**Financial Statements** 

December 31, 2017 and 2016



Table of Contents December 31, 2017 and 2016

	_ Page
Independent Auditors' Report	1
Financial Statements	
Statements of Financial Position	3
Statements of Activities and Changes in Net Assets	4
Statements of Cash Flows	6
Statements of Functional Expenses	7
Notes to Financial Statements	9



# **Independent Auditors' Report**

Board of Directors EB Research Partnership, Inc.

## **Report on the Financial Statements**

We have audited the accompanying financial statements of EB Research Partnership, Inc. which comprise the statement of financial position as of December 31, 2017 and 2016, and the related statements of activities and changes in net assets, cash flows and functional expenses 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.

#### **Auditors' 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 audits to obtain reasonable assurance about whether the financial statements are free from 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 auditors' judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. 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, the financial statements referred to above present fairly, in all material respects, the financial position of EB Research Partnership, Inc. as of December 31, 2017 and 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.

Melville, New York June 5, 2018

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Statements of Financial Position December 31, 2017 and 2016

	 2017	2016
Assets		
Current Assets Cash and cash equivalents Investments Contributions receivable, current portion Other current assets	\$ 7,783,629 4,011,066 136,916 83,879	\$ 5,252,100 1,818,750 1,385,060 12,654
Total current assets	 12,015,490	8,468,564
Investments	184,690	160,000
Contributions Receivable, Net	 199,866	 282,734
Total assets	\$ 12,400,046	\$ 8,911,298
Liabilities and Net Assets		
Current Liabilities Accounts payable Grants payable Other liabilities	\$ 10,619 342,170 28,483	\$ 3,472 929,712 54,101
Total liabilities	 381,272	987,285
Net Assets Unrestricted net assets Temporarily restricted net assets	 12,018,774	 6,874,013 1,050,000
Total net assets	 12,018,774	 7,924,013
Total liabilities and net assets	\$ 12,400,046	\$ 8,911,298

Statement of Activities and Changes in Net Assets Year Ended December 31, 2017

	Unrestricted		Unrestricted Temporarily Restricted		 Total
Support and Revenue					
Contributions	\$	1,428,927	\$	-	\$ 1,428,927
Fundraising events		2,217,675		-	2,217,675
Less direct expenses of fundraising events		(315,387)		-	(315,387)
Interest income		7,652		-	7,652
Net appreciation on investments		3,067,938		-	3,067,938
In-kind contributions		198,108		-	198,108
Net assets released from restrictions		1,050,000		(1,050,000)	 
Total support and revenue		7,654,913		(1,050,000)	 6,604,913
Expenses					
Program and research		1,866,523		-	1,866,523
Management and general		330,004		-	330,004
Fundraising		313,625			 313,625
Total expenses		2,510,152			2,510,152
Changes in net assets		5,144,761		(1,050,000)	4,094,761
Net Assets, Beginning of Year		6,874,013		1,050,000	 7,924,013
Net Assets, End of Year	\$	12,018,774	\$		\$ 12,018,774

Statement of Activities and Changes in Net Assets Year Ended December 31, 2016

	Ur	nrestricted	nporarily Restricted	 Total
Support and Revenue				
Contributions	\$	2,610,910	\$ 140,225	\$ 2,751,135
Fundraising events		1,770,401	-	1,770,401
Less direct expenses of fundraising events		(219,849)	-	(219,849)
Licensure income		1,057,500	-	1,057,500
Interest income		1,120	-	1,120
Net appreciation on investments		759,719	-	759,719
In-kind contributions		135,459	-	135,459
Net assets released from restrictions		1,083,274	(1,083,274)	 -
Total support and revenue		7,198,534	 (943,049)	 6,255,485
Expenses				
Program and research		2,513,319	-	2,513,319
Management and general		134,123	-	134,123
Fundraising		303,139		 303,139
Total expenses		2,950,581	 	 2,950,581
Changes in net assets		4,247,953	(943,049)	3,304,904
Net Assets, Beginning of Year		2,626,060	 1,993,049	 4,619,109
Net Assets, End of Year	\$	6,874,013	\$ 1,050,000	\$ 7,924,013

