EXTENDED TO AUGUST 17, 2015

Return of Organization Exempt From Income Tax

Under section 501(c), 527, or 4947(à)(1) of the Internal Revenue Code (except private foundations)

Do not enter social security numbers on this form as it may be made public.

Open to Public

OMB No. 1545-0047

Department of the Treasury Inspection Information about Form 990 and its instructions is at www.irs.gov/form990. Internal Revenue Service and ending A For the 2014 calendar year, or tax year beginning D Employer identification number Check if applicable; C Name of organization DYSTROPHIC EPIDERMOLYSIS BULLOSA Address Johange RESEARCH ASSOCIATION OF AMERICA 11-2519726 Name change Doing business as Number and street (or P.O. box if mail is not delivered to street address) Room/suite E Telephone number Initial return 212.868.1573 300 Final return/ 75 BROAD ST 1,715,382. G Gross receipts \$ City or town, state or province, country, and ZIP or foreign postal code termin-ated Amended return H(a) Is this a group return NEW YORK, NY 10004 for subordinates? Yes X No F Name and address of principal officer: BRETT KOPELAN Applica-H(b) Are all subordinates included? Yes pending SAME AS C ABOVE If "No," attach a list. (see instructions)) ◀ (insert no.) 4947(a)(1) or H(c) Group exemption number ▶ J Website: WWW.DEBRA.ORG L Year of formation: 1979 M State of legal domicile: NY Other 🕪 Association K Form of organization: X Corporation Trust Part I Summary 1 Briefly describe the organization's mission or most significant activities: DEBRA IS DEDICATED TO FINDING A CURE FOR EB, WHICH AFFECTS 1 OUT OF EVERY 50,000 LIVE BIRTHS IN THE Activities & Governance 2 Check this box > if the organization discontinued its operations or disposed of more than 25% of its net assets. 20 Number of voting members of the governing body (Part VI, line 1a) 19 Number of independent voting members of the governing body (Part VI, line 1b) 10 5 Total number of individuals employed in calendar year 2014 (Part V, line 2a) 0 6 6 Total number of volunteers (estimate if necessary) 0. 7 a Total unrelated business revenue from Part VIII, column (C), line 12 7a 0. b Net unrelated business taxable income from Form 990-T, line 34 **Prior Year Current Year** 1,052,447. 757,834 Contributions and grants (Part VIII, line 1h) Revenue 0. 0. Program service revenue (Part VIII, line 2g) 3,917 1,081. 10 Investment income (Part VIII, column (A), lines 3, 4, and 7d) 499,600. 633,937. 11 Other revenue (Part Vill, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e) 1,553,128. 1,395,688 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12) 0. 0. Grants and similar amounts paid (Part IX, column (A), lines 1-3) 0. 0. 14 Benefits paid to or for members (Part IX, column (A), line 4) 447,983. 497,297. Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10) 0. 16a Professional fundraising fees (Part IX, column (A), line 11e) b Total fundraising expenses (Part IX, column (D), line 25) \(\bigs \) 811,522. 543,817 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e) 991,800 1,308,819. Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25) 403,888. 244,309. Revenue less expenses. Subtract line 18 from line 12 End of Year Beginning of Current Year 1,7<u>22,111.</u> 1.547.797 20 Total assets (Part X, line 16) 61,663. 127,892 21 Total liabilities (Part X, line 26) 660,448. 419,905. Net assets or fund balances. Subtract line 21 from line 20 Part II Signature Block Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge. Signature of officer Sign EXEC.DIRECTOR BRETT KOPELAN, Here Type or print name and title Date PTIN Print/Type preparer's name Preparer's signature **ド・ノド・ノ** P00058320 self-employed BRIAN C. WHITE Firm's name STUDLEY, WHITE & ASSOCIATES, P.C. 06-0990132 Firm's EIN 👞 reparer Use Only Firm's address P.O. BOX 399 Phone no. 203.748.6517 DANBURY, CT 06813

May the IRS discuss this return with the preparer shown above? (see instructions)

X Yes

Form 990 (2014)

Par	rt III Statement of Program Service Accomplishments	
1 (1)	Check if Schedule O contains a response or note to any line in this Part III	X
1	Briefly describe the organization's mission:	
•	DEBRA IS DEDICATED TO FINDING A CURE FOR EB, WHICH AFFECTS 1 OU	T OF
	EVERY 50,000 LIVE BIRTHS IN THE UNITED STATES TODAY. EB IS A	
	GENETICALLY BASED DISEASE CHARACTERIZED BY CHRONIC, PAINFUL	
	BLISTERING. THE SKIN AND MUCOUS MEMBRANES ARE SO FRAGILE THAT T	HE
2	Did the organization undertake any significant program services during the year which were not listed on	
	the prior Form 990 or 990-EZ?	Yes X No
	If "Yes," describe these new services on Schedule O.	
3	Did the organization cease conducting, or make significant changes in how it conducts, any program services?	Yes X No
	If "Yes," describe these changes on Schedule O.	
4	Describe the organization's program service accomplishments for each of its three largest program services, as measured by e	xpenses.
	Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total exp	enses, and
	revenue, if any, for each program service reported.	
4a	(Code:) (Expenses \$)
	PUBLIC AND PROFESSIONAL EDUCATION - EDUCATE THE PUBLIC & HEALTH	
	PROFESSIONALS ABOUT DYSTROPHIC EPIDERMOLYSIS BULLOSA "EB"	
4b	(Code:) (Expenses \$ 741,033. including grants of \$) (Revenue \$)
Tij	PATIENT & FAMILY SERVICES - PROVIDE SERVICES FOR PEOPLE WITH EB	& THEIR
	FAMILIES THRU NEWSLETTERS, COUNSELING PEER SUPPORT SERVICES,	
	CONFERENCES AND SEMINARS	
4c	(Code:) (Expenses \$ 35,341. including grants of \$) (Revenue \$)	, rev
	ADVOCACY - NETWORK WITH OTHER PROFESSIONAL ORGANIZATIONS & MEET	<u> </u>
	LEGISLATORS TO INFORM THEM OF EB AND SECURE RESEARCH FUNDS	
	Other program services (Describe in Schedule O.)	
4d	(Expenses \$ 117,803 • including grants of \$) (Revenue \$)
	Total program service expenses ▶ 1,129,783.	
<u> 75</u>	1 Orani Principles Contract Co	Form 990 (2014)

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b If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?

