

Dystrophic Epidermolysis Bullosa
Research Association of America, Inc.

Financial Statements

December 31, 2017 and December 31, 2016

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

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Financial Statements
December 31, 2017**

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March 2, 2018

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, 2017 and 2016, 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, 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, 2017 and December 31, 2016, 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,**

	2017	2016
Assets		
Cash and cash equivalents	\$ 1,251,711	\$ 1,262,190
Investments	742,540	623,055
Accounts receivable	72,681	19,641
Inventory medical supplies	756,107	836,631
Prepaid expenses	49,098	86,368
Equipment, net	2,371	7,354
Total Assets	\$ 2,874,508	\$ 2,835,239
Liabilities and Net Assets		
<u>Liabilities:</u>		
Accounts payable	\$ 9,483	\$ 59,379
Accrued expenses	64,134	-
Agency funds held for others	91,906	42,988
Total Liabilities	165,523	102,367
<u>Net Assets:</u>		
Unrestricted - net assets	1,857,982	1,808,864
Temporarily Restricted Net Assets	851,003	924,008
Total Net Assets	2,708,985	2,732,872
Total Liabilities and Net Assets	\$ 2,874,508	\$ 2,835,239

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

	<u>2017</u>	<u>2016</u>
Unrestricted Net Assets		
<u>Revenues and Other Support:</u>		
Special events - revenue	\$ 987,870	\$ 1,078,645
- expenses	<u>(282,595)</u>	<u>(229,875)</u>
- net	705,275	848,770
Contributions and grants	656,801	606,178
In-kind revenue	1,015,581	967,437
Investment income (losses)	106,135	(41,876)
Other	<u>1,700</u>	<u>8,942</u>
Total Unrestricted Revenues and Other Support	2,485,492	2,389,451
Net Assets Released from Restrictions	<u>78,727</u>	<u>29,943</u>
Total Revenues and Other Support	<u>2,564,219</u>	<u>2,419,394</u>
<u>Expenses</u>		
<u>Program Services</u>		
Public and professional education	264,502	315,704
Patient and family services	1,880,300	1,668,498
Advocacy	39,674	47,354
Research	<u>132,250</u>	<u>157,854</u>
Total Program Services	<u>2,316,726</u>	<u>2,189,410</u>
<u>Support Services</u>		
Management and general	66,126	78,925
Fund raising	<u>132,249</u>	<u>172,289</u>
Total Support Services	<u>198,375</u>	<u>251,214</u>
Total Expenses	<u>2,515,101</u>	<u>2,440,624</u>
Increase on Unrestricted Net Assets	<u>49,118</u>	<u>(21,230)</u>
Temporarily Restricted Net Assets:		
Contributions	5,722	143,766
Net assets released from restrictions	<u>(78,727)</u>	<u>(29,943)</u>
Increase in temporarily restricted net assets	<u>(73,005)</u>	<u>113,823</u>
Increase in Net Assets	<u>(23,887)</u>	<u>92,593</u>
Net Assets, January 1,	<u>2,732,872</u>	<u>2,640,279</u>
Net Assets, December 31,	<u>\$ 2,708,985</u>	<u>\$ 2,732,872</u>

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

	<u>2017</u>	<u>2016</u>
Cash Flows from Operating Activities:		
Increase in net assets	\$ (23,887)	\$ 92,593
Adjustments to reconcile increase in net assets to net cash provided by operating activities:		
Add: Depreciation	4,983	6,213
Net realized and unrealized (gain) loss on investments	(105,581)	42,519
Less: Donated Inventory	85,440	(158,603)
	<u>(39,045)</u>	<u>(17,278)</u>
Changes in assets and liabilities:		
(Increase) decrease in:		
Accounts receivable	(53,040)	137,576
Prepaid expense	32,270	(68,643)
	<u>(20,770)</u>	<u>68,933</u>
Increase (decrease) in:		
Accounts payable and accrued expenses	14,238	21,544
Agency funds held for others	48,918	(12,495)
	<u>63,156</u>	<u>9,049</u>
Net cash provided by operating activities	<u>3,341</u>	<u>60,704</u>
Cash Flows from Investing Activities:		
Sale (purchase) of investments	(13,820)	-
Net cash provided by investing activities	<u>(13,820)</u>	<u>-</u>
Net increase in cash	(10,479)	60,704
Cash at beginning of year	<u>1,262,190</u>	<u>1,201,486</u>
Cash at end of year	<u>\$ 1,251,711</u>	<u>\$ 1,262,190</u>

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Statement of Functional Expenses
For the Year Ended December 31, 2017**

