

Dystrophic Epidermolysis Bullosa  
Research Association of America, Inc.

Financial Statements

December 31, 2014 and December 31, 2013

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

ACCOUNTING - TAX - AUDITING - CONSULTING

**DYSTROPHIC EPIDERMOLYSIS BULLOSA  
RESEARCH ASSOCIATION OF AMERICA, INC.  
Financial Statements  
December 31, 2014**

---

**Table of Contents**

	<b><u>Page</u></b>
Independent Auditor's Report.....	1 - 2
<b>Financial Statements:</b>	
Statements of Financial Position at December 31, 2014 and 2013 .....	3
Statements of Activities for the Years Ended December 31, 2014 and 2013.....	4
Statements of Cash Flows for the Years Ended December 31, 2014 and 2013 .....	5
Statement of Functional Expenses for the Years Ended December 31, 2014 and 2013 .....	6 - 7
Notes to Financial Statements .....	8 - 12

May 29, 2015

## **INDEPENDENT AUDITOR'S 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, 2014 and 2013, 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, 2014 and 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.

*Studley-White, P.C.*

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

---

	<b>2014</b>	<b>2013</b>
<b>Assets</b>		
Cash and cash equivalents	\$ 996,905	\$ 733,017
Investments	540,832	544,783
Accounts receivable	152,666	211,259
Prepaid expenses	13,209	10,576
Equipment, net	18,499	26,914
Security deposit	-	21,248
<b>Total Assets</b>	<b>\$ 1,722,111</b>	<b>\$ 1,547,797</b>
<b>Liabilities and Net Assets</b>		
<u>Liabilities:</u>		
Accounts payable	\$ 11,663	\$ 27,893
Research grants payable	50,000	100,000
<b>Total Liabilities</b>	<b>61,663</b>	<b>127,893</b>
<u>Net Assets:</u>		
Unrestricted - net assets	966,124	919,775
Temporarily Restricted Net Assets	694,324	500,129
<b>Total Net Assets</b>	<b>1,660,448</b>	<b>1,419,904</b>
<b>Total Liabilities and Net Assets</b>	<b>\$ 1,722,111</b>	<b>\$ 1,547,797</b>

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

	<b>2014</b>	<b>2013</b>
<b>Unrestricted Net Assets</b>		
<u>Revenues and Other Support:</u>		
Special events - revenue	\$ 648,365	\$ 758,470
- expenses	(162,254)	(136,420)
- net	486,111	622,050
Contributions and grants	819,178	716,217
In-kind revenue	437,302	370,269
Investment income	(2,683)	3,917
Other	13,488	11,886
Total Unrestricted Revenues and Other Support	1,753,396	1,724,339
Net Assets Released from Restrictions	38,699	36,556
<b>Total Revenues and Other Support</b>	<b>1,792,095</b>	<b>1,760,895</b>
<b><u>Expenses</u></b>		
<u>Program Services</u>		
Public and professional education	235,606	167,613
Patient and family services	1,159,760	908,129
Advocacy	35,341	25,142
Research	117,803	97,236
Total Program Services	1,548,510	1,198,120
<u>Support Services</u>		
Management and general	77,096	41,905
Fund raising	120,140	122,044
Total Support Services	197,236	163,949
<b>Total Expenses</b>	<b>1,745,746</b>	<b>1,362,069</b>
<b>Increase on Unrestricted Net Assets</b>	<b>46,349</b>	<b>398,826</b>
<b>Temporarily Restricted Net Assets:</b>		
Contributions	232,894	41,617
Net assets released from restrictions	(38,699)	(36,556)
<b>Increase in temporarily restricted net assets</b>	194,195	5,061
<b>Increase in Net Assets</b>	<b>240,544</b>	<b>403,887</b>
<b>Net Assets, January 1,</b>	<b>1,419,904</b>	<b>1,016,017</b>
<b>Net Assets, December 31,</b>	<b>\$ 1,660,448</b>	<b>\$ 1,419,904</b>

