

Dystrophic Epidermolysis Bullosa
Research Association of America, Inc.

Financial Statements

December 31, 2019 and December 31, 2018

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Financial Statements
December 31, 2019**

Table of Contents

	<u>Page</u>
Independent Auditor's Report.....	1 - 2
Financial Statements:	
Statements of Financial Position at December 31, 2019 and 2018	3
Statements of Activities for the Years Ended December 31, 2019 and 2018	4
Statements of Cash Flows for the Years Ended December 31, 2019 and 2018	5
Statement of Functional Expenses for the Years Ended December 31, 2019 and 2018	6 - 7
Notes to Financial Statements	8 - 17

April 3, 2020

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, 2019 and 2018, 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, 2019 and December 31, 2018, 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

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

	2019	2018
Assets		
Cash and cash equivalents	\$ 972,811	\$ 1,135,515
Investments	914,792	669,957
Accounts receivable	5,360	5,043
Inventory medical supplies	467,518	579,177
Prepaid expenses	38,570	8,807
Equipment, net	8,029	-
Total Assets	\$ 2,407,080	\$ 2,398,499
Liabilities and Net Assets		
<u>Liabilities:</u>		
Accounts payable	\$ 36,170	\$ 4,255
Accrued expenses	177,901	177,750
Agency funds held for others	97,611	97,611
Total Liabilities	311,682	279,616
<u>Net Assets:</u>		
Net assets without donor restrictions	1,283,751	1,304,758
Net assets with donor restrictions	811,647	814,125
Total Net Assets	2,095,398	2,118,883
Total Liabilities and Net Assets	\$ 2,407,080	\$ 2,398,499

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

	2019	2018
Net Assets without Donor Restrictions		
<u>Revenues and Other Support:</u>		
Special events - revenue	\$ 1,207,436	\$ 1,126,574
- expenses	(357,053)	(258,045)
- net	850,383	868,529
Contributions and grants	698,656	595,150
DEBRA care conference	-	345,369
In-kind revenue	1,080,786	931,177
Investment return, net	(4,584)	(71,923)
Other	3,347	6,126
Total Unrestricted Revenues and Other Support	2,628,588	2,674,428
Net Assets Released from Restrictions	9,694	44,315
Total Revenues and Other Support	2,638,282	2,718,743
<u>Expenses</u>		
<u>Program Services</u>		
Public and professional education	287,702	392,100
Patient and family services	1,968,804	2,330,927
Advocacy	43,155	58,815
Research	143,851	196,050
Total Program Services	2,443,512	2,977,892
<u>Support Services</u>		
Management and general	71,926	98,025
Fund raising	143,851	196,050
Total Support Services	215,777	294,075
Total Expenses	2,659,289	3,271,967
Change in Net Assets without Donor Restrictions	(21,007)	(553,224)
Net Assets with donor restrictions:		
Contributions	7,216	7,437
Net assets released from restrictions	(9,694)	(44,315)
Change in Net Assets with Donor Restrictions	(2,478)	(36,878)
Change in Net Assets	(23,485)	(590,102)
Net Assets, January 1,	2,118,883	2,708,985
Net Assets, December 31,	\$ 2,095,398	\$ 2,118,883

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

	2019	2018
Cash Flows from Operating Activities:		
Change in net assets	\$ (23,485)	\$ (590,102)
Adjustments to reconcile change in net assets to net cash used in operating activities:		
Add: Depreciation	380	2,371
Net realized and unrealized (gain) loss on investments	-	73,879
Change in Donated Inventory	(125,476)	175,634
	(148,581)	(338,218)
Changes in assets and liabilities:		
(Increase) decrease in:		
Accounts receivable	(317)	67,638
Prepaid expense	(29,763)	40,291
	(30,080)	107,929
Increase in:		
Accounts payable and accrued expenses	24,366	108,388
Agency funds held for others	-	5,705
	24,366	114,093
Net cash used in operating activities	(154,295)	(116,196)
Cash Flows from Investing Activities:		
Purchase of fixed assets	(8,409)	-
Net cash used in investing activities	(8,409)	-
Net decrease in cash and cash equivalents	(162,704)	(116,196)
Cash and cash equivalents at beginning of year	1,135,515	1,251,711
Cash and cash equivalents at end of year	\$ 972,811	\$ 1,135,515

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Statement of Functional Expenses
For the Year Ended December 31, 2019**

	PROGRAM SERVICES					SUPPORT SERVICES			Total Expenses
	Public and Professional Education	Patient and Family Services	Advocacy	Research	Total	Management and General	Fund Raising	Total	
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	1,608
Conferences/meetings	-	-	-	-	-	-	-	-	-
Equipment	2,280	5,929	342	1,140	9,691	570	1,140	1,710	11,401
Depreciation expense	74	196	13	39	322	19	39	58	380
Miscellaneous	5	12	1	2	20	2	2	4	24
Rent	20,294	52,765	3,044	10,147	86,250	5,074	10,147	15,221	101,471
Total Expenses	\$ 287,702	\$ 1,968,804	\$ 43,155	\$ 143,851	\$ 2,443,512	\$ 71,926	\$ 143,851	\$ 215,777	\$ 2,659,289

**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	1,749	11,657
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
Conferences/meetings	72,611	188,787	10,892	36,305	308,595	18,153	36,305	54,458	363,053
Bank charges	241	627	36	121	1,025	60	121	181	1,206
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	288	1,921
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.
Notes to Financial Statements
December 31, 2019**

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

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Notes to Financial Statements
December 31, 2019**

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

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

At December 31, 2019, the Organization had \$811,647 of net assets with donor restrictions (\$814,125 at December 31, 2018).