Part IV Checklist of Required Schedules (continued) Yes No Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or X domestic government on Part IX, column (A), line 1? If "Yes," complete Schedule I, Parts I and II 21 Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Х 22 Part IX, column (A), line 2? If "Yes," complete Schedule I, Parts I and III Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current 23 and former officers, directors, trustees, key employees, and highest compensated employees? If "Yes," complete Х 23 Schedule J 24a Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? If "Yes," answer lines 24b through 24d and complete Х 24a Schedule K. If "No", go to line 25a b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception? 24b c Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds? 24c d Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year? 25a Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit Х transaction with a disqualified person during the year? If "Yes," complete Schedule L, Part I b Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? If "Yes," complete Х Schedule L, Part I 25b 26 Did the organization report any amount on Part X, line 5, 6, or 22 for receivables from or payables to any current or former officers, directors, trustees, key employees, highest compensated employees, or disqualified persons? If "Yes," Х 26 complete Schedule L, Part II Did the organization provide a grant or other assistance to an officer, director, trustee, key employee, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity or family member X of any of these persons? If "Yes," complete Schedule L, Part III 27 Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV 28 instructions for applicable filing thresholds, conditions, and exceptions): a A current or former officer, director, trustee, or key employee? If "Yes," complete Schedule L, Part IV X 28a X A family member of a current or former officer, director, trustee, or key employee? If "Yes," complete Schedule L, Part IV 28b An entity of which a current or former officer, director, trustee, or key employee (or a family member thereof) was an officer, director, trustee, or direct or indirect owner? If "Yes," complete Schedule L, Part IV X 28c Did the organization receive more than \$25,000 in non-cash contributions? If "Yes," complete Schedule M 29 Х 29 Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation 30 X 30 contributions? If "Yes," complete Schedule M 31 Did the organization liquidate, terminate, or dissolve and cease operations? X 31 If "Yes," complete Schedule N, Part I Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? If "Yes," complete 32 Х Schedule N, Part II Did the organization own 100% of an entity disregarded as separate from the organization under Regulations X 33 sections 301.7701-2 and 301.7701-3? If "Yes," complete Schedule R, Part I Was the organization related to any tax-exempt or taxable entity? If "Yes," complete Schedule R, Part II, III, or IV, and Х 34 Part V, line 1 35a Did the organization have a controlled entity within the meaning of section 512(b)(13)? Х 35a b If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? If "Yes," complete Schedule R, Part V, line 2 35b Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? X If "Yes," complete Schedule R, Part V, line 2 36 Did the organization conduct more than 5% of its activities through an entity that is not a related organization X and that is treated as a partnership for federal income tax purposes? If "Yes," complete Schedule R, Part VI 37

Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 197

Note. All Form 990 filers are required to complete Schedule O

Form 990 (2014) RESEARCH ASSOCIATION OF AMERICA
Part V Statements Regarding Other IRS Filings and Tax Compliance

ı" at	Check if Schedule O contains a response or note to any line in this Part V				
	Officer in Confedure O Confeditio a response of flore to any line in this real of		······	Yes	No
4	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable	0			
	Enter the number reported in Box 3 of 1 offin 1030. Enter 40 in lot applicable	0	I		
D	Division of the second with health a withholding video for reportable payments to vendors and reportable gamin	g			
С	(gambling) winnings to prize winners?	l l	1c		
22	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements,				
Zđ	filed for the calendar year ending with or within the year covered by this return2a	10			
h	If at least one is reported on line 2a, did the organization file all required federal employment tax returns?		2b	Х	
D	Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)		-		
32	Did the organization have unrelated business gross income of \$1,000 or more during the year?		3a		X
h	If "Yes," has it filed a Form 990-T for this year? If "No," to line 3b, provide an explanation in Schedule O		3b		
42	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a	ι			
74	financial account in a foreign country (such as a bank account, securities account, or other financial account)?		4a		<u>X</u>
h	If "Yes," enter the name of the foreign country:	<u></u>	. [
	See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR)	J.			
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?		5a		<u>X</u> _
b	- various probability of the state of the st		5b		_X_
C	If "Yes." to line 5a or 5b, did the organization file Form 8886-T?		5c		
ĥа	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization	solicit			
	any contributions that were not tax deductible as charitable contributions?		6a		<u>X</u>
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts				
_	were not tax deductible?		6b		
7	Organizations that may receive deductible contributions under section 170(c).				
а	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to	the payor?	7 <u>a</u>		<u>X</u>
b	If "Yes." did the organization notify the donor of the value of the goods or services provided?		7b		
С	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required		_ أ		37
	to file Form 8282?	<u> </u>	7c	<u>_</u>	<u>X</u>
d	If "Yes," indicate the number of Forms 8282 filed during the year		_		
e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?		7e		
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?		7f		
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as rec	1009 C2	7g 7h		
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form	1096-01	-11		
8	Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the		8		
	sponsoring organization have excess business holdings at any time during the year?	·····	-		
9	Sponsoring organizations maintaining donor advised funds.		9a		
а	Did the sponsoring organization make any taxable distributions under section 4966?		9b		_
b	•		- 05		
10	Section 501(c)(7) organizations. Enter:				
а	Initiation lees and capital contributions moduce on that this wife to				
b	Gross receipts, included on Form 990, 1 are vin, and 12, 16, papers as 67 and 12				
11	Section 501(c)(12) organizations. Enter:		1	ĺ	
a	GIOSS IIICUITE BUILI DEBDETS OF STREET ORGAN				
b	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them.)				
	amounts due of received from trieff,		12a		
12a	12h!				
b	Section 501(c)(29) qualified nonprofit health insurance issuers.				
13	to the state of the second to leave qualified health plane in more than one state?		13 <u>a</u>		<u></u>
а	Note. See the instructions for additional information the organization must report on Schedule O.				
b					
Ŋ	organization is licensed to issue qualified health plans				
c	= 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1			<u> </u>	<u> </u>
14a	Did the organization receive any payments for indoor tanning services during the tax year?		14a	<u> </u>	X
b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O		14b	L	
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Part VI Governance, Management, and Disclosure For each "Yes" response to lines 2 through 7b below, and for a "No" response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes in Schedule O. See instructions. Check if Schedule O contains a response or note to any line in this Part VI Section A. Governing Body and Management No 20 1a Enter the number of voting members of the governing body at the end of the tax year ______ If there are material differences in voting rights among members of the governing body, or if the governing body delegated broad authority to an executive committee or similar committee, explain in Schedule O. 19 b Enter the number of voting members included in line 1a, above, who are independent Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other X officer, director, trustee, or key employee? Did the organization delegate control over management duties customarily performed by or under the direct supervision Х of officers, directors, or trustees, or key employees to a management company or other person? X Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? X Did the organization become aware during the year of a significant diversion of the organization's assets? Х Did the organization have members or stockholders? 7a Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or X more members of the governing body? b Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or Х persons other than the governing body? Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following: 8a a The governing body? X 8b b Each committee with authority to act on behalf of the governing body? Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the X organization's mailing address? If "Yes," provide the names and addresses in Schedule O Section B. Policies (This Section B requests information about policies not required by the Internal Revenue Code.) Yes No X 10a 10a Did the organization have local chapters, branches, or affiliates? b If "Yes," did the organization have written policies and procedures governing the activities of such chapters, affiliates, and branches to ensure their operations are consistent with the organization's exempt purposes? 10b X 11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? 11a **b** Describe in Schedule O the process, if any, used by the organization to review this Form 990. Х 12a 12a Did the organization have a written conflict of interest policy? If "No," go to line 13 X b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? 12b Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe 12c Х in Schedule O how this was done X 13 Did the organization have a written whistleblower policy? 13 14 Did the organization have a written document retention and destruction policy? 14 Did the process for determining compensation of the following persons include a review and approval by independent persons, comparability data, and contemporaneous substantiation of the deliberation and decision? Х a The organization's CEO, Executive Director, or top management official 15a Х 15b Other officers or key employees of the organization If "Yes" to line 15a or 15b, describe the process in Schedule O (see instructions). 16a Did the organization invest in, contribute assets to, or participate in a joint venture or similar arrangement with a Х 16a taxable entity during the year? b If "Yes," did the organization follow a written policy or procedure requiring the organization to evaluate its participation in joint venture arrangements under applicable federal tax law, and take steps to safeguard the organization's exempt status with respect to such arrangements? Section C. Disclosure List the states with which a copy of this Form 990 is required to be filed ▶NY, MI, MA, NJ, CA Section 6104 requires an organization to make its Forms 1023 (or 1024 if applicable), 990, and 990-T (Section 501(c)(3)s only) available for public inspection. Indicate how you made these available. Check all that apply. X Upon request Own website ____ Another's website Describe in Schedule O whether (and if so, how) the organization made its governing documents, conflict of interest policy, and financial statements available to the public during the tax year. State the name, address, and telephone number of the person who possesses the organization's books and records: BRETT KOPELAN - 212.868.1573 10004 75 BROAD ST SUITE 300, NEW YORK,

