

Dystrophic Epidermolysis Bullosa
Research Association of America, Inc.

Financial Statements

December 31, 2016 and December 31, 2015

Studley - White, P.C.
ACCOUNTING - TAX - AUDITING - CONSULTING

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Financial Statements
December 31, 2016**

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April 27, 2017

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. (D.E.B.R.A.) (a nonprofit organization), which comprise the statement of financial positions as of December 31, 2016 and 2015, 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.

Basis for Qualified Opinion

As explained in Note 1 to the financial statements, D.E.B.R.A. received donated medical supplies from families and various medical suppliers. There was no physical inventory performed at December 31, 2015 of the donated medical supplies and we were unable to reconcile the physical inventory quantities.

Opinion

In our opinion, except for the basis for a qualified opinion as stated above, 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, 2016 and December 31, 2015, 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,**

	2016	2015
Assets		
Cash and cash equivalents	\$ 1,262,190	\$ 1,201,486
Investments	623,055	640,324
Accounts receivable	19,641	167,405
Inventory medical supplies	836,631	680,595
Prepaid expenses	86,368	17,725
Equipment, net	7,354	13,567
Total Assets	\$ 2,835,239	\$ 2,721,102
Liabilities and Net Assets		
<u>Liabilities:</u>		
Accounts payable	\$ 59,379	\$ 37,835
Total Liabilities	59,379	37,835
<u>Net Assets:</u>		
Unrestricted - net assets	1,851,852	1,873,082
Temporarily Restricted Net Assets	924,008	810,185
Total Net Assets	2,775,860	2,683,267
Total Liabilities and Net Assets	\$ 2,835,239	\$ 2,721,102

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

	<u>2016</u>	<u>2015</u>
Unrestricted Net Assets		
<u>Revenues and Other Support:</u>		
Special events - revenue	\$ 1,078,645	\$ 1,286,722
- expenses	<u>(229,875)</u>	<u>(365,124)</u>
- net	848,770	921,598
Contributions and grants	606,178	356,209
In-kind revenue	967,437	1,374,112
Investment income (losses)	(41,876)	3,168
Other	<u>8,942</u>	<u>4,578</u>
Total Unrestricted Revenues and Other Support	2,389,451	2,659,665
Net Assets Released from Restrictions	<u>29,943</u>	<u>177,294</u>
Total Revenues and Other Support	<u>2,419,394</u>	<u>2,836,959</u>
<u>Expenses</u>		
<u>Program Services</u>		
Public and professional education	315,704	315,317
Patient and family services	1,668,498	1,231,316
Advocacy	47,354	47,298
Research	<u>157,854</u>	<u>157,659</u>
Total Program Services	<u>2,189,410</u>	<u>1,751,590</u>
<u>Support Services</u>		
Management and general	78,925	78,829
Fund raising	<u>172,289</u>	<u>224,659</u>
Total Support Services	<u>251,214</u>	<u>303,488</u>
Total Expenses	<u>2,440,624</u>	<u>2,055,078</u>
Increase on Unrestricted Net Assets	<u>(21,230)</u>	<u>781,881</u>
Temporarily Restricted Net Assets:		
Contributions	143,766	293,155
Net assets released from restrictions	<u>(29,943)</u>	<u>(177,294)</u>
Increase in temporarily restricted net assets	<u>113,823</u>	<u>115,861</u>
Increase in Net Assets	<u>92,593</u>	<u>897,742</u>
Net Assets, January 1,	<u>2,683,267</u>	<u>1,785,525</u>
Net Assets, December 31,	<u>\$ 2,775,860</u>	<u>\$ 2,683,267</u>

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

	<u>2016</u>	<u>2015</u>
Cash Flows from Operating Activities:		
Increase in net assets	\$ 92,593	\$ 897,742
Adjustments to reconcile increase in net assets to net cash provided by operating activities:		
Add: Depreciation	6,213	6,790
Less: Donated Inventory	<u>(128,579)</u>	<u>(555,608)</u>
	<u>(29,773)</u>	<u>348,924</u>
Changes in assets and liabilities:		
(Increase) decrease in:		
Accounts receivable	137,576	(14,739)
Prepaid expense	<u>(68,643)</u>	<u>(4,516)</u>
	68,933	(19,255)
Increase (decrease) in:		
Accounts payable and accrued expenses	21,544	26,172
Research grant payable	<u>-</u>	<u>(50,000)</u>
	21,544	(23,828)
Net cash provided by operating activities	<u>60,704</u>	<u>305,841</u>
Cash Flows from Investing Activities:		
Sale (purchase) of investments	<u>-</u>	<u>(69,402)</u>
Net cash provided by investing activities	<u>-</u>	<u>(69,402)</u>
Cash Flows from Financing Activities:		
Purchase of fixed assets	<u>-</u>	<u>(1,858)</u>
Net cash used by financing activities	<u>-</u>	<u>(1,858)</u>
Net increase in cash	60,704	234,581
Cash at beginning of year	<u>1,201,486</u>	<u>966,905</u>
Cash at end of year	<u>\$ 1,262,190</u>	<u>\$ 1,201,486</u>