Statements of Cash Flows Years Ended December 31, 2017 and 2016

	2017			2016		
Cash Flows from Operating Activities						
Changes in net assets	\$	4,094,761	\$	3,304,904		
Adjustments to reconcile changes in net assets to						
net cash flows from operating activities:						
Earned or donated investments		(11,170)		(1,059,031)		
Net appreciation on investments		(3,067,938)		(759,719)		
Changes in operating assets and liabilities:						
Contributions receivable		1,331,012		371,338		
Other current assets		(71,225)		(690)		
Accounts payable		7,147		(8,984)		
Grants payable		(587,542)		323,067		
Other liabilities		(25,618)		34,371		
Net cash flows from operating activities		1,669,427		2,205,256		
Cash Flows from Investing Activities						
Purchase of investments		(460,000)		(160,000)		
Sale of investments		1,322,102		97,450		
Net cash flows from investing activities		862,102		(62,550)		
Net change in cash and cash equivalents		2,531,529		2,142,706		
Cash and Cash Equivalents, Beginning of Year		5,252,100		3,109,394		
Cash and Cash Equivalents, End of Year	\$	7,783,629	\$	5,252,100		

# EB Research Partnership, Inc. Statement of Functional Expenses

Year Ended December 31, 2017

	Program and Research		nagement and General	Fu	ndraising	Total
Grants	\$	1,769,565	\$ -	\$	-	\$ 1,769,565
Salaries and benefits		5,189	7,264		101,910	114,363
Payroll taxes		548	768		9,854	11,170
Professional fees		86,250	308,996		122,900	518,146
Office expense		1,563	1,170		8,234	10,967
Payment processor fees		-	-		44,680	44,680
Information technology		1,375	8,056		4,471	13,902
Insurance		-	2,439		-	2,439
Travel		624	177		4,253	5,054
Meetings		599	-		2,727	3,326
Occupancy		810	 1,134		14,596	 16,540
Total	\$	1,866,523	\$ 330,004	\$	313,625	\$ 2,510,152

# EB Research Partnership, Inc. Statement of Functional Expenses

Year Ended December 31, 2016

	Program and Research		Management and General		and		and		Fundraising		Total	
Grants	\$ 2,400,639	\$	-	\$	-	\$	2,400,639					
Salaries and benefits	16,304		22,453		148,020		186,777					
Payroll taxes	1,090		1,562		10,145		12,797					
Professional fees	89,365		95,881		51,895		237,141					
Office expense	63		2,105		5,807		7,975					
Payment processor fees	-		-		30,753		30,753					
Information technology	3,000		6,868		17,817		27,685					
Insurance	-		2,146		915		3,061					
Travel	992		1,870		10,161		13,023					
Meetings	1,056		104		13,370		14,530					
Occupancy	810		1,134		14,256		16,200					
Total	\$ 2,513,319	\$	134,123	\$	303,139	\$	2,950,581					

Notes to Financial Statements December 31, 2017 and 2016

## 1. Organization and Nature of Activities

EB Research Partnership, Inc. ("EBRP") is a nonprofit 501(c)(3) New York corporation. EBRP's mission is curing and treating Epidermolysis Bullosa ("EB") a devastating and rare genetic disease. All funds raised will go towards funding research to cure EB. EBRP will provide research funding to accelerate research focused on curing and treating EB.

EBRP holds fundraisers in the forms of local events, receptions and an annual gala, Action for Jackson. EBRP also raised funds via online contributions and participation in various charitable athletic events such as marathons and half-marathons.

EBRP employs a venture philanthropy model with all of its research grant making. EBRP retains legal and beneficial rights to intellectual property developed under certain research grants and will share in that revenue stream when the investment becomes commercially viable.

#### 2. Summary of Significant Accounting Policies

#### **Basis of Presentation**

EBRP's accounting policy is to prepare its financial statements on the accrual basis of accounting.

#### **Net Assets**

The net assets of EBRP are classified in the accompanying financial statements in the categories that follow:

*Unrestricted net assets* - Net assets which are not subject to donor-imposed stipulations and are available for general operations.

Temporarily restricted net assets - Net assets subject to donor-imposed stipulations that will be met by action of EBRP and/or the passage of time.

Permanently restricted net assets - Net assets subject to donor-imposed stipulations that the principal be maintained permanently by EBRP. Generally, the donors of these assets permit EBRP to use all or part of the income earned on related investments for general or specific purposes. EBRP had no permanently restricted net assets at December 31, 2017 and 2016.