2014.03040 DYSTROPHIC EPIDERMOLYSIS BU DEBRA1

Part VII Compensation of Officers, Directors, Trustees, Key Employees, Highest Compensated **Employees, and Independent Contractors**

Check if Schedule O contains a response or note to any line in this Part VII

Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees

- 1a Complete this table for all persons required to be listed. Report compensation for the calendar year ending with or within the organization's tax year.
- List all of the organization's current officers, directors, trustees (whether individuals or organizations), regardless of amount of compensation. Enter 0 in columns (D), (E), and (F) if no compensation was paid.
 - List all of the organization's current key employees, if any. See instructions for definition of "key employee."
- List the organization's five current highest compensated employees (other than an officer, director, trustee, or key employee) who received reportable compensation (Box 5 of Form W-2 and/or Box 7 of Form 1099-MISC) of more than \$100,000 from the organization and any related organizations.
- List all of the organization's former officers, key employees, and highest compensated employees who received more than \$100,000 of reportable compensation from the organization and any related organizations.
- List all of the organization's former directors or trustees that received, in the capacity as a former director or trustee of the organization, more than \$10,000 of reportable compensation from the organization and any related organizations.

List persons in the following order: individual trustees or directors; institutional trustees; officers; key employees; highest compensated employees; and former such persons.

X Check this box if neither the organization (A)	(B)			(C	;)			(D)	(E)	(F)
Name and Title	Average	(do	not c	Posi heck r	more	than o	one	Reportable	Reportable	Estimated
	hours per	box	unle er an	ss per d a di	rson i irecto	is botl or/trus	h an tee)	compensation from	compensation from related	amount of other
	week (list any							the	organizations	compensation
	hours for	direc.				eg		organization	(W-2/1099-MISC)	from the
	related	stee 0	nstee			ensa		(W-2/1099-MISC)		organization
	organizations	al tru	onalt		ploye	CO m				and related organizations
	below	Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			Organization to
	1.00	프	=	5	×	= =	正			
(1) FAITH DANIELS	1.00	X		İ				0.	0.	0.
PRESIDENT EMERITUS	1.00	A_		-			_			
(2) J ALEC ALEXANDER	1.00	Х		х				0.	0.	0.
TREASURER	1.00	1	_	71			-			
(3) WILLIAM CORNMAN	1.00	Х		х				0.	0.	0.
SECRETARY	1.00									
(4) FRANK KACMARSKY	2,00	x						0.	0.	0.
DIRECTOR (5) RICHARD GALLAGHER	1.00	1	\vdash		$\overline{}$					
(5) RICHARD GALLAGHER VICE PRESIDENT		x		Х				0.	0.	0.
(6) TOM GILLESPIE	1.00									
DIRECTOR		X						0.	0.	0.
(7) DANIEL MARK SIEGEL MD	1.00						١			
DIRECTOR		Х	L				ļ.,	<u> </u>	0.	0.
(8) ROBERT MEIROWITZ MD	1.00								١	0
DIRECTOR		X	ļ		<u> </u>	1_	ļ	0.	0.	0.
(9) BRETT KOPELAN	40.00							100 050		0.
EXECUTIVE DIRECTOR		X	<u> </u>	_	X		_	138,850.	0.	
(10) ANDREW TAVANI	1.00	-						0.	0.	0.
DIRECTOR	1 00	Х	ļ <u>.</u>	-		-	ļ	<u> </u>	0.	
(11) JOHN LEE	1.00	٠,						0.	0.	0.
DIRECTOR	1 00	X	╁	├—	-		┼─			
(12) JOUNI UITTO MD	1.00	Х						0.	0.	0.
DIRECTOR	1.00	^	┢		┢		1-			
(13) KATHLEEN BROWN	1.00	X			ĺ			0.	0.	0.
DIRECTOR	1.00	Δ	-	 	-	+	-			
(14) SONYA WILANDER	1.00	Х	İ	x				0.	0.	0.
DIRECTOR	1.00		\vdash	21	✝		1			
(15) LESLIE RADER	1.00	Х						0.	0.	0.
PRESIDENT	1.00	+ -			T	1				
(16) THOMAS MISISCO		\mathbf{x}						0.	0.	0.
DIRECTOR (17) ANGELA CHRISTIANO PH.D.	1.00		1		\Box					
DIRECTOR		Х						0.	0.	0.
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RESEARCH ASSOCIATION OF AMERICA

