

Dystrophic Epidermolysis Bullosa
Research Association of America, Inc.

Financial Statements

December 31, 2018 and December 31, 2017

Studley - White, P.C.

ACCOUNTING - TAX - AUDITING - CONSULTING

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Financial Statements
December 31, 2018**

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March 7, 2019

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 position as of December 31, 2018 and 2017, 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, 2018 and December 31, 2017, 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,**

	2018	2017
Assets		
Cash and cash equivalents	\$ 1,135,515	\$ 1,251,711
Investments	669,957	742,540
Accounts receivable	5,043	72,681
Inventory medical supplies	579,177	756,107
Prepaid expenses	8,807	49,098
Equipment, net	-	2,371
Total Assets	\$ 2,398,499	\$ 2,874,508
Liabilities and Net Assets		
<u>Liabilities:</u>		
Accounts payable	\$ 4,255	\$ 9,483
Accrued expenses	177,750	64,134
Agency funds held for others	97,611	91,906
Total Liabilities	279,616	165,523
<u>Net Assets:</u>		
Net assets without donor restrictions	1,304,758	1,857,982
Net assets with donor restrictions	814,125	851,003
Total Net Assets	2,118,883	2,708,985
Total Liabilities and Net Assets	\$ 2,398,499	\$ 2,874,508

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

	2018	2017
Net Assets without Donor Restrictions		
<u>Revenues and Other Support:</u>		
Special events - revenue	\$ 1,126,574	\$ 987,870
- expenses	(258,045)	(282,595)
- net	868,529	705,275
Contributions and grants	595,150	656,801
DEBRA care conference	345,369	-
In-kind revenue	931,177	1,015,581
Investment income (losses)	(71,923)	106,135
Other	6,126	1,700
Total Unrestricted Revenues and Other Support	2,674,428	2,485,492
Net Assets Released from Restrictions	44,315	78,727
Total Revenues and Other Support	2,718,743	2,564,219
<u>Expenses</u>		
<u>Program Services</u>		
Public and professional education	392,100	264,502
Patient and family services	2,330,927	1,880,300
Advocacy	58,815	39,674
Research	196,050	132,250
Total Program Services	2,977,892	2,316,726
<u>Support Services</u>		
Management and general	98,025	66,126
Fund raising	196,050	132,249
Total Support Services	294,075	198,375
Total Expenses	3,271,967	2,515,101
Change in Net Assets without Donor Restrictions	(553,224)	49,118
Net Assets with donor restrictions:		
Contributions	7,437	5,722
Net assets released from restrictions	(44,315)	(78,727)
Change in Net Assets with Donor Restrictions	(36,878)	(73,005)
Change in Net Assets	(590,102)	(23,887)
Net Assets, January 1,	2,708,985	2,732,872
Net Assets, December 31,	\$ 2,118,883	\$ 2,708,985

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

	2018	2017
Cash Flows from Operating Activities:		
Change in net assets	\$ (590,102)	\$ (23,887)
Adjustments to reconcile change in net assets to net cash provided by operating activities:		
Add: Depreciation	2,371	4,983
Net realized and unrealized (gain) loss on investments	73,879	(105,581)
Less: Donated Inventory	175,634	85,440
	(338,218)	(39,045)
Changes in assets and liabilities:		
(Increase) decrease in:		
Accounts receivable	67,638	(53,040)
Prepaid expense	40,291	32,270
	107,929	(20,770)
Increase (decrease) in:		
Accounts payable and accrued expenses	108,388	14,238
Agency funds held for others	5,705	48,918
	114,093	63,156
Net cash provided by operating activities	(116,196)	3,341
Cash Flows from Investing Activities:		
Sale (purchase) of investments	-	(13,820)
Net cash provided by investing activities	-	(13,820)
Net increase in cash and cash equivalents	(116,196)	(10,479)
Cash and cash equivalents at beginning of year	1,251,711	1,262,190
Cash and cash equivalents at end of year	\$ 1,135,515	\$ 1,251,711

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Statement of Functional Expenses
For the Year Ended December 31, 2018**

