

Dystrophic Epidermolysis Bullosa  
Research Association of America, Inc.

Financial Statements

December 31, 2013 and December 31, 2012

**Studley - White, P.C.**

ACCOUNTING - TAX - AUDITING - CONSULTING

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**DYSTROPHIC EPIDERMOLYSIS BULLOSA  
RESEARCH ASSOCIATION OF AMERICA, INC.  
Financial Statements  
December 31, 2013**

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March 20, 2014

## 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, 2013 and 2012, 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, 2013, 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.

A handwritten signature in blue ink that reads "Studley White P.C." in a cursive style.

STUDLEY - WHITE, P.C.

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

	<b>2013</b>	<b>2012</b>
<b>Assets</b>		
Cash and cash equivalents	\$ 733,017	\$ 482,210
Investments	544,783	542,067
Accounts receivable	211,259	131,789
Prepaid expenses	10,576	5,047
Equipment, net	26,914	4,796
Security deposit	21,248	21,248
<b>Total Assets</b>	<b>\$ 1,547,797</b>	<b>\$ 1,187,157</b>
<b>Liabilities and Net Assets</b>		
<u>Liabilities:</u>		
Accounts payable	\$ 27,893	\$ 21,140
Research grants payable	100,000	150,000
<b>Total Liabilities</b>	<b>127,893</b>	<b>171,140</b>
<u>Net Assets:</u>		
Unrestricted - net assets	1,310,790	911,964
Temporarily Restricted Net Assets	109,114	104,053
<b>Total Net Assets</b>	<b>1,419,904</b>	<b>1,016,017</b>
<b>Total Liabilities and Net Assets</b>	<b>\$ 1,547,797</b>	<b>\$ 1,187,157</b>

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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,**

	<b>2013</b>	<b>2012</b>
<b>Unrestricted Net Assets</b>		
<u>Revenues and Other Support:</u>		
Special events - revenue	\$ 758,470	\$ 410,552
- expenses	(136,420)	(290,815)
- net	622,050	119,737
Contributions and grants	716,217	948,110
In-kind revenue	370,269	32,943
Investment income	3,917	2,892
Other	11,886	-
Total Unrestricted Revenues and Other Support	1,724,339	1,103,682
Net Assets Released from Restrictions	36,556	116,711
<b>Total Revenues and Other Support</b>	<b>1,760,895</b>	<b>1,220,393</b>
<u>Expenses</u>		
<u>Program Services</u>		
Public and professional education	167,613	147,880
Patient and family services	908,129	500,010
Advocacy	25,142	22,182
Research	97,236	313,709
Total Program Services	1,198,120	983,781
<u>Support Services</u>		
Management and general	41,905	36,970
Fund raising	122,044	73,939
Total Support Services	163,949	110,909
<b>Total Expenses</b>	<b>1,362,069</b>	<b>1,094,690</b>
<b>Increase (Decrease) on Unrestricted Net Assets</b>	<b>398,826</b>	<b>125,703</b>
<b>Temporarily Restricted Net Assets:</b>		
Contributions	41,617	95,677
Net assets released from restrictions	(36,556)	(116,711)
<b>Increase (decrease) in temporarily restricted net assets</b>	5,061	(21,034)
<b>Increase (Decrease) in Net Assets</b>	<b>403,887</b>	<b>104,669</b>
<b>Net Assets, January 1,</b>	<b>1,016,017</b>	<b>911,348</b>
<b>Net Assets, December 31,</b>	<b>\$ 1,419,904</b>	<b>\$ 1,016,017</b>

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,**

	<b>2013</b>	<b>2012</b>
<b>Cash Flows from Operating Activities:</b>		
Increase in net assets	\$ 403,887	\$ 104,669
Adjustments to reconcile increase in net assets to net cash provided by operating activities:		
Add: Depreciation	4,139	5,006
	408,026	109,675
<b>Changes in assets and liabilities:</b>		
(Increase) decrease in:		
Accounts receivable	(79,470)	(76,623)
Prepaid expense	(5,529)	(5,047)
	(84,999)	(81,670)
Increase (decrease) in:		
Accounts payable and accrued expenses	6,752	14,072
Deferred revenue	-	(13,000)
Research grant payable	(50,000)	150,000
	(43,248)	151,072
<b>Net cash provided (used) by operating activities</b>	<b>279,779</b>	<b>179,077</b>
<b>Cash Flows from Investing Activities:</b>		
Sale (purchase) of investments	(4,954)	(2,634)
<b>Net cash provided by investing activities</b>	<b>(4,954)</b>	<b>(2,634)</b>
<b>Cash Flows from Financing Activities:</b>		
Purchase of fixed assets	(24,018)	(5,674)
<b>Net cash used by financing activities</b>	<b>(24,018)</b>	<b>(5,674)</b>
<b>Net increase (decrease) in cash</b>	<b>250,807</b>	<b>170,769</b>
Cash at beginning of year	482,210	311,441
<b>Cash at end of year</b>	<b>\$ 733,017</b>	<b>\$ 482,210</b>

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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, 2013**