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

	<b>2014</b>	<b>2013</b>
<b>Cash Flows from Operating Activities:</b>		
Increase in net assets	\$ 240,538	\$ 403,887
Adjustments to reconcile increase in net assets to net cash provided by operating activities:		
Add: Depreciation	7,694	4,139
	<b>248,232</b>	<b>408,026</b>
<b>Changes in assets and liabilities:</b>		
(Increase) decrease in:		
Accounts receivable	58,593	(79,470)
Security deposit	21,247	-
Prepaid expense	(2,627)	(5,529)
	<b>77,213</b>	<b>(84,999)</b>
Increase (decrease) in:		
Accounts payable and accrued expenses	(16,229)	5,070
Deferred revenue	-	-
Research grant payable	(50,000)	(50,000)
	<b>(66,229)</b>	<b>(44,930)</b>
<b>Net cash provided by operating activities</b>	<b>259,216</b>	<b>278,097</b>
<b>Cash Flows from Investing Activities:</b>		
Sale (purchase) of investments	6,532	(4,954)
<b>Net cash provided by investing activities</b>	<b>6,532</b>	<b>(4,954)</b>
<b>Cash Flows from Financing Activities:</b>		
Purchase of fixed assets	(1,860)	(22,336)
<b>Net cash used by financing activities</b>	<b>(1,860)</b>	<b>(22,336)</b>
<b>Net increase in cash</b>	<b>263,888</b>	<b>250,807</b>
<b>Cash at beginning of year</b>	<b>733,017</b>	<b>482,210</b>
<b>Cash at end of year</b>	<b>\$ 996,905</b>	<b>\$ 733,017</b>

**DYSTROPHIC EPIDERMOLYSIS BULLOSA  
RESEARCH ASSOCIATION OF AMERICA, INC.  
Statement of Functional Expenses  
For the Year Ended December 31, 2014**

	PROGRAM SERVICES					SUPPORT SERVICES			
	Public and Professional Education	Patient and Family Services	Advocacy	Research	Total	Management and General	Fund Raising	Total	Total Expenses
Salaries	\$ 83,602	\$ 217,366	\$ 12,540	\$ 41,801	\$ 355,309	\$ 20,901	\$ 41,801	\$ 62,702	\$ 418,011
Payroll taxes	8,105	21,074	1,216	4,053	34,448	2,026	4,053	6,079	40,527
Fringe benefits	7,752	20,154	1,163	3,876	32,945	1,938	3,876	5,814	38,759
Professional fees	6,060	15,755	909	3,030	25,754	1,515	3,030	4,545	30,299
Telephone	2,699	7,016	405	1,349	11,469	675	1,349	2,024	13,493
Office supplies	5,285	13,742	793	2,643	22,463	1,321	2,643	3,964	26,427
Insurance	971	2,526	146	486	4,129	237	486	723	4,852
Equipment maintenance	107	279	16	54	456	27	54	81	537
Postage	4,385	11,400	658	2,192	18,635	1,096	2,192	3,288	21,923
Travel	75,223	195,580	11,283	37,611	319,697	18,506	37,611	56,117	375,814
Printing	6,850	17,811	1,028	3,425	29,114	1,713	3,425	5,138	34,252
Research Grant Assistance	-	-	-	-	-	-	-	-	-
	-	128,457	-	-	128,457	-	-	-	128,457
Dues and subscriptions	4,914	12,775	737	2,457	20,883	1,228	2,457	3,685	24,568
Fees	932	2,424	140	466	3,962	233	466	699	4,661
In-kind legal services	-	-	-	-	-	18,200	-	18,200	18,200
In-kind medical supplies	-	418,727	-	-	418,727	-	-	-	418,727
Advertising	8,250	21,451	1,238	4,125	35,064	2,063	4,125	6,188	41,252
Bank charges	411	1,068	62	205	1,746	103	205	308	2,054
Equipment	1,836	4,773	275	918	7,802	459	918	1,377	9,179
Bad debts	-	-	-	-	-	-	2,337	2,337	2,337
Interest expense	-	-	-	-	-	-	-	-	-
Depreciation expense	1,539	4,001	231	769	6,540	685	769	1,454	7,994
Miscellaneous	1,552	4,036	231	777	6,596	387	777	1,164	7,760
Rent	15,133	39,345	2,270	7,566	64,314	3,783	7,566	11,349	75,663
Total Expenses before Fund Raising									
	235,606	1,159,760	35,341	117,803	1,548,510	77,096	120,140	197,236	1,745,746
Special Events	-	-	-	-	-	-	162,254	162,254	162,254
Total Expenses	\$ 235,606	\$ 1,159,760	\$ 35,341	\$ 117,803	\$ 1,548,510	\$ 77,096	\$ 282,394	\$ 359,490	\$ 1,908,000