#### **Revenue Recognition**

All contributions are considered available for EBRP's general programs unless specifically restricted by the donor. Contributions including unconditional promises to give (pledges) are recognized as revenues in the period received. Conditional promises to give are not recognized until they become unconditional, that is, when the conditions on which they depend are substantially met.

EBRP retains legal and beneficial rights to intellectual property developed under certain grant agreements. In 2016, under one of these agreements, EBRP earned one-time licensure income of \$1,057,500.

Notes to Financial Statements December 31, 2017 and 2016

## **Donor-Imposed Restrictions**

EBRP reports gifts of cash and other assets as restricted assets if they are received with donor stipulations that limit the use of the donated assets. Donor restricted contributions whose restrictions are met in the same reporting period are reported as unrestricted net assets. When a donor restriction expires, that is, when a stipulated time restriction ends or purpose restriction is accomplished, temporarily restricted net assets are reclassified to unrestricted net assets and reported in the statement of activities and changes in net assets as net assets released from restrictions.

EBRP reports gifts of land, buildings and equipment as unrestricted support unless explicit donor stipulations specify how the donated assets must be used. Gifts of long-lived assets with explicit restrictions that specify how the assets are to be used and gifts of cash or other assets that must be used to acquire long-lived assets are reported as restricted support. Absent explicit donor stipulations about how long those long-lived assets must be maintained, EBRP reports expirations of donor restrictions when the donated or acquired long-lived assets are placed in service.

#### **Contributions Receivable**

Unconditional promises to give by donors (contributions receivable) are recorded at net realizable value if expected to be collected in one year. Unconditional promises to give that are expected to be collected in future years are recorded at the present value of their estimated future cash flows. The discounts on those amounts are computed using a discount rate applicable to the year in which the promises are received. Amortization of the discounts is included in contribution revenue.

#### In-Kind Contributions and Contributed Services

EBRP recognizes the fair value of in-kind contributions and contributed services received if such services (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 contributed. EBRP receives services from a large number of volunteers who give significant amounts of their time to EBRP's programs and fundraising campaigns but do not meet the criteria for financial statement recognition.

#### **Income Tax Status**

EBRP is exempt from federal and state income tax under the provisions of Section 501(c)(3) of the Internal Revenue Code; therefore, no provision for income taxes has been made in these financial statements. EBRP has also been classified as an entity that is not a private foundation within the meaning of Section 509(a) and qualifies for deductible contributions as provided in Section 170(b)(1)(A)(vi).

#### **Uncertain Tax Positions**

Management evaluated EBRP's tax positions and concluded that EBRP has not taken any uncertain tax positions that would require adjustment to the financial statements to comply with the provisions of Financial Accounting Standards Board ("FASB") Accounting Standards Codification ("ASC") No. 740.

Notes to Financial Statements December 31, 2017 and 2016

#### **Cash and Cash Equivalents**

EBRP considers all highly liquid investments with maturities of three months or less, when purchased, to be cash equivalents. EBRP maintains its cash with a high quality financial institution.

#### Investments

Investments are recorded on the trade date and are carried at fair value. Unrealized gains and losses and realized gains and losses, determined on the basis of the cost of the specific securities sold, are included in the changes in net assets. Investments acquired by gift are recorded at their fair value at the date of the gift.

Mission related direct investments are direct investments in which EBRP takes an equity position. EBRP's ownership in the mission related direct investments has been evaluated to determine if they are variable interest entities and should be consolidated. Management has determined that EBRP does not possess decision making control through a combination of the following: lack of significant ownership interests, voting rights, participation rights, and/or kick-out rights. The mission related direct investments are carried at fair value and are evaluated for impairment on an annual basis.

#### Fair Value

Fair value refers to the price that would be received to sell an asset or paid to transfer a liability in an orderly transaction between market participants in the market in which the entity transacts. EBRP must determine whether its assets and liabilities recorded at fair value were based on Level 1 (valued based on quoted prices in an active market for identical assets and liabilities), Level 2 (valued based on observable market based inputs or unobservable inputs that are corroborated by market data) or Level 3 (valued based on unobservable inputs that are not corroborated by market data) measurements within the fair value hierarchy.

#### **Research Grants and Grants Payable**

EBRP awards medical/scientific grants and contracts for a one year period. Grants are awarded contingent upon renewal criteria at the beginning of each award period. Grants payable represent unconditional obligations of EBRP to provide funds in connection with research grant agreements.

