

Dystrophic Epidermolysis Bullosa

Research Association of America, Inc.

Financial Statements with Independent Auditor's Report

December 31, 2020 and 2019

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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 statements of financial position as of December 31, 2020 and 2019, 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 audits. We conducted our audits 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, 2020 and 2019, 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.

Nanavaty. Davenport. Studley & White. LLP

March 15, 2021

Statements of Financial Postion

At December 31,

		2020		2019
Assets				
Cash and cash equivalents	\$	651,965	\$	972,811
Investments		1,083,049		914,792
Accounts receivable		527,541		5,360
Inventory medical supplies		648,724		467,518
Prepaid expenses		58,958		38,570
Equipment, net		6,248		8,029
Total Assets	\$	2,976,485	\$	2,407,080
Liabilities and Net Assets Liabilities:				
Accounts payable	\$	9,270	\$	36,170
Accrued expenses	π	312,314	т	177,901
Agency funds held for others	_	-		97,611
Total Liabilities		321,584		311,682
<u>Net Assets</u> :				
Net assets without donor restrictions		2,107,054		1,283,751
Net assets with donor restrictions		547,847		811,647
Total Net Assets		2,654,901		2,095,398
Total Liabilities and Net Assets	\$	2,976,485	\$	2,407,080

Statements of Financial Position

For the Years Ended December 31,

	2020	 2019
Net Assets without Donor Restrictions		
Revenues and Other Support:		
Special events - revenue	\$ 1,032,492	\$ 1,207,436
- expenses	(99,635)	 (357,053)
- net	932,857	850,383
Contributions and grants	936,305	690,271
In-kind revenue	495,605	1,080,786
Investment return, net	139,735	4,584
Other	5,640	 2,586
Total Unrestricted Revenues and Other Support	2,510,142	2,628,610
Net Assets Released from Restrictions	 263,800	 9,694
Total Revenues and Other Support	2,773,942	 2,638,304
Expenses:		
Program Services	1,749,213	2,443,513
Management and general	67,140	71,925
Fund raising	 134,286	 143,850
Total Expenses	 1,950,639	 2,659,288
Change in Net Assets without Donor Restrictions	 823,303	 (20,984)
Net Assets with donor restrictions:		
Contributions	-	7,216
Net assets released from restrictions	(263,800)	 (9,694)
Change in Net Assets with Donor Restrictions	 (263,800)	 (2,478)
Change in Net Assets	 559,503	 (23,462)
Net Assets, January 1,	 2,095,398	 2,118,860
Net Assets, December 31,	\$ 2,654,901	\$ 2,095,398

Statements of Cash Flows

For the Years Ended December 31,

	 2020	2019
Cash Flows from Operating Activities:		
Change in net assets	\$ 559,503	\$ (23,462)
Adjustments to reconcile change in net assets to net cash used in operating activities:		
Add: Depreciation	2,968	380
Net realized and unrealized (gain) on investments	(139,359)	(244,834)
Change in donated inventory	 (181,206)	 111,660
	 241,906	 (156,256)
Changes in assets and liabilities:		
(Increase) in:		
Accounts receivable	(522,181)	(317)
Prepaid expense	 (20,388)	 (29,763)
	(542,569)	(30,080)
Increase (decrease) in:		
Accounts payable and accrued expenses	107,513	32,041
Agency funds held for others	 (97,611)	 -
	 9,902	 32,041
Net cash used in operating activities	 (290,761)	 (154,295)
Cash Flows from Investing Activities:		
Purchase of investments	(28,898)	
Purchase of fixed assets	 (1,187)	 (8,409)
Net cash used in investing activities	(30,085)	 (8,409)
Net decrease in cash and cash equivalents	(320,846)	(162,704)
Cash and cash equivalents at beginning of year	972,811	 1,135,515
Cash and cash equivalents at end of year	\$ 651,965	\$ 972,811