(B) Average hours per week (list any hours for related organizations below line) (B) Average hours per week (list any hours for related organizations below line) (B) Average hours per week (list any hours for related organizations below line) (B) Average hours per week (list any hours for related organizations below line) (C) Position (do not check more than one box, unless person is both an officer and a director/trustee) (Ist any hours for related organizations below line) (W-2/1099-MISC) (D) Reportable compensation from related organization (W-2/1099-MISC) (W-2/1099-MISC) (W-2/1099-MISC) (W-2/1099-MISC)	Part VII Section A. Officers, Directors, Trus	tees, Key Em	ploy	ees,	, and	d Hi	ighe	st C	ompensated Employe	es (continued)			
Total number of independent compensation from the compensation of the compensation from the compensation from the compensation below from the compensation below from the compensation below from the compensation below from the compensation below from the compensation below from the compensation below from the compensation below from the compensation from the compensation below from the compensation from the compensa		(B) (C)							(D)	(E)			
Compensation from the organization Displayed and the organizat	Name and title	1	(do					one					
Sub-total			box	, unle	ss pe	rson	is bot	h an	,	•			ot
Note Property Pr		1	\vdash	1			Π	Ĺ			cc		tion
(18) JAMES WETRICH 1.00		1 '	direc				25			•			
(18) JAMES WETRICH 1.00			tee or	ustee			ensat		(W-2/1099-MISC)			•	
(18) JAMES WETRICH 1.00		~	al trus	nal tr		loyee	ding a						
(18) JAMES WETRICH 1.00			Jividu	stitutio	floer	уешр	ghest	Шeг			0	ryanizan	UIIS
DERECTOR X		ļ	르	Ë	8	<u>x</u>	宝豆	윤			+		
115 Sub-total	(18) JAMES WETRICH	1.00	.						n	n			ο.
DIRRCTOR 1.00 X 0.0.0.0.0.0.0.0.0.0.0.0.0.0.0.0.0.0.0		1 00	Λ		 		-		· ·		•		
11. Sub-total Compensation from continuation sheets to Part VII, Section A Total from continuation sheets to Part VII, Section A Total food lines 15 and 1c) Total food lines 15 and 1c) Total food lines 15 and 1c) Total from continuation sheets to Part VII, Section A Total food lines 15 and 1c) Total food lines 16 and 1c) Total food lines 16 and 1c) Total food lines 16 and 1c) Total food lines 16 and 1c) Total food lines 16 and 1c) Total food lines 16 and 1c) Total food lines 16 and 1c) Total food lines 16 and 1c) Total food lines 16 and 1c) Total food lines 1c) Total		1.00	v						Λ.	0			0.
The Sub-total Total from continuation sheets to Part VII, Section A Total (add lines 1) and 10) Total (add lines 1		1 00	Δ						· ·		-		
1b Sub-total		1.00	v						n.	0			0.
Total from continuation sheets to Part VII, Section A	DIRECTOR		^_			┢╌	\vdash				1		
Total from continuation sheets to Part VII, Section A			ł										
Total from continuation sheets to Part VII, Section A						 	-	\vdash			1-		
Total from continuation sheets to Part VII, Section A											1		
Total from continuation sheets to Part VII, Section A			-	-		-							
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Total from continuation sheets to Part VII, Section A							<u> </u>						
Total from continuation sheets to Part VII, Section A								İ					
Total from continuation sheets to Part VII, Section A			<u> </u>				†	-					
Total from continuation sheets to Part VII, Section A			1			ļ					İ		
Total from continuation sheets to Part VII, Section A			H				1	Ì					
Total from continuation sheets to Part VII, Section A			1										_
c Total from continuation sheets to Part VII, Section A	th Sub-total			1		<u>.</u> s	1		138,850.	0			
Total number of individuals (including but not limited to those listed above) who received more than \$100,000 of reportable compensation from the organization 1									0.	0	•		0.
Total number of individuals (including but not limited to those listed above) who received more than \$100,000 of reportable compensation from the organization Yes No 1								•	138,850.	0			0.
Section B. Independent Contractors Section B. Independent Contractors Section B. Independent Contractors Section B. None and business address None Non	2 Total number of individuals (including but i	not limited to th	1056	liste	ed a	bov	e) w	no r		,000 of reportable			
Section B. Independent Contractors Section B. Independent Contractors Section B. Independent Contractors Section B. No No No No No No No No No No No No No	· ·												<u> </u>
line 1a? If "Yes," complete Schedule J for such individual For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? If "Yes," complete Schedule J for such individual 5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? If "Yes," complete Schedule J for such person Section B. Independent Contractors 1 Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year. (A) Name and business address NONE Bescription of services Compensation 1 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization from th	301113011001111111111111111111111111111											Yes	No
line 1a? If "Yes," complete Schedule J for such individual For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? If "Yes," complete Schedule J for such individual 5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? If "Yes," complete Schedule J for such person Section B. Independent Contractors 1 Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year. (A) Name and business address NONE Bescription of services Compensation 1 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization from th	3 Did the organization list any former officer	, director, or tru	uste	e, ke	y er	mplo	oyee	, or	highest compensated e	mployee on			
For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? If "Yes," complete Schedule J for such individual Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? If "Yes," complete Schedule J for such person Section B. Independent Contractors Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year. (A) (B) (C) Compensation Compensation Total number of independent contractors (including but not limited to those listed above) who received more than	line 1a? If "Yes," complete Schedule J for s	such individual									. 3	3	X
and related organizations greater than \$150,000? If "Yes," complete Schedule J for such individual	4 For any individual listed on line 1a, is the s	um of reportab	le c	omp	ens	atio	n an	d ot	her compensation from	the organization			
5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? If "Yes," complete Schedule J for such person	and related organizations greater than \$15	0,000? If "Yes,	" cc	mple	ete .	Sch	edul	e J	for such individual		. 4	<u> </u>	X
Section B. Independent Contractors 1 Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year. (A) Name and business address NONE (B) Compensation Compensation Compensation 2 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization ▶ 1 Compensation from the organization ↑ 1 Complete this table for your five highest compensation from the organization ↑ 1 Complete this table for your five highest compensation from the organization ↑ 1 Complete this table for your five highest compensation from the organization ↑ 2 Total number of independent contractors (including but not limited to those listed above) who received more than ↑ 1 Complete this table for your five highest compensation from the organization ↑ 2 Total number of independent contractors (including but not limited to those listed above) who received more than ↑ 1 Complete this table for your five highest compensation from the organization ↑ 2 Total number of independent contractors (including but not limited to those listed above) who received more than ↑ 1 Complete this table for your five highest compensation from the organization ↑ 2 Total number of independent contractors (including but not limited to those listed above) who received more than ↑	5 Did any person listed on line 1a receive or	accrue compe	nsat	tion 1	from	an	y uni	elat	ted organization or indiv	idual for services			
Section B. Independent Contractors 1 Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year. (A) (B) (C) Compensation Compensation Compensation Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization 0	rendered to the organization? If "Yes," con	nplete Schedul	e J	for s	uch	per	son				5	<u>. </u>	<u> X</u>
the organization. Report compensation for the calendar year ending with or within the organization's tax year. (A) Name and business address NONE Description of services Compensation Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization 0	Section B. Independent Contractors												
the organization. Report compensation for the calendar year ending with or within the organization's tax year. (A) Name and business address NONE Description of services Compensation Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization 0	1 Complete this table for your five highest co	mpensated in	dep	ende	ent c	cont	ract	ors i	that received more than	\$100,000 of compe	nsatio	n from	
Name and business address NONE Description of services Compensation 2 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization 0	the organization. Report compensation for	the calendar y	⁄ear	endi	ng v	with	or w	<u>ithi</u>	n the organization's tax	year.			
2 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization \$\infty\$										condicae	Com	(C) nensatio	าก
\$100,000 of compensation from the organization	Name and business	address	N	ON	E				Description of s	Sel vices	00111	poriodic	
\$100,000 of compensation from the organization													
\$100,000 of compensation from the organization													
\$100,000 of compensation from the organization										Annie de la companya			
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\$100,000 of compensation from the organization													
\$100,000 of compensation from the organization			-					-					
\$100,000 of compensation from the organization													
\$100,000 of compensation from the organization					ناه است			ot o	d abough who received a	nore than		<u> </u>	
			not l	mite	a to			SI6(u abovej wno received r	nore triall			
	\$100,000 of compensation from the organ	ization 📂					U				Fo	rm 990	(2014)

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Page 9

	•	Check if Schedule O conta			(A)	(B)	(C)	(D) Revenue excluded
				· . ·	Total revenue	Related or exempt function revenue	Unrelated business revenue	from tax under sections 512 - 514
হ হ	1 a	Federated campaigns	1a					
Contributions, Gifts, Grants and Other Similar Amounts		Membership dues				;		
ا څ ت		Fundraising events			·			
i k		Related organizations	.,					
الَّانِّ		Government grants (contribut						
e is		All other contributions, gifts, gran	, I					
돌힐	1	similar amounts not included above		052,447.				
Ξŏ	~	Noncash contributions included in lines	-					
5 2		Total, Add lines 1a-1f			1,052,447.			
<u> </u>	- ''	Total, Add into to A		Business Code	1			
a l	0 0			Businedo Codo				
<u>Š</u>	2 a							
Program Service Revenue	b							
Εğ	C							
84	d							
입	e	All other program service reve						
_		Total. Add lines 2a-2f						
		Investment income (including						
	3	other similar amounts)			1,081.			1,081.
		Income from investment of ta			1,0011			
	4							
1	5	Royalties		(ii) Personal				
	_		(i) Real	(II) Fersonal	-			
		Gross rents			-			
					†]		
		Rental income or (loss) Net rental income or (loss)		>				
		-	(i) Securities	(ii) Other				
	7 a	Gross amount from sales of	(i) Securities	(ii) Other	-			
		assets other than inventory		-	-			
	b	Less: cost or other basis						
		and sales expenses						
		Gain or (loss)		•	-			
1		Net gain or (loss)						
e l	8 a	Gross income from fundraisin						
e l		including \$		***************************************				
Other Revenue		contributions reported on line		648,365.				
힏		Part IV, line 18		162,254.				
₹		Less: direct expenses		>	486,111.			486,111.
l		Net income or (loss) from fund			400/111			
	9 a	Gross income from gaming ac						
		Part IV, line 19						
		Less: direct expenses						
		Net income or (loss) from gam						
	10 a	Gross sales of inventory, less						
		and allowances		3	1			L
		Less: cost of goods sold			-			
-	с	Net income or (loss) from sale						
}		Miscellaneous Revenu		Business Code 900099	13,489.	13,489.		
		MISCELLANEOUS I	NCOME	900033	13,409.	10,405.		
ļ	b							
	C							
		All other revenue			13 /00			
ļ	е	Total. Add lines 11a-11d	,		$\frac{13,489}{1,553,128}$		0	. 487,192
	12	Total revenue. See instructions.		8 >	ш.::::::::::::::::::::::::::::::::::::	1 1J,40J		· · · · · · · · · · · · · · · · · · ·