## **Functional Allocation of Expenses**

The costs of providing the various programs and other activities have been summarized on a functional basis in the statement of activities and changes in net assets. Accordingly, certain costs have been allocated among the programs and supporting services benefited.

Notes to Financial Statements December 31, 2017 and 2016

#### Use of Estimates

The preparation of financial statements in conformity with accounting principles generally accepted in the United States of America 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.

#### Allowance for Doubtful Accounts

Management must make estimates of the uncollectability of contributions receivable. Management considers past payment experience and historical trends when assessing the adequacy of allowance for doubtful accounts. There was no allowance recorded as of December 31, 2017 and 2016.

#### **Recent Accounting Pronouncements**

In August 2016, the FASB issued Accounting Standards Update ("ASU") 2016-14, *Not-for-Profit Entities (Topic 958): Presentation of Financial Statements of Not-for-Profit Entities.* The new guidance is intended to improve and simplify the current net asset classification requirements and information presented in financial statements and notes that is useful in assessing a not-for-profit's liquidity, financial performance and cash flows. ASU 2016-14 is effective for fiscal years beginning after December 15, 2017, with early adoption permitted. ASU 2016-14 is to be applied retroactively with transition provisions. Management is currently evaluating the impact of ASU 2016-14 on EBRP's financial statements.

In November 2016, the FASB issued ASU 2016-18, *Statement of Cash Flows (Topic 230): Restricted Cash.* The amendments in this update require that a statement of cash flows explain the change during the period in the total of cash, cash equivalents and amounts generally described as restricted cash or restricted cash equivalents. Amounts generally described as restricted cash and restricted cash equivalents should be included with cash and cash equivalents when reconciling the beginning-of-period and end-of-period amounts shown on the statement of cash flows. ASU 2016-18 is effective for EBRP for fiscal years beginning after December 15, 2018, with early adoption permitted. ASU 2016-18 is to be applied retroactively with transition provisions. Management is currently evaluating the impact of ASU 2016-18 on EBRP's financial statements.

#### 3. Investments and Fair Value

A summary of investments held is as follows at December 31, 2017 and 2016:

	2017			2016
Marketable securities: Public company stock Private company stock	\$	4,011,066 184,690	\$	1,818,750 160,000
Total	\$	4,195,756	\$	1,978,750

Notes to Financial Statements December 31, 2017 and 2016

The shares of the public company stock are subject to restrictions on selling, transferring or otherwise disposing until agreed upon time periods have passed.

#### **Fair Value Hierarchy**

Accounting guidance requires disclosures about assets and liabilities carried at fair value and defines fair value as the prices 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 (exit price). It also establishes a hierarchy which requires an entity to maximize the use of observable inputs and minimized the use of unobservable inputs when measuring fair value. The guidance describes three levels of inputs that may be used to measure fair value.

#### **Valuation Techniques and Inputs**

Level 1 - Inputs are quoted prices (unadjusted) in active markets for identical assets or liabilities that the reporting entity can access at the measurement date.

Level 2 - Inputs other than quoted prices included in Level 1 that are observable for the asset or liability, either directly or indirectly. This includes quoted prices for similar assets or liabilities in active markets, quoted prices for identical or similar assets or liabilities in markets that are not active, inputs or other than quoted prices that are observable for the asset or liability, or market-corroborated inputs.

Level 3 - Inputs are unobservable for the asset or liability. Unobservable inputs reflect the assumptions that market participants would use in pricing the asset or liability including assumptions about risk using the best information available in the circumstances, which may include using the reporting entity's own data.

Assets measured at fair value on a recurring basis are summarized below as of December 31:

			20	17		
		Level 1	Level 2	Level	3	Total
Marketable securities, Stocks	\$	4,011,066	\$ 184,690	\$		\$ 4,195,756
			20	16		
Marketable securities, Stocks	<u>\$</u>	1,818,750	\$ 160,000	\$		\$ 1,978,750

Notes to Financial Statements December 31, 2017 and 2016

#### 4. Research Grants and Grants Payable

EBRP entered into master research agreements with research grants. The agreements with various institutions allow EBRP to acquire an exclusive royalty license on the technology that may be developed as a result of the research.