Statement of Functional Expenses

For the Year Ended December 31, 2020

	_			PROGR	AM S	SERVICE	ES				SUPI	POR	SERVIC	ES			
	P	ublic and	Pa	atient and						N	A anagement				_		
	P	rofessional		Family							and		Fund				Total
	I	Education		Services	Ac	dvocacy	R	esearch	 Total		General		Raising		Total	E	Expenses
Salaries	\$	170,413	\$	443,074	\$	25,562	\$	85,206	\$ 724,255	\$	42,603	\$	85,206	\$	127,809	\$	852,064
Payroll taxes		13,754		35,760		2,063		6,877	58,454		3,438		6,877		10,315		68,769
Fringe benefits		20,025		52,066		3,004		10,013	85,108		5,006		10,013		15,019		100,127
Professional fees		1,660		4,316		249		830	7,055		415		830		1,245		8,300
Telephone		3,493		9,081		524		1,746	14,844		873		1,746		2,619		17,463
Office supplies		8,637		22,457		1,296		4,319	36,709		2,159		4,319		6,478		43,187
Insurance		4,657		12,107		698		2,328	19,790		1,164		2,328		3,492		23,282
Postage		57		148		9		28	242		14		28		42		284
Travel		3,832		9,964		575		1,916	16,287		958		1,916		2,874		19,161
Printing		3,087		8,026		463		1,543	13,119		772		1,543		2,315		15,434
Assistance		-		317,354		-		-	317,354		-		-		-		317,354
Dues and subscriptions		661		1,719		99		331	2,810		165		331		496		3,306
Fees		407		1,057		61		203	1,728		102		203		305		2,033
In-kind services		6,253		16,257		938		3,126	26,574		1,563		3,126		4,689		31,263
In-kind medical supplies		-		290,416		-		-	290,416		-		-		-		290,416
Advertising		2,035		5,290		305		1,017	8,647		509		1,017		1,526		10,173
Bank charges		3,033		7,887		455		1,517	12,892		758		1,517		2,275		15,167
Conferences/meetings		2,870		7,462		431		1,435	12,198		718		1,435		2,153		14,351
Equipment		2,162		5,620		324		1,081	9,187		540		1,081		1,621		10,808
Depreciation expense		594		1,543		89		297	2,523		148		297		445		2,968
Miscellaneous		161		418		24		80	683		40		80		120		803
Rent		20,785		54,042		3,118		10,393	 88,338		5,195		10,393		15,588		103,926
Total Expenses	\$	268,576	\$	1,306,064	\$	40,287	\$	134,286	\$ 1,749,213	\$	67,140	\$	134,286	\$	201,426	\$	1,950,639

Statement of Functional Expenses

For the Year Ended December 31, 2019

				PRO	GRA	M SERV	ICE	S			SUPI	POR	T SERVIC	ES			
	Pı	ublic and	Pa	atient and						Ν	lanagement						
	Pro	ofessional		Family							and		Fund				Total
	E	ducation		Services	A	dvocacy	R	esearch	 Total		General		Raising		Total	F	Expenses
Salaries	\$	154,556	\$	401,845	\$	23,183	\$	77,278	\$ 656,862	\$	38,639	\$	77,278	\$	115,917	\$	772,779
Payroll taxes		13,229		34,396		1,984		6,615	56,224		3,307		6,615		9,922		66,146
Fringe benefits		21,361		55,538		3,204		10,680	90,783		5,340		10,680		16,020		106,803
Professional fees		24,331		63,261		3,650		12,166	103,408		6,083		12,166		18,249		121,657
Telephone		3,418		8,886		513		1,709	14,526		854		1,709		2,563		17,089
Office supplies		11,123		28,919		1,668		5,561	47,271		2,781		5,561		8,342		55,613
Insurance		3,482		9,052		522		1,741	14,797		870		1,741		2,611		17,408
Postage		1,173		3,050		176		587	4,986		293		587		880		5,866
Travel		15,795		41,067		2,369		7,897	67,128		3,949		7,897		11,846		78,974
Printing		3,409		8,863		511		1,704	14,487		852		1,704		2,556		17,043
Assistance		-		55,476		-		-	55,476		-		-		-		55,476
Dues and subscriptions		4,549		11,827		682		2,274	19,332		1,137		2,274		3,411		22,743
Fees		1,047		2,722		157		523	4,449		262		523		785		5,234
In-kind services		5,658		14,711		849		2,829	24,047		1,415		2,829		4,244		28,291
In-kind medical supplies		-		1,165,303		-		-	1,165,303		-		-		-		1,165,303
Advertising		1,596		4,150		239		798	6,783		399		798		1,197		7,980
Bank charges		322		836		48		161	1,367		80		161		241		1,609
Equipment		2,280		5,929		342		1,140	9,691		570		1,140		1,710		11,401
Depreciation expense		76		198		11		38	323		19		38		57		380
Miscellaneous		5		12		1		2	20		1		2		3		23
Rent		20,294		52,765		3,044		10,147	86,250		5,074		10,147		15,221		101,471
Total Expenses	\$	287,704	\$	1,968,806	\$	43,153	\$	143,850	\$ 2,443,513	\$	71,925	\$	143,850	\$	215,775	\$	2,659,288

Note 1 - Organization

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.