Form 990 (2014)

Form 990 (2014)

RESEARCH ASSOCIATION OF AMERICA

	t IX Statement of Functional Expens				
Secti	ion 501(c)(3) and 501(c)(4) organizations must com	plete all columns. All othe	er organizations must co	mplete column (A).	
	Check if Schedule O contains a respor		this Part IX	(0)	(D)
	not include amounts reported on lines 6b, 8b, 9b, and 10b of Part VIII.	(A) Total expenses	(B) Program service expenses	(C) Management and general expenses	(D) Fundraising expenses
1	Grants and other assistance to domestic organizations				
	and domestic governments. See Part IV, line 21				
2	Grants and other assistance to domestic				
	individuals. See Part IV, line 22				
3	Grants and other assistance to foreign				
	organizations, foreign governments, and foreign				
	individuals. See Part IV, lines 15 and 16				
4	Benefits paid to or for members				
5	Compensation of current officers, directors,				
_	trustees, and key employees				
6	Compensation not included above, to disqualified persons (as defined under section 4958(f)(1)) and				
	persons (as defined under section 4950(f)(1)) and persons described in section 4958(c)(3)(B)				
7	Other salaries and wages	418,012.	355,310.	20,901.	41,801.
7 8	Pension plan accruals and contributions (include	220,020			
0	section 401(k) and 403(b) employer contributions)				
9	Other employee benefits	38,758.	32,944.	1,938.	3,876.
10	Payroll taxes	40,527.	34,448.	2,026.	4,053.
11	Fees for services (non-employees):	, , , , , , , , , , , , , , , , , , , ,			
''	Management				
b	Legal				
c	a v				
d	Lobbying				
e	Professional fundraising services. See Part IV, line 17				
f	Investment management fees				
g	Other. (If line 11g amount exceeds 10% of line 25,			4 545	2 020
	column (A) amount, list line 11g expenses on Sch O.)	30,299.	25,754.	1,515.	3,030.
12	Advertising and promotion	41,253.	35,065.	2,063.	4,125. 8,260.
13	Office expenses	82,602.	70,212.	4,130.	0,200.
14	Information technology				
15	Royalties	FF 660	C4 212	3,783.	7,566.
16	Occupancy	75,662.	64,313.	18,806.	37,611.
17	Travel	376,115.	319,698.	10,000.	37,011.
18	Payments of travel or entertainment expenses				
	for any federal, state, or local public officials				
19	Conferences, conventions, and meetings				
20	Interest				
21	Payments to affiliates	7,694.	6,540.	385.	769.
22	Depreciation, depletion, and amortization	4,852.	4,129.	237.	486.
23	Other expenses. Itemize expenses not covered	4,0321			
24	above. (List miscellaneous expenses in line 24e. If line 24e amount exceeds 10% of line 25, column (A) amount, list line 24e expenses on Schedule 0.)				
а	PATIENT ASSISTANCE	128,457.	128,457.		
b	DUES & SUBSCRIPTIONS	24,567.	20,882.	1,228.	<u>2,457.</u>
c	TELEPHONE	13,493.	11,469.	675.	1,349.
d	EQUIPMENT	9,180.	7,803.	459.	918.
	All other expenses	17,348.	12,759.	750.	3,839.
25	Total functional expenses. Add lines 1 through 24e	1,308,819.	1,129,783.	58,896.	120,140.
26	Joint costs. Complete this line only if the organization				
	reported in column (B) joint costs from a combined				
	educational campaign and fundraising solicitation.				
	Check here if following SOP 98-2 (ASC 958-720)				C 000 (00: 4)
					Form 990 (2014)

Par	t X	Balance Sheet			
		Check if Schedule O contains a response or note to any line in this Part X			
			(A) Beginning of year		(B) End of year
	1	Cash - non-interest-bearing	733,017.	1	996,905.
	2	Savings and temporary cash investments	544,783.	2	<u>540,832.</u>
	3	Pledges and grants receivable, net		3	
	4	Accounts receivable, net	211,259.	4	152,666.
1	5	Loans and other receivables from current and former officers, directors,			
l	Ū	trustees, key employees, and highest compensated employees. Complete		ì	
		Part II of Schedule L		5	
Ì	6	Loans and other receivables from other disqualified persons (as defined under			
	-	section 4958(f)(1)), persons described in section 4958(c)(3)(B), and contributing			
		employers and sponsoring organizations of section 501(c)(9) voluntary			
Ø		employees' beneficiary organizations (see instr). Complete Part II of Sch L		6	
Assets	7	Notes and loans receivable, net		7	
As	8	Inventories for sale or use		8	
	9	Prepaid expenses and deferred charges	10,576.	9	13,209.
- 1	10a				
		basis. Complete Part VI of Schedule D 10a 32,629.			10 100
	b	Less: accumulated depreciation 10b 14,130.	<u> 26,914.</u>	10c	18,499.
	11	Investments - publicly traded securities		11	
	12	Investments - other securities. See Part IV, line 11		12	
	13	Investments - program-related. See Part IV, line 11		13	
	14	Intangible assets	04 040	14	
	15	Other assets. See Part IV, line 11	21,248.	15	$\frac{0.}{1,722,111.}$
	16	Total assets. Add lines 1 through 15 (must equal line 34)	1,547,797.	16	
	17	Accounts payable and accrued expenses	27,892.	17	11,663. 50,000.
	18	Grants payable	100,000.	1	30,000.
	19	Deferred revenue		19	
	20	Tax-exempt bond liabilities		20	
Ì	21	Escrow or custodial account liability. Complete Part IV of Schedule D		21	
es	22	Loans and other payables to current and former officers, directors, trustees,			
		key employees, highest compensated employees, and disqualified persons.		22	
Liabilities		Complete Part II of Schedule L		23	
_	23	Secured mortgages and notes payable to unrelated third parties		24	
	24	Unsecured notes and loans payable to unrelated third parties			
	25	Other liabilities (including federal income tax, payables to related third			
		parties, and other liabilities not included on lines 17-24). Complete Part X of		25	
:		Schedule D Total liabilities. Add lines 17 through 25	127,892.	}	61,663.
	26	Organizations that follow SFAS 117 (ASC 958), check here ► X and			
		complete lines 27 through 29, and lines 33 and 34.			
Se	07	Unrestricted net assets	919,776.	27	966,124.
lan	27	Temporarily restricted net assets	500,129.		694,324.
l Ba	28	Permanently restricted net assets		29	
PL I	29	Organizations that do not follow SFAS 117 (ASC 958), check here			
Γ̈́		and complete lines 30 through 34.			
Net Assets or Fund Balances	20	Capital stock or trust principal, or current funds		30	
šše	30 31	Paid-in or capital surplus, or land, building, or equipment fund		31	
t As	32	Retained earnings, endowment, accumulated income, or other funds		32	
Š	33	Total net assets or fund balances	1,419,905.	33	1,660,448.
	34	Total liabilities and net assets/fund balances	1,547,797.	34	1,722,111.
	, <u></u>				Form 990 (2014)