The components of research grants and grants payable, used to support further research to find a cure for EB, as of and for the years ended December 31, 2017 and 2016 are as follows:

	2017	2016		
Stanford University	\$ 172,680	\$	931,532	
University of Minnesota Tufts University	260,846 19,163		279,667 145,825	
IPS Cell Consortium	465,642		380,035	
Thomas Jefferson University	322,393		148,028	
University of Southern California	89,250		130,410	
Regents of University of California	100,000		112,913	
Universite Laval Research Centre	-		85,706	
Tel Aviv University	85,000		-	
Seattle Children's Research Institute	-		67,486	
University of Freiburg	59,108		-	
Corium	98,500		-	
EBCRC	 96,983		119,037	
Total	\$ 1,769,565	\$	2,400,639	

Grants payable were \$342,170 and \$929,712 as of December 31, 2017 and 2016, respectively.

*EBCRC* - The EB Clinical Research Consortium ("EBCRC") is a coalition of 15 institutions that work together to facilitate faster research trials and improve the lives of those suffering from EB. EBCRC has provided grants to various universities during 2017 and 2016.

IPS Cell Consortium - The EB IPS Cell Consortium announced its formation in August 2016. The newly formed EB IPS Cell Consortium is a unique partnership that includes research teams at Columbia University Medical Center, Stanford University School of Medicine and University of Colorado Anschutz Medical Campus. These teams will work together to find new treatments for EB on an accelerated timeline using an IPS Cell approach to gene therapy. IPS stands for "induced pluripotent stem" cells, whereby cells from a patient are modified, reproduced and given back to the patient.

Notes to Financial Statements December 31, 2017 and 2016

## 5. Special Events

EBRP participated in several fundraising events in order to fund various research projects to find a cure for EB. Revenues are included as fundraising events, and are offset by direct expenses of those events in the statement of activities and changes in net assets.

A summary of the revenue and expenses resulting from special events is as follows for the years ended December 31, 2017 and 2016:

	2017			2016		
Gross revenue: Action for Jackson Local events Marathons	\$	1,281,738 675,031 260,906	\$	1,112,673 382,454 275,274		
Total	\$	2,217,675	\$	1,770,401		
Direct expenses: Action for Jackson Local events Marathons	\$	188,920 113,547 12,920	\$	135,945 51,578 32,326		
Total	\$	315,387	\$	219,849		
Net revenue over expenses: Action for Jackson Local events Marathons	\$	1,092,818 561,484 247,986	\$	976,728 330,876 242,948		
Total	\$	1,902,288	\$	1,550,552		

#### 6. Contributions Receivable

Contributions receivable are reported at fair value using a discount rate that is appropriate for the expected collection period. The discount rate for pledges due within one to five years during the years was 1.06%. Contributions receivable, net are summarized as follows as of December 31, 2017 and 2016:

	2017			2016		
Amounts due in: One year or less Two to five years	\$	136,916 210,000	\$	1,385,060 300,000		
Gross contributions receivable		346,916		1,685,060		
Less present value adjustment		10,134		17,266		
Contributions receivable, net	\$	336,782	\$	1,667,794		

Notes to Financial Statements December 31, 2017 and 2016

#### 7. In-Kind Contributions and Contributed Services

EBRP benefited from in-kind contributions for the years ended December 31, 2017 and 2016. These amounts have been reported as both in-kind revenue and in-kind expense on the statements of activities and changes in net assets. The value of such services for the years ended December 31, 2017 and 2016 are as follows:

	2017		2016	
Occupancy and office expense Vehicle	\$	17,464	\$	17,459 75,000
Professional fees		180,644		43,000
Total	\$	198,108	\$	135,459

#### 8. Concentration of Credit Risk

EBRP has cash balances in financial institutions in excess of amounts federally insured. The uninsured balances totaled approximately \$7,212,301 and \$4,732,000 as of December 31, 2017 and 2016, respectively. EBRP maintains its cash with high quality financial institutions which EBRP believes limits these risks.

EBRP invests primarily in equity securities. Investments are exposed to various risks such as interest rate, market volatility, credit and liquidity risks. Due to the level of uncertainty related to changes in interest rates, market volatility, credit and liquidity risks, it is reasonably possible that changes in these risks could materially affect the fair value of the investments reported in the statement of financial position.

#### 9. Subsequent Event

Management has evaluated subsequent events through June 5, 2018, which is the date the financial statements were available to be issued. There were no subsequent events that require disclosure.