a nonprofit organization), which comprise the statement of financial positions as of December 31, 2012 and 2011, and the related statements of activities, functional expenses and cash flows for the years then ended, and the related notes to the financial statements.

Management's Responsibility for the Financial Statements

Management is responsible for the preparation and fair presentation of these financial statements in accordance with accounting principles generally accepted in the United States of America; this includes the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

Auditor's Responsibility

Our responsibility is to express an opinion on these financial statements based on our audit. We conducted our audit 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 involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgement, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or errors. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Opinion

In our opinion, the financial statements referred to above present fairly, in all material respects the financial position of Dystrophic Epidermolysis Bullosa Research Association of America, Inc. as of December 31, 2012, and the changes in its net assets and its cash flows for the years then ended in accordance with accounting principles generally accepted in the United States of America.



STUDLEY, WHITE & ASSOCIATES, P.C.

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Statements of Financial Position
December 31,**

	2012	2011
Assets		
Cash and cash equivalents	\$ 482,210	\$ 311,411
Investments	542,067	539,461
Accounts receivable	131,789	55,166
Prepaid expenses	5,047	-
Equipment, net	4,796	4,130
Security deposit	21,248	21,248
Total Assets	\$ 1,187,157	\$ 931,416
 Liabilities and Net Assets		
<u>Liabilities:</u>		
Accounts payable	\$ 21,140	\$ 7,068
Research grants payable	150,000	-
Deferred revenue	-	13,000
Total Liabilities	171,140	20,068
<u>Net Assets:</u>		
Unrestricted - net assets	911,964	786,262
Temporarily Restricted Net Assets	104,053	125,086
Total Net Assets	1,016,017	911,348
Total Liabilities and Net Assets	\$ 1,187,157	\$ 931,416

See independent auditors' report and accompanying notes to these financial statements.

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Statements of Activities
For the Years Ended December 31,**

	<u>2012</u>	<u>2011</u>
Unrestricted Net Assets		
<u>Revenues and Other Support:</u>		
Special events - revenue	\$ 410,552	\$ 189,106
- expenses	(290,815)	(125,822)
- net	119,737	63,284
Contributions and grants	948,110	719,454
In-kind revenue	32,943	84,021
Investment income	2,892	788
Other	-	3,707
Total Unrestricted Revenues and Other Support	1,103,682	871,254
Net Assets Released from Restrictions	116,711	(15,001)
Total Revenues and Other Support	1,220,393	856,253
<u>Expenses</u>		
<u>Program Services</u>		
Public and professional education	147,880	134,323
Patient and family services	500,010	443,018
Advocacy	22,182	20,150
Research	313,709	67,164
Total Program Services	983,781	664,655
<u>Support Services</u>		
Management and general	36,970	33,576
Fund raising	73,939	82,164
Total Support Services	110,909	115,740
Total Expenses	1,094,690	780,395
Increase (Decrease) on Unrestricted Net Assets	125,703	75,858
Temporarily Restricted Net Assets:		
Contributions	95,677	16,607
Net assets released from restrictions	(116,711)	(15,001)
Increase (decrease) in temporarily restricted net assets	(21,034)	1,606
Increase (Decrease) in Net Assets	104,669	77,464
Net Assets, January 1,	911,348	833,884
Net Assets, December 31,	\$ 1,016,017	\$ 911,348

See independent auditors' report and accompanying notes to these financial statements.

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Statements of Cash Flows
For the Years Ended December 31,**

	2012	2011
Cash Flows from Operating Activities:		
Increase (Decrease) in net assets	\$ 104,669	\$ 77,464
Adjustments to reconcile increase (decrease) in net assets to net cash provided by operating activities:		
Add: Depreciation	5,006	3,599
	109,675	81,063
Changes in assets and liabilities:		
(Increase) decrease in:		
Accounts receivable	(76,623)	(7,830)
Prepaid expense	(5,047)	-
	(81,670)	(7,830)
Increase (decrease) in:		
Accounts payable and accrued expenses	14,072	(48,280)
Deferred revenue	(13,000)	13,000
Research grant payable	150,000	-
	151,072	(35,280)
Net cash provided (used) by operating activities	179,077	37,953
Cash Flows from Investing Activities:		
Sale (purchase) of investments	(2,634)	(4,727)
Net cash provided by investing activities	(2,634)	(4,727)
Cash Flows from Financing Activities:		
Purchase of fixed assets	(5,674)	(1,419)
Net cash used by financing activities	(5,674)	(1,419)
Net increase (decrease) in cash	170,769	31,807
Cash at beginning of year	311,441	279,634
Cash at end of year	\$ 482,210	\$ 311,441

See independent auditors' report and accompanying notes to these financial statements.