**DYSTROPHIC EPIDERMOLYSIS BULLOSA  
RESEARCH ASSOCIATION OF AMERICA, INC.  
Statement of Functional Expenses  
For the Year Ended December 31, 2013**

	PROGRAM SERVICES					SUPPORT SERVICES			
	Public and Professional Education	Patient and Family Services	Advocacy	Research	Total	Management and General	Fund Raising	Total	Total Expenses
Salaries	\$ 75,103	\$ 195,267	\$ 11,265	\$ 37,551	\$ 319,186	\$ 18,776	\$ 37,551	\$ 56,327	\$ 375,513
Payroll taxes	6,775	17,614	1,016	3,387	28,792	1,694	3,387	5,081	33,873
Fringe benefits	7,719	20,070	1,158	3,860	32,807	1,930	3,860	5,790	38,597
Professional fees	3,136	8,154	470	1,568	13,328	784	1,568	2,352	15,680
Telephone	2,190	5,694	329	1,095	9,308	548	1,095	1,643	10,951
Office supplies	4,650	12,089	697	2,325	19,761	1,162	2,325	3,487	23,248
Insurance	1,824	4,741	274	912	7,751	456	912	1,368	9,119
Equipment maintenance	879	2,284	132	439	3,734	220	439	659	4,393
Postage	2,783	7,235	417	1,391	11,826	696	1,391	2,087	13,913
Travel	13,357	34,729	2,004	6,679	56,769	3,339	6,679	10,018	66,787
Printing	9,614	24,997	1,442	4,807	40,860	2,404	4,807	7,211	48,071
Research Grant	-	-	-	13,430	13,430	-	-	-	13,430
Assistance	-	123,315	-	-	123,315	-	-	-	123,315
Dues and subscriptions	3,486	9,064	523	1,743	14,816	872	1,743	2,615	17,431
Fees	2,579	6,706	387	1,290	10,962	645	1,290	1,935	12,897
In-kind legal services	4,286	11,143	643	2,143	18,215	1,071	2,143	3,214	21,429
In-kind medical supplies	-	349,021	-	-	349,021	-	-	-	349,021
Advertising	4,904	12,751	736	2,452	20,843	1,226	2,452	3,678	24,521
Bank charges	468	1,218	70	234	1,990	117	234	351	2,341
Equipment	1,936	5,034	290	968	8,228	484	968	1,452	9,680
Bad debts	-	-	-	-	-	-	38,422	38,422	38,422
Interest expense	24	63	4	12	103	6	12	18	121
Depreciation expense	828	2,152	124	414	3,518	207	414	621	4,139
Miscellaneous	3,094	8,046	464	1,547	13,151	774	1,363	2,137	15,288
Rent	17,978	46,742	2,697	8,989	76,406	4,494	8,989	13,483	89,889
Total Expenses before Fund Raising									
Fund Raising	167,613	908,129	25,142	97,236	1,198,120	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	\$ 1,198,120	\$ 41,905	\$ 258,464	\$ 300,369	\$ 1,498,489

**DYSTROPHIC EPIDERMOLYSIS BULLOSA  
RESEARCH ASSOCIATION OF AMERICA, INC.  
Notes to Financial Statements  
December 31, 2014**

---

**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***

***Net Asset Categories***

To ensure observance of limitations and restrictions that may be placed on the use of resources available, the accounts of the Organization are maintained in the following net asset categories:

**Unrestricted** – Unrestricted net assets represent available resources other than donor restricted contributions. Donor restricted contributions which are satisfied in the same reporting period when the contribution is received are treated as unrestricted contributions. Included in unrestricted net assets are grants and contracts that are earmarked for the general-purpose use of the Organization.