Note 2 - Summary of Significant Accounting Policies

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 D.E.B.R.A. comply with the Financial Statements of Not-for-Profit Organizations topic of the FASB Codification. Under this topic, D.E.B.R.A. reports information regarding it financial position and activities according to the following net assets classifications:

Net assets without donor restrictions – Net assets that are not subject to donorimposed 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 D.E.B.R.A.'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 D.E.B.R.A. 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.

At December 31, 2020, D.E.B.R.A. had \$547,847 of net assets with donor restrictions (\$811,647 at December 31, 2019).

Note 2 - Summary of Significant Accounting Policies (continued) Revenue and Revenue Recognition

Contributions

D.E.B.R.A recognizes contributions when cash, securities or other assets; an unconditional promise to give; or a notification of a beneficial interest is received. Conditional promises to give -that is, those with a measurable performance or other barrier and a right of return – are not recognized until the conditions on which they depend are met.

Unconditional contributions are recognized as revenues or gains in the period received and as assets or decreases of liabilities or expenses, depending on the form of the benefit received. Conditional promises to give are recognized when the conditions on which they depend are substantially met. Unconditional promises to give that are expected to be collected within one year are recorded at their net realizable value, while those expected to be collected in future years are recorded at the present value of the expected future receipts.

Contributions received are recorded as net assets without donor restrictions or net assets with donor restrictions. Support that is restricted by the donor is reported as an increase in net assets without donor restriction if the restriction expires in the reporting period in which the support is recognized. All other donor-restricted support is reported as an increase in net assets with donor restrictions. When a restriction (i.e., when a time or purpose restriction is met), net assets with donor restrictions are reclassified to net assets without donor restrictions and reported in the statement of activities as net assets released from restrictions.

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.

Note 2 - Summary of Significant Accounting Policies (continued)

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 and a useful life greater than one year are capitalized.

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, 2017 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

D.E.B.R.A.'s accounting for compensated absences conforms to generally accepted accounting principles and recognizes vacation pay when earned. Accrued vacation was \$-0- at December 31, 2020 and 2019.

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.

Notes to Financial Statements

Note 2 - 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.

Concentration of Credit Risk

Cash and cash equivalents - D.E.B.R.A. places its cash deposits with high credit-quality financial institutions. Such deposits may exceed federal depository insurance limits at times during the year. However, management believes that these deposits are not subject to significant credit risk. The money market funds held in brokerage accounts is not protected by federal depository insurance.

Investments – D.E.B.R.A.'s investments are comprised of various common and preferred stocks. The value of these investments is subject to fluctuations due to general market conditions and interest rates.

Subsequent Events

Management has evaluated events and transactions subsequent to December 31, 2020 through March 15, 2021, the date the financial statements were available to be issued. There were no subsequent events that require disclosure.

Note 3 - Equipment, Net

Equipment, net is summarized as follows at December 31:

	 2020	2019
Equipment	\$ 44,083	\$ 42,896
Less accumulated depreciation	 (37,835)	 (34,867)
Equipment, net	\$ 6,248	\$ 8,029

Note 4 - Inventory

The value of donated medical supplies is based on published prices of major medical suppliers. Inventory at December 31, 2020 and 2019 consists of bandages, creams, ointments and dressings. The value of the donated medical supplies inventory at December 31, 2020 was \$648,724 and \$467,518 at 2019.

Note 5 - Operating Leases

D.E.B.R.A. 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, 2021	\$ 86,628
2022	88,577
2023	90,570
2024	 30,869
	\$ 296,644

Note 6 - Donated Services, Materials, Facilities

D.E.B.R.A. 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 and medical supplies and other professional services was \$495,605 for the year ended December 31, 2020 and \$1,080,786 for the year ended 2019. The medical supplies were distributed directly to the families of children afflicted with the disease.

Note 7 - Net Assets with donor restrictions

D.E.B.R.A. 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 at December 31::

	2020	2019
Programs and E.B. Support Groups	\$ 547,847	\$ 811,647

Note 8 - Fair Value of Financial Instruments

The Financial Accounting Standards Board ("FASB") Topic 820, under the FASB Accounting Standards Codification ("ASC") defines fair value, establishes a framework for measuring fair value, and expands disclosures about fair value measurements. This standard provides a consistent definition of fair value, which focuses on an exit price between market participants in an orderly transaction. The standard also prioritizes the use of observable inputs and minimizes the use of unobservable inputs by requiring that observable inputs be used when available.