Form	990 (2014) RESEARCH ASSOCIATION OF AMERICA	<u> </u>	2140	Fau	<u> </u>			
	rt XI Reconciliation of Net Assets							
	Check if Schedule O contains a response or note to any line in this Part XI							
1	Total revenue (must equal Part VIII, column (A), line 12)		1,55					
2	Total expenses (must equal Part IX, column (A), line 25)	2	1,30					
3	Revenue less expenses. Subtract line 2 from line 1	3	244,309. 1,419,905.					
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	4						
5	Net unrealized gains (losses) on investments	5	<	3,7	<u>65.</u> >			
6	6 Donated services and use of facilities							
7	Investment expenses	7						
8	Prior period adjustments	8						
9	Other changes in net assets or fund balances (explain in Schedule O)	9			0.			
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 33,			^ 4	4.0			
	column (B))	10	<u>1,66</u>	U,4	<u>49.</u>			
Pa	rt XII Financial Statements and Reporting							
	Check if Schedule O contains a response or note to any line in this Part XII				<u> </u>			
				Yes	No			
1	Accounting method used to prepare the Form 990: Cash X Accrual Other							
	If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule	Ο.			77			
2a			. <u>2a</u>		<u>X</u>			
	If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed	on a						
	separate basis, consolidated basis, or both:							
	Separate basis Consolidated basis Both consolidated and separate basis			х				
b	Were the organization's financial statements audited by an independent accountant?		2b					
	If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate	e basis,						
	consolidated basis, or both:							
	X Separate basis Consolidated basis Both consolidated and separate basis							
C	If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the	e audit,	0-		Х			
	review, or compilation of its financial statements and selection of an independent accountant?		2c		Λ_			
	If the organization changed either its oversight process or selection process during the tax year, explain in Sch	eaule U.						
За	As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Si		За		х			
	Act and OMB Circular A-133?	irod nudit	<u>sa</u>		27			
þ	If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the requ	neu auun	3b					
	or audits, explain why in Schedule O and describe any steps taken to undergo such audits		. L SD	990	(2014)			

SCHEDULE A

Department of the Treasury

Internal Revenue Service

(Form 990 or 990-EZ)

Public Charity Status and Public Support Complete if the organization is a section 501(c)(3) organization or a section 4947(a)(1) nonexempt charitable trust.

▶ Attach to Form 990 or Form 990-EZ.

Information about Schedule A (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.

Inspection

OMB No. 1545-0047

Name of the organization

DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA

Employer identification number 11-2519726

Part	П	Reason for Public C		Il organizations must co		s part.) Se	e instructions.					
		ation is not a private founda	ition because it is: (F	or lines 1 through 11, c	heck only	one box.)						
1		A church, convention of chu					(A)(i).					
2		A school described in section										
3 E		A hospital or a cooperative h			ction 170	(b)(1)(A)(iii).					
4	= 1 7	A medical research organiza	tion operated in con	junction with a hospital	described	in section	, n 170(b)(1)(A)(iii), Enter t	he hospital's name,				
4 ∟		city, and state:	Mon operator in co	,			, ,, ,, ,,					
, F	—)	An organization operated for	r the henefit of a coll	ege or university owned	or operat	ed by a go	vernmental unit describ	ed in				
5 L				ogo or arrivoroity ourroa	or opera.	va, g						
		section 170(b)(1)(A)(iv). (Co		antal unit described in a	sastian 17	O(6\/.4\/.6\/	nd.					
6	≓′	A federal, state, or local gov	ernment or governm	entarum described in s	rom a gov	otok ikuk semontali	vj. unit or from the general i	oublic described in				
7 L		An organization that normall		itiai part oi its support ii	ioni a gove	annientar	utilit of from the general i	papilo accombaz				
-		section 170(b)(1)(A)(vi). (Co										
8 _	⊣ ′	A community trust described in section 170(b)(1)(A)(vi). (Complete Part II.)										
9 🗆	An organization that normally receives: (1) more than 33 1/3% of its support from contributions, membership fees, and gross receipts from activities related to its exempt functions - subject to certain exceptions, and (2) no more than 33 1/3% of its support from gross investment											
	á	activities related to its exem	pt functions - subjec	t to certain exceptions,	and (2) no	more than	133 1/3% of its support	-there have 90, 1075				
		ncome and unrelated busin		(less section 511 tax) fro	om busine	sses acqui	red by the organization	arter June 30, 1975.				
	{	See section 509(a)(2). (Con	plete Part III.)									
10 💄		An organization organized a	nd operated exclusi	vely to test for public sa	fety. See s	section 50	9(a)(4).					
11 🗆		An organization organized a	nd operated exclusi	vely for the benefit of, to	perform t	he functio	ns of, or to carry out the	purposes of one of				
	1	more publicly supported org	anizations describe	d in section 509(a)(1) o	r section (509(a)(2). S	See section 509(a)(3). O	heck the box in				
	I	ines 11a through 11d that o	lescribes the type of	supporting organization	n and com	plete lines	11e, 11f, and 11g.					
а		Type I. A supporting organ	nization operated, su	pervised, or controlled	by its sup	ported org	anization(s), typically by	giving				
		the supported organizatio	n(s) the power to req	jularly appoint or elect a	a majority o	of the direc	ctors or trustees of the s	upporting				
		organization. You must co	omplete Part IV, Se	ctions A and B.								
b		Type II. A supporting orga	nization supervised	or controlled in connec	tion with it	s supporte	ed organization(s), by ha	ving				
		control or management of	the supporting orga	inization vested in the s	ame perso	ns that co	ntrol or manage the sup	ported				
		organization(s). You must	complete Part IV,	Sections A and C.								
С		Type III functionally integ	grated. A supporting	organization operated	in connec	tion with, a	and functionally integrate	ed with,				
-		its supported organization	ı(s) (see instructions)). You must complete F	Part IV, Se	ctions A,	D, and E.					
d		Type III non-functionally	integrated. A suppo	orting organization oper	ated in co	nnection w	ith its supported organi	zation(s)				
-		that is not functionally inte	grated. The organiz	ation generally must sat	isty a dist	ribution red	quirement and an attenti	veness				
		requirement (see instruction	ons). You must com	plete Part IV, Sections	A and D,	and Part	V.					
e		Check this box if the orga	nization received a v	vritten determination fro	m the IRS	that it is a	Type I, Type II, Type III					
•		functionally integrated, or	Type III non-function	nally integrated support	ing organiz	zation.						
f I	⊏nt≙r	the number of supported o	rganizations									
		de the following information		d organization(s).								
		Name of supported	(ii) EIN	(lii) Type of organization	(iv) Is the o	rganization	(v) Amount of monetary	(vi) Amount of				
		organization		(described on lines 1-9	listed i governing o		support (see	other support (see Instructions)				
				above or IRC section (see instructions))	Yes	No	Instructions)	instructions)				
			1									
								1				

LHA For Paperwork Reduction Act Notice, see the Instructions for

Form 990 or 990-EZ. 432021 09-17-14

Schedule A (Form 990 or 990-EZ) 2014

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Schedule A (Form 990 or 990-EZ) 2014 RESEARCH ASSOCIATION OF AMERICA 11-2519 Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)

(Complete only if you checked the box on line 5, 7, or 8 of Part I or if the organization failed to qualify under Part III. If the organization fails to qualify under the tests listed below, please complete Part III.)