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Statement of Functional Expenses
For the Year Ended December 31, 2012**

	Public and Professional Education	Patient and Family Services	Advocacy	Research	Total	Management and General	Fund Raising	Total	Total Expenses
Salaries	\$ 61,190	\$ 159,093	\$ 9,178	\$ 30,595	\$ 260,056	\$ 15,297	\$ 30,595	\$ 45,892	\$ 305,948
Payroll taxes	5,568	14,477	835	2,784	23,664	1,392	2,784	4,176	27,840
Fringe benefits	4,222	10,976	633	2,111	17,942	1,055	2,111	3,166	21,108
Professional fees	7,458	19,391	1,119	3,729	31,697	1,864	3,729	5,593	37,290
Telephone	1,892	4,920	284	946	8,042	473	946	1,419	9,461
Office supplies	1,631	4,242	245	816	6,934	408	816	1,224	8,158
Insurance	1,936	5,033	290	968	8,227	484	968	1,452	9,679
Equipment maintenance	794	2,064	119	397	3,374	199	397	596	3,970
Postage	4,002	10,404	600	2,001	17,007	1,000	2,001	3,001	20,008
Travel	9,477	24,641	1,422	4,739	40,279	2,369	4,739	7,108	47,387
Printing	3,528	9,174	529	1,764	14,995	882	1,764	2,646	17,641
Research Grant	-	-	-	239,768	239,768	-	-	-	239,768
Assistance	-	115,523	-	-	115,523	-	-	-	115,523
Dues and subscriptions	1,361	3,540	204	681	5,786	340	681	1,021	6,807
Fees	1,937	5,035	290	968	8,230	484	969	1,453	9,683
In-kind expense	6,589	17,130	988	3,295	28,002	1,647	3,294	4,941	32,943
Advertising	12,877	33,480	1,932	6,439	54,728	3,219	6,439	9,658	64,386
Bank charges	301	782	45	150	1,278	75	150	225	1,503
Equipment	2,094	5,443	314	1,047	8,898	523	1,047	1,570	10,468
Interest expense	5	13	1	3	22	1	3	4	26
Depreciation expense	1,000	2,605	150	501	4,256	250	500	750	5,006
Miscellaneous	823	2,136	125	409	3,493	209	408	617	4,110
Rent	19,195	49,908	2,879	9,598	81,580	4,799	9,598	14,397	95,977
Total Expenses before Fund Raising	147,880	500,010	22,182	313,709	983,781	36,970	73,939	110,909	1,094,690
Special Events	-	-	-	-	-	-	290,815	290,815	290,815
Total Expenses	\$ 147,880	\$ 500,010	\$ 22,182	\$ 313,709	\$ 983,781	\$ 36,970	\$ 364,754	\$ 401,724	\$ 1,385,505

See independent auditors' report and accompanying notes to these financial statements.

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Statement of Functional Expenses
For the Year Ended December 31, 2011**