	PROGRAM SERVICES					SUPPORT SERVICES			Total Expenses
	Public and Professional Education	Patient and Family Services	Advocacy	Research	Total	Management and General	Fund Raising	Total	
Salaries	\$ 152,648	\$ 396,886	\$ 22,897	\$ 76,324	\$ 648,755	\$ 38,162	\$ 76,324	\$ 114,486	\$ 763,241
Payroll taxes	13,327	34,649	1,999	6,663	56,638	3,332	6,663	9,995	66,633
Fringe benefits	19,920	51,792	2,988	9,960	84,660	4,980	9,960	14,940	99,600
Professional fees	1,516	3,942	227	758	6,443	379	758	1,137	7,580
Telephone	3,345	8,697	502	1,672	14,216	836	1,672	2,508	16,724
Office supplies	11,087	28,827	1,663	5,544	47,121	2,772	5,544	8,316	55,437
Insurance	2,558	6,651	384	1,279	10,872	640	1,279	1,919	12,791
Postage	3,021	7,854	453	1,510	12,838	755	1,510	2,265	15,103
Travel	18,233	47,405	2,735	9,116	77,489	4,558	9,116	13,674	91,163
Printing	2,052	5,334	308	1,026	8,720	513	1,026	1,539	10,259
Assistance	-	114,270	-	-	114,270	-	-	-	114,270
Dues and subscriptions	5,916	15,380	887	2,958	25,141	1,479	2,958	4,437	29,578
Fees	1,025	2,666	154	513	4,358	256	513	769	5,127
In-kind services	4,040	10,503	606	2,020	17,169	1,010	2,020	3,030	20,199
In-kind medical supplies	-	1,078,329	-	-	1,078,329	-	-	-	1,078,329
Advertising	4,350	11,310	653	2,175	18,488	1,088	2,175	3,263	21,751
Bank charges	256	666	38	128	1,088	64	128	192	1,280
Equipment	2,415	6,278	362	1,207	10,262	604	1,207	1,811	12,073
Depreciation expense	997	2,591	149	498	4,235	249	498	747	4,982
Miscellaneous	3	7	-	2	12	1	1	2	14
Rent	17,793	46,263	2,669	8,897	75,622	4,448	8,897	13,345	88,967
Total Expenses	\$ 264,502	\$ 1,880,300	\$ 39,674	\$ 132,250	\$ 2,316,726	\$ 66,126	\$ 132,249	\$ 198,375	\$ 2,515,101

**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.
Notes to Financial Statements
December 31, 2017**

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, 2017, the Organization had \$851,003 of temporarily restricted assets (\$924,008 at December 31, 2016) and no permanently restricted net assets.

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

Notes to Financial Statements

December 31, 2017

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 2014 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, 2017 and December 31, 2016.

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

Notes to Financial Statements

December 31, 2017

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.

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, 2017	December 31, 2016
Equipment	\$ 34,487	\$ 34,487
Less accumulated depreciation	(32,116)	(27,133)
Property and equipment, net	<u>\$ 2,371</u>	<u>\$ 7,354</u>

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

Notes to Financial Statements

December 31, 2017

Note 3 – Investments

Investments at December 31, 2017 and 2016 were comprised of the following:

	Fair Value	
	December 31, 2017	December 31, 2016
	Money market funds	\$ 742,540

Investment income is comprised of the following at December 31:

	December 31, 2017	December 31, 2016
Dividends and interest	\$ 554	\$ 303
Realized and unrealized gains (losses)	105,581	(42,179)
	\$ 106,135	\$ (41,876)

Note 4 – Inventory

The value of donated medical supplies is based on published prices of major medical suppliers. Inventory at December 31, 2017 consists of bandages, creams, ointments, dressings. The value of the medical supplies inventory at December 31, 2017 was \$756,107.

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, 2018	74,242
2019	82,857
2020	84,722
2021	86,628
2022	88,577
	\$ 417,026

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

Notes to Financial Statements

December 31, 2017

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 \$20,199 for the year ended December 31, 2017 and \$23,804 for the year ended December 31, 2016. The value of donated medical supplies was \$756,107 for the year ended December 31, 2017 and \$943,633 at December 31, 2016. 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:

	December 31, 2017	December 31, 2016
Programs and E. B. Support Groups	<u>\$ 851,003</u>	<u>\$ 924,008</u>

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, 2017

Note 9 – Subsequent Events

The date at which events occurring after December 31, 2017, the date of the most recent balance sheet, have been evaluated for possible adjustment to the financial statements on disclosure is March 2, 2018, which is the date on which the financial statements were available to be issued.