**Temporarily Restricted** – Temporarily restricted net assets represent contributions that are restricted by the donor either as to purpose or as to time of expenditure.

**Permanently Restricted** – Permanently restricted net assets represent contributions that are limited by donor-imposed stipulations that neither expire by passage of time nor can be fulfilled or otherwise removed by actions of the Organization.

At December 31, 2014, the Organization had \$694,324 temporarily restricted assets (\$500,129 at December 31, 2013) and no permanently restricted net assets.

**DYSTROPHIC EPIDERMOLYSIS BULLOSA  
RESEARCH ASSOCIATION OF AMERICA, INC.  
Notes to Financial Statements  
December 31, 2014**

---

**Note 1 - Summary of Significant Accounting Policies (continued)**

***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.

***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.

The Organization recognizes the effect of tax positions only when they are more than likely than not of being sustained. Management has determined that the Organization had no uncertain tax positions that would require financial statement recognition. Tax years dating back to 2011 remain open by federal and state authorities.

***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, 2014 and December 31, 2013.

***Investments***

Investments in equity securities with readily determinable fair market values and all investments in debt services are reported at fair value with gains and losses included in the

**DYSTROPHIC EPIDERMOLYSIS BULLOSA  
RESEARCH ASSOCIATION OF AMERICA, INC.  
Notes to Financial Statements  
December 31, 2014**

---

**Note 1 - Summary of Significant Accounting Policies (continued)**

***Investments (continued)***

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, 2014</u>	<u>December 31, 2013</u>
Equipment	\$ 32,629	\$ 33,350
Less accumulated depreciation	(14,130)	(6,436)
Property and equipment, net	<u>\$ 18,499</u>	<u>\$ 26,914</u>

**Note 3 – Investments**

Investments at December 31, 2014 and 2013 were comprised of the following:

	<u>Fair Value</u>	
	<u>December 31, 2014</u>	<u>December 31, 2013</u>
Money market funds	<u>\$ 540,832</u>	<u>\$ 544,783</u>

Investment income is comprised of the following at December 31:

	<u>December 31, 2014</u>	<u>December 31, 2013</u>
Dividends and interest	\$ 1,081	\$ 1,317
Realized and unrealized gains (losses)	(3,764)	2,600
	<u>\$ (2,683)</u>	<u>\$ 3,917</u>

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

**Notes to Financial Statements**

**December 31, 2014**

---

**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, 2015	69,448
2016	71,011
2017	72,609
2018	74,242
2019	82,857
	\$ 370,167

**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 2014. The remaining balance of \$50,000 is due in 2015.

**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 \$18,200 for the year ended December 31, 2014 and \$21,248 for the year ended December 31, 2013. The value of donated medical supplies was \$418,727 for the year ended December 31, 2014 and \$349,021 at December 31, 2013. The medical supplies were distributed directly to the families of children afflicted with the disease.

**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:

	<b>December 31, 2014</b>	<b>December 31, 2013</b>
Programs and E. B. Support Groups	<u>\$ 694,324</u>	<u>\$ 500,129</u>

**DYSTROPHIC EPIDERMOLYSIS BULLOSA  
RESEARCH ASSOCIATION OF AMERICA, INC.  
Notes to Financial Statements  
December 31, 2014**

---

**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 9 – Subsequent Events**

The date at which events occurring after December 31, 2014, the date of the most recent balance sheet, have been evaluated for possible adjustment to the financial statements on disclosure is April 29, 2015, which is the date on which the financial statements were available to be issued.