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Statement of Functional Expenses
For the Year Ended December 31, 2016**

	PROGRAM SERVICES					SUPPORT SERVICES			Total Expenses
	Public and Professional Education	Patient and Family Services	Advocacy	Research	Total	Management and General	Fund Raising	Total	
Salaries	\$ 148,604	\$ 386,370	\$ 22,291	\$ 74,302	\$ 631,567	\$ 37,151	\$ 74,302	\$ 111,453	\$ 743,020
Payroll taxes	12,656	32,905	1,898	6,328	53,787	3,164	6,328	9,492	63,279
Fringe benefits	16,941	44,047	2,541	8,471	72,000	4,235	8,471	12,706	84,706
Professional fees	3,027	7,871	454	1,514	12,866	757	1,514	2,271	15,137
Telephone	3,088	8,029	463	1,544	13,124	772	1,544	2,316	15,440
Office supplies	10,040	26,103	1,506	5,020	42,669	2,510	5,020	7,530	50,199
Insurance	2,173	5,649	326	1,086	9,234	543	1,086	1,629	10,863
Equipment maintenance	787	2,046	118	394	3,345	197	394	591	3,936
Postage	1,252	3,255	188	626	5,321	313	626	939	6,260
Travel	5,526	14,366	829	2,763	23,484	1,381	2,763	4,144	27,628
Printing	2,925	7,605	439	1,462	12,431	731	1,462	2,193	14,624
Assistance	-	47,177	-	-	47,177	-	-	-	47,177
Dues and subscriptions	6,989	18,172	1,048	3,495	29,704	1,747	3,495	5,242	34,946
Fees	705	1,834	106	353	2,998	176	353	529	3,527
In-kind services	4,761	12,378	714	2,380	20,233	1,190	2,381	3,571	23,804
In-kind medical supplies	-	800,493	-	-	800,493	-	-	-	800,493
Advertising	15,012	39,030	2,252	7,506	63,800	3,753	7,506	11,259	75,059
Bank charges	394	1,025	59	197	1,675	99	197	296	1,971
Equipment	2,323	6,040	348	1,162	9,873	581	1,162	1,743	11,616
Meetings	56,869	147,860	8,530	28,435	241,694	14,217	28,434	42,651	284,345
Bad debts	-	-	-	-	-	-	14,435	14,435	14,435
Depreciation expense	1,243	3,231	186	621	5,281	311	621	932	6,213
Miscellaneous	1,979	5,147	297	990	8,413	495	990	1,485	9,898
Rent	18,410	47,865	2,761	9,205	78,241	4,602	9,205	13,807	92,048
Total Expenses	\$ 315,704	\$ 1,668,498	\$ 47,354	\$ 157,854	\$ 2,189,410	\$ 78,925	\$ 172,289	\$ 251,214	\$ 2,440,624

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Statement of Functional Expenses
For the Year Ended December 31, 2015**