	PROGRAM SERVICES					SUPPORT SERVICES			
	Public and Professional Education	Patient and Family Services	Advocacy	Research	Total	Management and General	Fund Raising	Total	Total Expenses
Salaries	\$ 55,543	\$ 144,412	\$ 8,331	\$ 27,771	\$ 236,057	\$ 13,886	\$ 27,771	\$ 41,657	\$ 277,714
Payroll taxes	4,911	12,770	737	2,456	20,874	1,228	2,456	3,684	24,558
Fringe benefits	3,936	10,233	590	1,968	16,727	984	1,968	2,952	19,679
Professional fees	7,139	18,562	1,071	3,570	30,342	1,785	3,570	5,355	35,697
Telephone	1,972	5,128	296	986	8,382	493	986	1,479	9,861
Office supplies	1,262	3,280	189	631	5,362	315	631	946	6,308
Insurance	1,599	4,158	240	800	6,797	400	800	1,200	7,997
Equipment maintenance	1,457	3,789	219	729	6,194	364	729	1,093	7,287
Postage	3,874	10,072	581	1,937	16,464	968	1,937	2,905	19,369
Travel	3,106	8,075	466	1,553	13,200	776	1,553	2,329	15,529
Printing	4,129	10,736	619	2,065	17,549	1,032	2,065	3,097	20,646
Assistance	-	93,777	-	-	93,777	-	-	-	93,777
Dues and subscriptions	1,496	3,888	224	748	6,356	374	748	1,122	7,478
Fees	210	546	32	105	893	53	105	158	1,051
In-kind expense	16,804	43,691	2,521	8,402	71,418	4,201	8,402	12,603	84,021
Advertising	5,272	13,706	791	2,636	22,405	1,318	2,636	3,954	26,359
Bank charges	577	1,501	87	289	2,454	144	289	433	2,887
Equipment	1,259	3,273	189	629	5,350	315	629	944	6,294
Bad debt	-	-	-	-	-	-	15,000	15,000	15,000
Depreciation expense	720	1,871	108	360	3,059	180	360	540	3,599
Miscellaneous	479	1,247	72	240	2,038	115	240	355	2,393
Occupancy	18,578	48,303	2,787	9,289	78,957	4,645	9,289	13,934	92,891
Total Expenses before Fund Raising	134,323	443,018	20,150	67,164	664,655	33,576	82,164	115,740	780,395
Special Events	-	-	-	-	-	-	125,822	125,822	125,822
Total Expenses	\$ 134,323	\$ 443,018	\$ 20,150	\$ 67,164	\$ 664,655	\$ 33,576	\$ 207,986	\$ 241,562	\$ 906,217

See independent auditors' report and accompanying notes to these financial statements.

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Notes to Financial Statements
December 31, 2012**

Note 1 - Summary of Significant Accounting Policies

General

The Dystrophic Epidermolysis Bullosa Research Association of America, Inc. (D.E.B.R.A.) was incorporated as a not-for-profit, publicly supported corporation on January 24, 1980 under the laws of the State of New York. D.E.B.R.A. was formed to promote and support research regarding dystrophic epidermolysis bullosa, and to disseminate information to, and serve as an advocate for, those afflicted with this disease as well as their families, the general public and health professionals.

Basis of Accounting

The Organization prepares its financial statements on the accrual basis of accounting in accordance with generally accepted accounting principles.

The presentation of financial statements follows the recommendations of the Financial Accounting Standards Board's Accounting Standards Codification 958 (SFAS No. 117), "*Financial Statements of Not-for-Profit Organizations*". Under Codification 958, the Organization is required to report information regarding its financial position and activities according to three classes of net assets: Unrestricted Net Assets, Temporarily Restricted Net Assets, and Permanently Restricted Net Assets. At December, 31, 2011, the Organization had no temporarily restricted assets and \$10,918 in permanently restricted net assets.

Use of Estimates

The preparation of financial statements in conformity with generally accepted accounting principles requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities and disclosures of contingent assets and liabilities at the date of the financial statements. They also affect the reported amounts of revenues and expenses during the reporting period. Actual results could differ from those estimates.

Property and Equipment

All expenditures for equipment in excess of \$1,000 are capitalized and depreciation is provided over the estimated useful lives of the assets. Estimated useful lives of the assets range from 3 to 7 years.

Cash and Cash Equivalents

For financial statement purposes, D.E.B.R.A. considers funds in demand deposits, certificates of deposits, money market funds and all highly liquid debt instruments purchased with a maturity of three months or less to be cash equivalents.

See independent auditors' report.

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Notes to Financial Statements
December 31, 2012**

Note 1 - Summary of Significant Accounting Policies (Continued)

Income Taxes

The Dystrophic Epidermolysis Bullosa Research Association of America, Inc. is exempt from income taxes under Section 501(c)(3) of the Internal Revenue Code. The Internal Revenue Service has also determined that it is not a private foundation in accordance with Section 170(b)(1)(A)(IV) of the Internal Revenue Code.

Functional Expenses

Functional expenses have been allocated between program services and supporting services based on an analysis of personnel time and space utilized for the related activities.