	PROGRAM SERVICES					SUPPORT SERVICES			Total Expenses
	Public and Professional Education	Patient and Family Services	Advocacy	Research	Total	Management and General	Fund Raising	Total	
Salaries	\$ 161,266	\$ 419,291	\$ 24,190	\$ 80,633	\$ 685,380	\$ 40,316	\$ 80,633	\$ 120,949	\$ 806,329
Payroll taxes	14,311	37,208	2,147	7,155	60,821	3,578	7,155	10,733	71,554
Fringe benefits	21,486	55,863	3,223	10,743	91,315	5,371	10,743	16,114	107,429
Professional fees	36,897	95,932	5,535	18,449	156,813	9,224	18,449	27,673	184,486
Telephone	3,806	9,897	571	1,903	16,177	952	1,903	2,855	19,032
Office supplies	14,469	37,620	2,170	7,235	61,494	3,617	7,235	10,852	72,346
Insurance	2,621	6,815	393	1,311	11,140	655	1,311	1,966	13,106
Postage	867	2,255	130	434	3,686	217	434	651	4,337
Travel	28,219	73,369	4,233	14,109	119,930	7,055	14,109	21,164	141,094
Printing	1,593	4,141	239	796	6,769	398	796	1,194	7,963
Assistance	-	204,965	-	-	204,965	-	-	-	204,965
Dues and subscriptions	6,033	15,686	905	3,017	25,641	1,508	3,017	4,525	30,166
Fees	1,025	2,665	154	513	4,357	256	513	769	5,126
In-kind services	2,331	6,061	350	1,166	9,908	583	1,166	1,748	11,656
In-kind medical supplies	-	1,106,503	-	-	1,106,503	-	-	-	1,106,503
Advertising	1,880	4,889	282	940	7,991	470	940	1,410	9,401
Bank charges	241	627	36	121	1,025	60	121	181	1,206
Conferences/meetings	72,611	188,787	10,892	36,305	308,595	18,153	36,305	54,458	363,053
Equipment	2,744	7,136	412	1,372	11,664	686	1,372	2,058	13,722
Depreciation expense	474	1,233	71	237	2,015	119	237	356	2,371
Miscellaneous	386	1,000	56	191	1,633	97	191	289	1,922
Rent	18,840	48,984	2,826	9,420	80,070	4,710	9,420	14,130	94,200
Total Expenses	\$ 392,100	\$ 2,330,927	\$ 58,815	\$ 196,050	\$ 2,977,892	\$ 98,025	\$ 196,050	\$ 294,075	\$ 3,271,967

**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.
Notes to Financial Statements
December 31, 2018**

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 accompanying financial statements have been prepared on the accrual basis of accounting in accordance with accounting principles generally accepted in the United States of America.

Basis of Presentation

The financial statements of the Organization comply with the Financial Statements of Not-for-Profit Organizations topic of the FASB Codification. Under this topic, the Organization reports information regarding its financial position and activities according to the following net assets classifications:

Net assets without donor restrictions – Net assets that are not subject to donor-imposed restrictions and may be expended for any purpose in performing the primary objectives of the organization. These net assets may be used at the discretion of the Organization's management and Board of Directors.

Net assets with donor restrictions – Net assets subject to stipulations imposed by donors and grantors. Some donor restrictions are temporary in nature; those restrictions will be met by actions of the Organization or by the passage of time. Other donor restrictions are perpetual in nature, where-by the donor has stipulated the funds be maintained in perpetuity.

Donor restricted contributions are reported as increases in net assets with donor restrictions. When a restriction expires, net assets are reclassified from net assets with donor restrictions to net assets without donor restrictions in the statements of activities.

New Accounting Pronouncement

On August 18, 2016, the FASB issued ASU 2016-14, Not-for-Profit Entities (Topic 958) – Presentation of Financial Statements of Not-for-Profit Entities. The update addresses the complexity and understandability of net asset classification, deficiencies in information about liquidity and availability of resources, and the lack of consistency in the type of information provided about expenses and investment return. The Organization has adjusted the presentation

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Notes to Financial Statements
December 31, 2018**

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

of these financial statements accordingly. The ASU has been applied retrospectively to all periods presented.

At December 31, 2018, the Organization had \$814,125 of net assets with donor restrictions (\$851,003 at December 31, 2017).

Contributions

In accordance with financial accounting standards, the Organization records contributions received as without donor restrictions or with donor restrictions depending on the existence and or nature of any donor restrictions. Restricted net assets are reclassified to net assets without donor restrictions upon the satisfaction of the time or purpose restrictions.

All contributions are considered to be available for unrestricted use unless specifically restricted by the donor. Support that is restricted by the donor, grantor or other outside party for particular operating purposes or for fixed asset acquisitions is reported as an increase in net assets without donor restrictions if the restriction expires in the reporting period in which the support is recognized.

Cash and Cash Equivalents

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

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

Property and equipment is recorded at cost when purchased and fair value when donated. Depreciation is computed using the straight line method over the estimated useful lives of 3 – 7 years of the respective assets. All expenditures for equipment in excess of \$1,000 are capitalized.

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Notes to Financial Statements
December 31, 2018**

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. A ruling from the Internal Revenue Service has determined that the Organization will be treated as a publicly supported organization, and not a private foundation. This qualifies the Organization for the 50% charitable contribution deduction for individual donors. Consequently, the accompanying financial statements do not include any provision for income taxes.