	Management and Fund					Total Expenses		
	Public and Professional Education	Patient and Family Services	Advocacy	Research	General		Raising	
Salaries	\$ 75,103	\$ 195,267	\$ 11,265	\$ 37,551	\$ 18,776	\$ 37,551	\$ 56,327	\$ 375,513
Payroll taxes	6,775	17,614	1,016	3,387	1,694	3,387	5,081	33,873
Fringe benefits	7,719	20,070	1,158	3,860	1,930	3,860	5,790	38,597
Professional fees	3,136	8,154	470	1,568	784	1,568	2,352	15,680
Telephone	2,190	5,694	329	1,095	548	1,095	1,643	10,951
Office supplies	4,650	12,089	697	2,325	1,162	2,325	3,487	23,248
Insurance	1,824	4,741	274	912	456	912	1,368	9,119
Equipment maintenance	879	2,284	132	439	220	439	659	4,393
Postage	2,783	7,235	417	1,391	696	1,391	2,087	13,913
Travel	13,357	34,729	2,004	6,679	3,339	6,679	10,018	66,787
Printing	9,614	24,997	1,442	4,807	2,404	4,807	7,211	48,071
Research Grant				13,430	13,430		-	13,430
Assistance		123,315						123,315
Dues and subscriptions	3,486	9,064	523	1,743	872	1,743	2,615	17,431
Fees	2,579	6,706	387	1,290	645	1,290	1,935	12,897
In-kind legal services	4,286	11,143	643	2,143	1,071	2,143	3,214	21,429
In-kind medical supplies		349,021						349,021
Advertising	4,904	12,751	736	2,452	1,226	2,452	3,678	24,521
Bank charges	468	1,218	70	234	117	234	351	2,341
Equipment	1,936	5,034	290	968	484	968	1,452	9,680
Baf debts						38,422	38,422	38,422
Interest expense	24	63	4	12	6	12	18	121
Depreciation expense	828	2,152	124	414	207	414	621	4,139
Miscellaneous	3,094	8,046	464	1,547	774	1,363	2,137	15,288
Rent	17,978	46,742	2,697	8,989	4,494	8,989	13,483	89,889
Total Expenses before Fund Raising	167,613	908,129	25,142	97,236	41,905	122,044	163,949	1,362,069
Special Events	-	-	-	-	-	136,420	136,420	136,420
Total Expenses	\$ 167,613	\$ 908,129	\$ 25,142	\$ 97,236	\$ 41,905	\$ 258,464	\$ 300,369	\$ 1,498,489

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.  
Notes to Financial Statements  
December 31, 2013**

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**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, 1979 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, 2013, the Organization had temporarily restricted assets of \$109,114 and no 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.

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See independent auditors' report.

**DYSTROPHIC EPIDERMOLYSIS BULLOSA  
RESEARCH ASSOCIATION OF AMERICA, INC.**

**Notes to Financial Statements**

**December 31, 2013**

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**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, 2013 and December 31, 2012.

***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, 2013</u>	<u>December 31, 2012</u>
Equipment	\$ 33,350	\$ 26,440
Less accumulated depreciation	(6,436)	(21,644)
Property and equipment, net	<u>\$ 26,914</u>	<u>\$ 4,796</u>

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See independent auditors' report.

**DYSTROPHIC EPIDERMOLYSIS BULLOSA  
RESEARCH ASSOCIATION OF AMERICA, INC.  
Notes to Financial Statements  
December 31, 2013**

**Note 3 – Investments**

Investments at December 31, 2013 and 2012 were comprised of the following:

	Fair Value	
	December 31, 2013	December 31, 2012
Money market funds	\$ 544,783	\$ 542,067

Investment income is comprised of the following at December 31:

	December 31, 2013	December 31, 2012
Dividends and interest	\$ 1,317	\$ 1,682
Realized and unrealized gains (losses)	2,600	1,210
	\$ 3,917	\$ 2,892

**Note 4 - Operating Leases**

The Agency entered into a lease agreement for office space in June 2013. The term of the lease is for 124 months and expires April 30, 2024. Lease payments for the next five years are as follows:

December 31, 2014	\$ 67,920
2015	69,448
2016	71,011
2017	72,609
2018	74,242
	\$ 355,230

**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 was paid in 2013 and 2012. The balance of \$100,000 is due in 2014.

**Note 6 - Donated Services, Materials, Facilities**

The Agency receives donated services from a variety of unpaid volunteers. No amounts have been recognized in the accompanying statement of activities because the criteria for recognition of such volunteer effort under ASC 958 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 \$21,248 for the year ended December 31, 2013 and \$32,943 for the year ended December 31, 2012. The value of donated medical supplies was \$349,021 for the year ended December 31, 2013. The medical supplies were distributed directly to the families of children afflicted with the disease.

See independent auditors' report.

**DYSTROPHIC EPIDERMOLYSIS BULLOSA  
RESEARCH ASSOCIATION OF AMERICA, INC.  
Notes to Financial Statements  
December 31, 2013**

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**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,</u> <u>2013</u>	<u>December 31,</u> <u>2012</u>
Programs and E. B. Support Groups	\$ 109,114	\$ 104,053

**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, 2013, the date of the most recent balance sheet, have been evaluated for possible adjustment to the financial statements on disclosure is March 20, 2014, which is the date on which the financial statements were available to be issued.