Compensated Absences

Dystrophic Epidermolysis Bullosa Research Association of America, Inc.'s accounting for compensated absences conforms to generally accepted accounting principles and recognizes vacation pay when earned. Accrued vacation was \$0 at December 31, 2012 and December 31, 2011.

Investments

Investments in equity securities with readily determinable fair market values and all investments in debt securities are reported at fair value with gains and losses included in the statement of activities. If received as a donation, the investment is stated at fair value at the date of donation.

Reclassifications

Certain accounts in the prior-year financial statements have been reclassified for comparative purposes to conform with the presentation in the current-year financial statements.

Note 2 - Equipment, Net

Equipment, net is summarized as follows:

	<u>December 31, 2012</u>	<u>December 31, 2011</u>
Equipment	\$ 26,440	\$ 20,766
Less accumulated depreciation	(21,644)	(16,636)
Property and equipment, net	<u>\$ 4,796</u>	<u>\$ 4,130</u>

See independent auditors' report.

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Notes to Financial Statements
December 31, 2012**

Note 3 – Investments

Investments at December 31, 2012 and 2011 were comprised of the following:

	Fair Value	
	December 31, 2012	December 31, 2011
Money market funds	\$ 542,067	\$ 539,461

Investment income is comprised of the following at December 31:

	December 31, 2012	December 31, 2011
	Dividends and interest	\$ 1,682
Realized and unrealized gains (losses)	1,210	296
	\$ 2,892	\$ 788

Note 4 - Operating Leases

The Agency rents its office facilities under a non cancellable operating lease. The lease term expires October 30, 2013. Minimum future lease payments under non cancellable leases as of December 31, 2012 are as follows:

December 31, 2014	\$ 70,828
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Note 5 – Research Grant Payable

Dystrophic Epidermolysis Bullosa Research Association of America, Inc. has pledged \$200,000 to the Minnesota Medical Foundation to fund research to find a cure for Epidermolysis Bullosa, \$50,000 is to be paid in 2013 and the balance of \$100,000 is due in 2014.

Note 6 - Donated Services, Materials, Facilities

The Agency receives donated services and medical supplies of approximately \$318,000 from a variety of unpaid volunteers. The medical supplies were distributed directly to the families of children afflicted with the disease. No amounts have been recognized in the accompanying statement of activities because the criteria for recognition of such volunteer effort under SFAS No. 116 have not been satisfied. The contributions of services are recognized if the services received (a) create or enhance nonfinancial assets or (b) require specialized skills that are provided by individuals possessing those skills and would typically need to be purchased if not provided by donation. The value of donated legal services was \$32,943 for the year ended December 31, 2012 and \$84,021 for the year ended December 31, 2011.

See independent auditors' report.

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Notes to Financial Statements
December 31, 2012**

Note 7 – Temporarily Restricted Net Assets

The Agency has received funds from E.B. support groups, corporations, and individuals who have designated their funds to a specific program or purpose. These funds are to be used for the education and outreach programs of local support groups, Family Crisis Fund, Wound Care, Nurse Assistance, New Family Advocate Program, Research, and the dissemination of information concerning the disease E.B. Temporarily restricted net assets were as follows:

	<u>December 31, 2012</u>	<u>December 31, 2011</u>
Programs and E. B. Support Groups	\$ 104,053	\$ 125,086

Note 8 – Fair Value of Financial Instruments

In accordance with ASC 820, the Agency is required to measure the fair value of its assets and liabilities under a three-level hierarchy, as follows:

Level 1: Quoted market prices for identical assets or liabilities to which an entity has access at the measurement date.

Level 2: Inputs and information other than quoted market indices included in Level 1 that are observable for the asset or liability, either directly or indirectly.

Level 3: Unobservable inputs for the assets or liability. Unobservable inputs should be used to measure the fair value to the extent that observable inputs are not available.

The carrying amounts reflected in the accompanying statements of financial position for cash and cash equivalents and investments approximate their respective fair values due to the short maturities of those instruments.

Note 8 – Subsequent Events

The date at which events occurring after December 31, 2012, the date of the most recent balance sheet, have been evaluated for possible adjustment to the financial statements on disclosure is March 15, 2013, which is the date on which the financial statements were available to be issued

See independent auditors' report.