Observable inputs are inputs that market participants would use in pricing the respective asset or liability based on market data obtained from independent sources. Unobservable inputs reflect assumptions that market participants would use in pricing the asset or liability based on the best information available in the circumstances. The hierarchy is categorized into three levels based on the transparency of inputs as follows:

- Level 1 Quoted prices are available in active markets for identical assets or liabilities as of the report date. A quoted price for an identical asset or liability in an active market provides the most reliable fair value measurement because it is directly observable to the market.
- Level 2 Pricing inputs are other than quoted prices in active markets, which are either directly or indirectly observable as of the report date. The nature of these securities includes investments for which quoted prices are available but traded less frequently and investments that are fair valued using other securities, the parameters of which can be directly observed. Also included in Level 2 are investments measured using a net asset value ("NAV") per share, or its equivalent, that may be redeemed at NAV at the date of the statement of financial position or in the near term, which D.E.B.R.A. has determined to be within 90 days.
- Level 3 Investments that have little to no pricing observability as of the report date. These investments are measured using management's best estimate of fair value, where the inputs into the determination of fair value are not observable and require significant management judgment or estimation.

Note 8 - Fair Value of Financial Instruments (continued)

Inputs are used in applying the various valuation techniques and broadly refer to the assumptions that market participants use to make valuation decisions, including assumptions about risk. Inputs may include price information, volatility statistics, specific and broad credit data, liquidity statistics, and other factors. A financial instrument's level within the fair value hierarchy is based on the lowest level of any input that is significant to the fair value measurement. However, the determination of what constitutes "observable" requires significant judgment by D.E.B.R.A. D.E.B.R.A. considers observable data to be that market data that is readily available, regularly distributed or updated, reliable and verifiable, not proprietary, and provided by independent sources that are actively involved in the relevant market.

The categorization of a financial instrument within the hierarchy is based upon the pricing transparency of the instrument and does not necessarily correspond to D.E.B.R.A.s' perceived risk of that instrument.

D.E.B.R.A.s' policy is to recognize transfers in and transfers out of levels at the end of the reporting period.

The following is a description of the valuation methodologies used for assets measured at fair value:

Exchange Traded Funds, Common Stocks and Mutual Funds – These items are valued at the closing price reported in the active market in which the individual securities are traded.

There have been no changes in the methodologies used at December 31, 2020 and 2019.

Assets Measured at Fair-Value on a Recurring Basis – The following is a summary of the source of fair-value measurements for assets that are measured at fair-value on a recurring basis as of December 31:

		2020										
	Level 1	Level 2	Level 3	Total								
Common stocks	\$303,466	\$ -	\$ -	\$ 303,466								
Mutual funds	529,583	-		529,583								
Preferred stock			250,000	250,000								
Total	\$833,049	\$ -	\$250,000	\$1,083,049								

Note 9 - Fair Value of Financial Instruments (continued)

		2019											
	Level 1	Level 2	Level 3	Total									
Common stocks	\$135,146	\$ -	\$ -	\$ 135,146									
Mutual funds	529,646	-	-	529,646									
Preferred stock			250,000	250,000									
Total	\$664,792	\$ -	\$250,000	\$ 914,792									

D.E.B.R.A. has made a \$250,000 investment in a Preferred Stock purchase agreement in a privately held biotechnology company. The purpose of the investment is to leverage the research performed by this company to find a cure for EB as well as provide future funds to D.E.B.R.A. to support its on-going mission of finding a cure for EB.

Note 10 - Availability and Liquidity

The following represents D.E.B.R.A.'s financial assets at December 31,:

	2020	2021
Financial Assets at year end:		
Cash and cash equivalents	\$ 651,965	\$ 972,811
Investments	1,083,049	914,792
Accounts receivable	527,541	5,360
Total Financial assets	2,262,555	1,892,963
Less amounts not available to be within one year		
Net assets with donor restrictions	547,847	811,647
Financial assets available to meet general expenditures over the next twelve months	\$ 1,714,708	\$1,081,316

D.E.B.R.A.'s 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 11 - Other

D.E.B.R.A. has been named the beneficiary of a charitable remainder unitrust. The trustee will distribute the principal and income of the trust estate upon the death of the beneficiary.

Note 12 - Risks and Uncertainties

The recent COVID-19 outbreak has caused economic disruptions through mandated voluntary closings of businesses and organizations throughout the United States. The extent of the impact of COVID-19 on D.E.B.R.A.'s operational and financial performance will depend on certain developments, including the duration and spread of the outbreak and its impact on D.E.B.R.A.'s donors, employees, investments and vendors, all of which at present cannot be determined. Accordingly, the extent to which COVID-19 may impact D.E.B.R.A.'s financial position and changes in net assets and cash flows is uncertain and the accompanying financial statements include no adjustments relating to the effects of the pandemic.