Revenue and Revenue Recognition

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.

D.E.B.R.A has adopted Accounting Standards Update (ASU) No. 2018-08 *Not -for-Profit Entities: Clarifying the Scope and the Accounting Guidance for Contributions received and Contributions Made (Topic 605)* as management believes the standard improves the usefulness and understandability of the Foundation's financial reporting.

Analysis of various provisions of this standard resulted in no significant changes in the way D.E.B.R.A. recognizes revenue, therefore no changes to the previously issued audited financial statements were required on a retrospective basis. The presentation and disclosures of revenue have been enhanced in accordance with the standard.

Contributions

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.

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Notes to Financial Statements
December 31, 2019**

Note 1 - Summary of Significant Accounting Policies (continued)

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.

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.

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Notes to Financial Statements
December 31, 2019**

Note 1 - Summary of Significant Accounting Policies (continued)

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, 2016 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, 2019 and December 31, 2018.

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.

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.

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Notes to Financial Statements
December 31, 2019**

Note 1 - Summary of Significant Accounting Policies (continued)

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.

Note 2 - Equipment, Net

Equipment, net is summarized as follows:

	December 31, 2019	December 31, 2018
Equipment	\$ 42,896	\$ 34,487
Less accumulated depreciation	(34,867)	(34,487)
Property and equipment, net	<u>\$ 8,029</u>	<u>\$ -</u>

Note 3 – Inventory

The value of donated medical supplies is based on published prices of major medical suppliers. Inventory at December 31, 2019 consists of bandages, creams, ointments and dressings. The value of the donated medical supplies inventory at December 31, 2019 was \$467,518 and \$579,177 at December 31, 2018.

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

Notes to Financial Statements

December 31, 2019

Note 4 - 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, 2020	\$	84,722
2021		86,628
2022		88,577
2023		90,570
2024		30,869
		<u>\$ 381,366</u>

Note 5 - 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 \$28,291 for the year ended December 31, 2019 and \$11,656 for the year ended December 31, 2018. The value of donated medical supplies was \$467,518 for the year ended December 31, 2019 and \$579,177 at December 31, 2018. The medical supplies were distributed directly to the families of children afflicted with the disease.

Note 6 –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:

	<u>December 31, 2019</u>	<u>December 31, 2018</u>
Programs and E. B. Support Groups	<u>\$ 811,647</u>	<u>\$ 814,125</u>

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Notes to Financial Statements
December 31, 2019**

Note 7 – 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.

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Notes to Financial Statements
December 31, 2019**

Note 7 – 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, 2019 and 2018.

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

**Notes to Financial Statements
December 31, 2019**

Note 7 – Fair Value of Financial Instruments (continued)

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:

Investment Description	2019			Total
	Level 1	Level 2	Level 3	
Common stocks	\$ 135,146	\$ -	\$ -	\$ 135,146
Mutual funds	529,646	-	-	529,646
Preferred stock	-	-	250,000	250,000
Total investments at fair value	<u>\$ 664,792</u>	<u>\$ -</u>	<u>\$ 250,000</u>	<u>\$ 914,792</u>

Investment Description	2018			Total
	Level 1	Level 2	Level 3	
Common stocks	\$ 141,084	\$ -	\$ -	\$ 141,084
Mutual funds	528,873	-	-	528,873
Total investments at fair value	<u>\$ 669,957</u>	<u>\$ -</u>	<u>\$ -</u>	<u>\$ 669,957</u>

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.

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA, INC.
Notes to Financial Statements
December 31, 2019**

Note 8 – Availability and Liquidity

The following represents the Organizations financial assets at December 31, 2019 and 2018:

	<u>2019</u>	<u>2018</u>
Financial Assets at year end:		
Cash and cash equivalents	\$ 972,811	\$ 1,135,515
Investments	914,792	669,957
Accounts receivable	5,360	5,043
Total financial assets	<u>1,892,963</u>	<u>1,810,515</u>
Less amounts not available to be used within one year:		
Net assets with donor restrictions	<u>811,647</u>	<u>814,125</u>
Financial assets available to meet general expenditures over the next twelve months	<u>\$ 1,081,316</u>	<u>\$ 996,390</u>

The organization’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 9 – Other

The Organization 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 10 – Subsequent Events

Management has evaluated events and transactions subsequent to December 31, 2019 through April 3, 2020, the date the financial statements were available to be issued.

The COVID-19 outbreak in the United States has caused business interruption through mandated and voluntary closings of businesses and schools. While the interruption is currently expected to be temporary, there is considerable uncertainty around the duration of the closings. The Organization expects this matter to negatively impact financial results. However, the related financial impact and duration cannot be reasonably estimated at this time.