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 qualify for either recognition or disclosure in the financial statements. In the normal course of business the Organization's tax filings are subject to examination by federal and state authorities. The tax returns for the years ended December 31, 2015 and forward are subject to examination by taxing authorities.

Functional Expenses

The Organization allocates expenses on a functional basis among programs and support services. Expenses that can be specifically identified are charged directly to the related program or support service. Other expenses that are common to several functions are allocated based on estimates made by management.

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, 2018 and December 31, 2017.

Investments

Investments in equity securities with readily determinable fair market values and all investments in debt instruments are reported at fair value in the statement of financial position. Realized gains or losses and unrealized appreciation or depreciation are reflected in the accompanying statement of activities. If received as a donation, the investment is stated at fair value at the date of donation.

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Notes to Financial Statements
December 31, 2018**

Note 1 - Summary of Significant Accounting Policies (continued)

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:

	<u>December 31, 2018</u>	<u>December 31, 2017</u>
Equipment	\$ 34,487	\$ 34,487
Less accumulated depreciation	(34,487)	(32,116)
Property and equipment, net	<u>\$ -</u>	<u>\$ 2,371</u>

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Notes to Financial Statements
December 31, 2018**

Note 3 – Investments

Investments at December 31, 2018 and 2017 were comprised of the following:

	<u>Fair Value</u>	
	<u>December 31, 2018</u>	<u>December 31, 2017</u>
Money market funds	<u>\$ 670,702</u>	<u>\$ 742,540</u>

Investment income is comprised of the following at December 31:

	<u>December 31, 2018</u>	<u>December 31, 2017</u>
Dividends and interest	\$ 1,956	\$ 554
Realized and unrealized gains (losses)	<u>(73,879)</u>	<u>105,581</u>
	<u>\$ (71,923)</u>	<u>\$ 106,135</u>

Note 4 – Inventory

The value of donated medical supplies is based on published prices of major medical suppliers. Inventory at December 31, 2018 consists of bandages, creams, ointments, dressings. The value of the medical supplies inventory at December 31, 2018 was \$579,177 and \$756,107 at December 31, 2017.

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, 2019	\$ 82,857
2020	84,722
2021	86,628
2022	88,577
2023	<u>90,570</u>
	<u>\$ 433,354</u>

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

**Notes to Financial Statements
December 31, 2018**

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 \$11,656 for the year ended December 31, 2018 and \$20,199 for the year ended December 31, 2017. The value of donated medical supplies was \$579,177 for the year ended December 31, 2018 and \$756,107 at December 31, 2017. The medical supplies were distributed directly to the families of children afflicted with the disease.

Note 7 –Net Assets with donor restrictions

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. Net assets with donor restrictions were as follows:

	December 31, 2018	December 31, 2017
Programs and E. B. Support Groups	<u>\$ 814,125</u>	<u>\$ 851,003</u>

Note 8 – Fair Value of Financial Instruments

Financial Accounting Standards Board (FASB) Accounting Standards Codification (ASC) 820 defines fair value, requires certain disclosures about fair value measurements, and establishes a three level hierarchy for fair value measurements based on observable inputs to the valuation of an asset or liability at the measurement date. Fair value is defined as the price that would be received to sell an asset or paid to transfer a liability in an orderly transaction between market participants at the measurement date.

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: Observable prices that are based on inputs not quoted in active markets, but corroborated by market data.

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Notes to Financial Statements
December 31, 2018**

Note 8 – Fair Value of Financial Instruments (continued)

Level 3: Unobservable inputs for the assets or liability when little or no market data is 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.

The fair value measurement of investments is Level 1 at December 31, 2018 and 2017.

Note 9 – Availability and Liquidity

The following represents the Organizations financial assets at December 31, 2018 and 2017:

	<u>2018</u>	<u>2017</u>
Financial Assets at year end:		
Cash and cash equivalents	\$ 1,135,515	\$ 1,251,711
Investments	669,957	742,540
Accounts receivable	5,043	72,681
Total financial assets	<u>1,810,515</u>	<u>2,066,932</u>
Less amounts not available to be used within one year:		
Net assets with donor restrictions	<u>814,125</u>	<u>851,003</u>
Financial assets available to meet general expenditures over the next twelve months	<u>\$ 996,390</u>	<u>\$ 1,215,929</u>

The organizations goal is generally to maintain financial assets by receiving support from various sources including individual, corporate, foundation and Board contributions, as well as income from investment sources.

Note 10 – Subsequent Events

Management has evaluated events and transactions subsequent to December 31, 2018 through March 7, 2019, the date the financial statements were available to be issued, and has determined that there are no material events that would require disclosure in the financial statements.