	PROGRAM SERVICES					SUPPORT SERVICES			Total Expenses
	Public and Professional Education	Patient and Family Services	Advocacy	Research	Total	Management and General	Fund Raising	Total	
Salaries	\$ 113,264	\$ 294,487	\$ 16,990	\$ 56,632	\$ 481,373	\$ 28,316	\$ 56,632	\$ 84,948	\$ 566,321
Payroll taxes	10,619	27,610	1,593	5,310	45,132	2,655	5,310	7,965	53,097
Fringe benefits	12,529	32,577	1,879	6,265	53,250	3,132	6,265	9,397	62,647
Professional fees	2,121	5,515	318	1,061	9,015	530	1,061	1,591	10,606
Telephone	2,886	7,503	433	1,443	12,265	721	1,443	2,164	14,429
Office supplies	8,786	22,843	1,318	4,393	37,340	2,196	4,393	6,589	43,929
Insurance	1,685	4,382	253	843	7,163	421	843	1,264	8,427
Equipment maintenance	50	130	8	25	213	13	25	38	251
Postage	4,281	11,131	642	2,141	18,195	1,070	2,141	3,211	21,406
Travel	17,821	46,336	2,673	8,911	75,741	4,455	8,911	13,366	89,107
Printing	7,868	20,456	1,180	3,934	33,438	1,967	3,934	5,901	39,339
Assistance	-	46,361	-	-	46,361	-	-	-	46,361
Dues and subscriptions	5,787	15,047	868	2,894	24,596	1,447	2,894	4,341	28,937
Fees	842	2,188	126	421	3,577	210	421	631	4,208
In-kind services	90,675	235,754	13,601	45,337	385,367	22,669	45,337	68,006	453,373
In-kind medical supplies	-	365,131	-	-	365,131	-	-	-	365,131
Advertising	8,329	21,655	1,249	4,164	35,397	2,082	4,164	6,246	41,643
Bank charges	269	698	40	134	1,141	67	134	201	1,342
Equipment	2,017	5,245	303	1,009	8,574	504	1,009	1,513	10,087
Bad debts	-	-	-	-	-	-	67,000	67,000	67,000
Depreciation expense	1,358	3,531	204	679	5,772	340	679	1,019	6,791
Miscellaneous	8,003	20,807	1,201	4,000	34,011	2,002	4,000	6,002	40,013
Rent	16,127	41,929	2,419	8,063	68,538	4,032	8,063	12,095	80,633
Total Expenses	\$ 315,317	\$ 1,231,316	\$ 47,298	\$ 157,659	\$ 1,751,590	\$ 78,829	\$ 224,659	\$ 303,488	\$ 2,055,078

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Notes to Financial Statements
December 31, 2016**

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, 2016, the Organization had \$924,008 of temporarily restricted assets (\$810,185 at December 31, 2015) and no permanently restricted net assets.

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

Notes to Financial Statements

December 31, 2016

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 2013 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, 2016 and December 31, 2015.

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

Notes to Financial Statements

December 31, 2016

Note 1 - Summary of Significant Accounting Policies (continued)

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.

Inventory – Medical Supplies

D.E.B.R.A. receives various medical supplies (bandages, creams, ointments) from families affected with E.B. and various medical companies. The medical supplies represent items received by these families that are either no longer needed or incompatible with treating E.B. for the child.

D.E.B.R.A. values the donated supplies based on published prices of major medical suppliers.

D.E.B.R.A. did not conduct a physical inventory at December 31, 2015. We were unable to verify the physical quantities on hand at year end.

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:

	December 31, 2016	December 31, 2015
Equipment	\$ 34,487	\$ 34,487
Less accumulated depreciation	(27,133)	(20,920)
Property and equipment, net	\$ 7,354	\$ 13,567

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

Notes to Financial Statements

December 31, 2016

Note 3 – Investments

Investments at December 31, 2016 and 2015 were comprised of the following:

	<u>Fair Value</u>	
	<u>December 31, 2016</u>	<u>December 31, 2015</u>
Money market funds	\$ 623,055	\$ 640,324

Investment income is comprised of the following at December 31:

	<u>December 31, 2016</u>	<u>December 31, 2015</u>
	Dividends and interest	\$ 303
Realized and unrealized gains (losses)	(42,179)	2,798
	<u>\$ (41,876)</u>	<u>\$ 3,168</u>

Note 4 – Inventory

The value of donated medical supplies is based on published prices of major medical suppliers. Inventory at December 31, 2016 consists of bandages, creams, ointments, dressings. The value of the medical supplies inventory at December 31, 2016 was \$836,631.

D.E.B.R.A. did not conduct a physical inventory at December 31, 2015. We were unable to verify the physical quantities on hand at the end of the year.

Note 5 - 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, 2017	72,609
2018	74,242
2019	82,857
2020	84,722
2021	86,628
	<u>\$ 401,058</u>

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

Notes to Financial Statements

December 31, 2016

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 and other professional services was \$23,804 for the year ended December 31, 2016 and \$453,373 for the year ended December 31, 2015. The value of donated medical supplies was \$943,633 for the year ended December 31, 2016 and \$920,739 at December 31, 2015. 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:

	<u>December 31,</u> <u>2016</u>	<u>December 31,</u> <u>2015</u>
Programs and E. B. Support Groups	\$ 924,008	\$ 810,185

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.

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

Notes to Financial Statements

December 31, 2016

Note 9 – Subsequent Events

The date at which events occurring after December 31, 2016, the date of the most recent balance sheet, have been evaluated for possible adjustment to the financial statements on disclosure is April 27, 2017, which is the date on which the financial statements were available to be issued.