Se	ction A. Public Support						
Cale	endar year (or fiscal year beginning in)	(a) 2010	(b) 2011	(c) 2012	(d) 2013	(e) 2014	(f) Total
	Gifts, grants, contributions, and						
	membership fees received. (Do not						
	include any "unusual grants.")	489,432.	719,454.	948,110.	757,834.	1052072.	3966902.
2	Tax revenues levied for the organ-						
	ization's benefit and either paid to						
	or expended on its behalf						
3	The value of services or facilities						
	furnished by a governmental unit to]	
	the organization without charge						
4	Total. Add lines 1 through 3	489,432.	719,454.	948,110.	757,834.	1052072.	3966902.
5	The portion of total contributions						
	by each person (other than a						
	governmental unit or publicly				'		
	supported organization) included						
	on line 1 that exceeds 2% of the						
	amount shown on line 11,						
	column (f)						
6	Public support. Subtract line 5 from line 4.			,			3966902.
Sec	ction B. Total Support						
Cale	ndar year (or fiscal year beginning in) ►	(a) 2010	(b) 2011	(c) 2012	(d) 2013	(e) 2014	(f) Total
7	Amounts from line 4	489,432.	719,454.	948,110.	757,834.	1052072.	<u>3966902.</u>
8	Gross income from interest,						
	dividends, payments received on						
	securities loans, rents, royalties						
	and income from similar sources	974.	2,892.	788.	3,917.	1,081.	9,652.
9	Net income from unrelated business	***************************************					
	activities, whether or not the						
	business is regularly carried on						
10	Other income. Do not include gain						
	or loss from the sale of capital						
	assets (Explain in Part VI.)						
11	Total support. Add lines 7 through 10						3 <u>976554</u> .
12	Gross receipts from related activities,	etc. (see instruction	ons)			12	599,658.
13	First five years. If the Form 990 is for	the organization's	first, second, thire	d, fourth, or fifth ta	ıx year as a sectio	n 501(c)(3)	
	organization, check this box and stop	here					<u></u>
Sec	ction C. Computation of Publ	ic Support Pe	rcentage				
14	Public support percentage for 2014 (I	ine 6, column (f) di	vided by line 11, c	olumn (f))		14	99.76 %
	Public support percentage from 2013						99.59 <u>%</u>
16a	33 1/3% support test - 2014. If the o						
	stop here. The organization qualifies						
b	33 1/3% support test - 2013. If the o	rganization did no	t check a box on li	ne 13 or 16a, and	line 15 is 33 1/3%	or more, check th	is box
	and stop here. The organization quali						
17a	10% -facts-and-circumstances test						
	and if the organization meets the "fac	ts-and-circumstan	ces" test, check th	is box and stop h	ere. Explain in Par	t VI how the organ	ization
	meets the "facts-and-circumstances"						
b	10% -facts-and-circumstances test						10% or
	more, and if the organization meets th	ie "facts-and-circui	mstances" test, ch	eck this box and	stop here. Explain	in Part VI how the	
	organization meets the "facts-and-circ		-				
18	Private foundation. If the organization	n did not check a l	oox on line 13, 16a	ı, 16b, 17a, or 17b			
					Scho	dule A (Form 998)	or 990-FZ) 2014

Schedule A (Form 990 or 990-EZ) 2014 | Part III | Support Schedule for Organizations Described in Section 509(a)(2)

ran	Support Schedule for U	_				ort II. If the organize	tion fails to
	(Complete only if you checked			rganization failed t	o quality under Pa	urn. II the organiza	MOIT IAIIS 10
Saat	qualify under the tests listed be ion A. Public Support	low, please com	piete Part II.)				
		(a) 2010	(b) 2011	(c) 2012	(d) 2013	(e) 2014	(f) Total
	lar year (or fiscal year beginning in)	(a) 2010	(1) 2011	(0) 2012	(4) 25.5	107	
	nembership fees received. (Do not						
	nclude any "unusual grants.")						
	· · · · · · · · · · · · · · · · · · ·						
n fe a	Proces receipts from admissions, nerchandise sold or services per- prmed, or facilities furnished in in activity that is related to the irganization's tax-exempt purpose						
3 (Gross receipts from activities that		***				
а	re not an unrelated trade or bus-			:			
ıi	ness under section 513			-			·
4 T	ax revenues levied for the organ-					,	
iz	zation's benefit and either paid to						
	r expended on its behalf						
5 7	he value of services or facilities						
	urnished by a governmental unit to				ļ	1	
ŧ	he organization without charge						
6 1	otal. Add lines 1 through 5		<u> </u>				
7a /	Amounts included on lines 1, 2, and						
	received from disqualified persons						
fe e	mounts included on lines 2 and 3 received om other than disqualified persons that xceed the greater of \$5,000 or 1% of the mount on line 13 for the year						
c/	Add lines 7a and 7b				<u> </u>		
•	Public support (Subtract line 7c from line 6.)			ļ	<u> </u>		<u> </u>
	ion B. Total Support			ſ	() 0040	(-) 0014	(f) Total
Calen	lar year (or fiscal year beginning in) ► 🏻	(a) 2010	(b) 2011	(c) 2012	(d) 2013	(e) 2014	(I) IOIAI
	Amounts from line 6			<u> </u>			
(5	Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
bl	Inrelated business taxable income						
,	less section 511 taxes) from businesses						
8	cquired after June 30, 1975						
11 i	Add lines 10a and 10b Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
	Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI.)						
13	Total SUDDOIT. (Add lines 9, 10c, 11, and 12.)				<u> </u>	1	
14 I	First five years. If the Form 990 is for	the organization	's first, second, thi	rd, fourth, or fifth t	tax year as a section	on 501(c)(3) organi	zation,
(check this box and stop here				<u></u>		
Sect	tion C. Computation of Publi	c Support Pe	ercentage			T T	0/
15	Public support percentage for 2014 (li	ne 8, column (f)	divided by line 13,	column (f))		15	%
16 l	Public support percentage from 2013	Schedule A, Par	t III, line 15			16	%
Sec	tion D. Computation of Inves	tment Incon	ne Percentage	<u> </u>		1	
17	nvestment income percentage for 20	14 (line 10c, colu	ımn (f) divided by l	ine 13, column (f))		17	%
18	nvestment income percentage from 2	2013 Schedule A	, Part III, line 17			18	%
19a	33 1/3% support tests - 2014. If the	organization did	not check the box	on line 14, and lin	e 15 is more than	33 1/3%, and line 	JON 21 \
	more than 33 1/3%, check this box at	nd stop here. Th	ne organization qua	lifies as a publicly	supported organia	zation	P
h:	33 1/3% support tests - 2013, if the	organization did	not check a box o	n line 14 or line 19	a, and line 16 is m	ore than 33 1/3%,	and
	ine 18 is not more than 33 1/3%, che	ck this box and	stop here. The org	anization qualifies	as a publicly supp	ported organization	·►¦
20	Private foundation. If the organization	n did not check a	a box on line 14, 1	9a, or 19b, check t	this box and see ir	istructions	

Schedule A (Form 990 or 990-EZ) 2014 RESEARCH ASSOCIATION OF AMERICA

Part IV Supporting Organizations

(Complete only if you checked a box on line 11 of Part I. If you checked 11a of Part I, complete Sections A and B. If you checked 11b of Part I, complete Sections A and C. If you checked 11c of Part I, complete Sections A, D, and E. If you checked 11d of Part I, complete Sections A and D, and complete Part V.)

Sec	tion A. All Supporting Organizations			
			Yes	No
1	Are all of the organization's supported organizations listed by name in the organization's governing			
	documents? If "No" describe in Part VI how the supported organizations are designated. If designated by			
	class or purpose, describe the designation. If historic and continuing relationship, explain.	1		
2	Did the organization have any supported organization that does not have an IRS determination of status			
	under section 509(a)(1) or (2)? If "Yes," explain in Part VI how the organization determined that the supported			
	organization was described in section 509(a)(1) or (2).	2		
3a	Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? If "Yes," answer			
	(b) and (c) below.	За		
h	Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and			
	satisfied the public support tests under section 509(a)(2)? If "Yes," describe in Part VI when and how the			
	organization made the determination.	3b		İ
_	Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)			
G	(B) purposes? If "Yes," explain in Part VI what controls the organization put in place to ensure such use.	3с		
4-	Was any supported organization not organized in the United States ("foreign supported organization")? If			
4a	"Yes" and if you checked 11a or 11b in Part I, answer (b) and (c) below.	4a		
	Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign			
b				
	supported organization? If "Yes," describe in Part VI how the organization had such control and discretion	4b		
	despite being controlled or supervised by or in connection with its supported organizations.	-40		
С	Did the organization support any foreign supported organization that does not have an IRS determination	1		
	under sections 501(c)(3) and 509(a)(1) or (2)? If "Yes," explain in Part VI what controls the organization used			
	to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B)	4c		
	purposes.	40	 	\vdash
5a	Did the organization add, substitute, or remove any supported organizations during the tax year? If "Yes,"			
	answer (b) and (c) below (if applicable). Also, provide detail in Part VI, including (i) the names and EIN			
	numbers of the supported organizations added, substituted, or removed, (ii) the reasons for each such action,			
	(iii) the authority under the organization's organizing document authorizing such action, and (iv) how the action	-	ŀ	
	was accomplished (such as by amendment to the organizing document).	<u>5a</u>	<u> </u>	
b			-	
	designated in the organization's organizing document?	5b	-	+
С	Substitutions only. Was the substitution the result of an event beyond the organization's control?	_5c_	<u> </u>	\vdash
6	Did the organization provide support (whether in the form of grants or the provision of services or facilities) to			1
	anyone other than (a) its supported organizations; (b) individuals that are part of the charitable class			
	benefited by one or more of its supported organizations; or (c) other supporting organizations that also			1
	support or benefit one or more of the filing organization's supported organizations? If "Yes," provide detail in			
	Part VI.	6	 	├
7	Did the organization provide a grant, loan, compensation, or other similar payment to a substantial			
	contributor (defined in IRC 4958(c)(3)(C)), a family member of a substantial contributor, or a 35-percent			
	controlled entity with regard to a substantial contributor? If "Yes," complete Part I of Schedule L (Form 990).	7	<u> </u>	
8	Did the organization make a loan to a disqualified person (as defined in section 4958) not described in line 7?			
	If "Yes," complete Part I of Schedule L. (Form 990).	8	<u> </u>	-
9a	Was the organization controlled directly or indirectly at any time during the tax year by one or more			
	disqualified persons as defined in section 4946 (other than foundation managers and organizations described			
	in section 509(a)(1) or (2))? If "Yes," provide detail in Part VI.	9a	ļ <u> </u>	
b	we will be a second to the Orall be controlling interest in any ontity in which			
	the supporting organization had an interest? If "Yes," provide detail in Part VI.	9b	_	-
С	The state of the s		1	
	from, assets in which the supporting organization also had an interest? If "Yes," provide detail in Part VI.	<u>9c</u>		
10a	Was the organization subject to the excess business holdings rules of IRC 4943 because of IRC 4943(f)			
	(regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting			***************************************
	organizations)? If "Yes," answer (b) below.	10a		1
h	Did the organization have any excess business holdings in the tax year? (Use Schedule C, Form 4720, to			1
~	determine whether the organization had excess business holdings.)	10b		1

Schedule A (Form 990 or 990-EZ) 2014 RESEARCH ASSOCIATION OF AMERICA

Part	t IV Supporting Organizations (continued)			
			Yes	No
11	Has the organization accepted a gift or contribution from any of the following persons?			
	A person who directly or indirectly controls, either alone or together with persons described in (b) and (c)			
	below, the governing body of a supported organization?	11a		
	A family member of a person described in (a) above?	11b		
	A 35% controlled entity of a person described in (a) or (b) above? If "Yes" to a, b, or c, provide detail in Part VI.	11c		
	tion B. Type I Supporting Organizations			
0000	Mon Bi Typo / oupporting organizations		Yes	No
4	Did the directors, trustees, or membership of one or more supported organizations have the power to			
1	regularly appoint or elect at least a majority of the organization's directors or trustees at all times during the			
	tax year? If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or			
	controlled the organization's activities. If the organization had more than one supported organization,			
	describe how the powers to appoint and/or remove directors or trustees were allocated among the supported	1		
	organizations and what conditions or restrictions, if any, applied to such powers during the tax year.	-		
2	Did the organization operate for the benefit of any supported organization other than the supported			
	organization(s) that operated, supervised, or controlled the supporting organization? If "Yes," explain in			
	Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated,			
	supervised, or controlled the supporting organization.	2		
Sect	tion C. Type II Supporting Organizations		T. T	
			Yes	No
1	Were a majority of the organization's directors or trustees during the tax year also a majority of the directors			
	or trustees of each of the organization's supported organization(s)? If "No," describe in Part VI how control			
	or management of the supporting organization was vested in the same persons that controlled or managed			
	the supported organization(s).	1_		
Sect	tion D. Type III Supporting Organizations			
			Yes	No
1	Did the organization provide to each of its supported organizations, by the last day of the fifth month of the			
	organization's tax year, (1) a written notice describing the type and amount of support provided during the prior tax			
	year, (2) a copy of the Form 990 that was most recently filed as of the date of notification, and (3) copies of the			
	organization's governing documents in effect on the date of notification, to the extent not previously provided?	11	ļ	
2	Were any of the organization's officers, directors, or trustees either (I) appointed or elected by the supported			
_	organization(s) or (ii) serving on the governing body of a supported organization? If "No," explain in Part VI how			
	the organization maintained a close and continuous working relationship with the supported organization(s).	2	L	
3	By reason of the relationship described in (2), did the organization's supported organizations have a			
Ū	significant voice in the organization's investment policies and in directing the use of the organization's			
	income or assets at all times during the tax year? If "Yes," describe in Part VI the role the organization's	1		
	supported organizations played in this regard.	3		
Sect	tion E. Type III Functionally-Integrated Supporting Organizations			
1	Check the box next to the method that the organization used to satisfy the Integral Part Test during the year(see Instructions)	<i>:</i>		
ı a	The organization satisfied the Activities Test, Complete line 2 below.			
a b	The organization is the parent of each of its supported organizations. Complete line 3 below.			
	The organization supported a governmental entity. Describe in Part VI how you supported a government entity (see in	structions	s)	
C	Activities Test. Answer (a) and (b) below.		Yes	No
2	Did substantially all of the organization's activities during the tax year directly further the exempt purposes of			
а	the supported organization(s) to which the organization was responsive? If "Yes," then in Part VI identify			
	those supported organizations and explain how these activities directly furthered their exempt purposes,			
	how the organization was responsive to those supported organizations, and how the organization determined]
	that these activities constituted substantially all of its activities.	2a_	L	
	Did the activities described in (a) constitute activities that, but for the organization's involvement, one or more			
b	of the organization's supported organization(s) would have been engaged in? If "Yes," explain in Part VI the			
	reasons for the organization's position that its supported organization(s) would have engaged in these			
		2b		
	activities but for the organization's involvement.			
3	Parent of Supported Organizations. <i>Answer (a) and (b) below.</i>			
а	Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or	3a		
_	trustees of each of the supported organizations? Provide details in <i>Part VI</i> .			
b	Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? If "Yes," describe in <i>Part VI</i> the role played by the organization in this regard.	3b		
	of its supported organizations? It "Yes," describe in Part VI the role played by the organization in this regard.		1	

	dule A (Form 990 or 990 EZ) 2014 RESEARCH ASSOCIATION OF	AMER	ICA	LI-2519/26 Page
Pai	t V Type III Non-Functionally Integrated 509(a)(3) Supportin			Δ11
1	Check here if the organization satisfied the Integral Part Test as a qualifying			uctions. All
Sect	other Type III non-functionally integrated supporting organizations must co	mpiete Se	(A) Prior Year	(B) Current Year (optional)
1	Net short-term capital gain	1		
	Recoveries of prior-year distributions	2		
3	Other gross income (see instructions)	3		
4	Add lines 1 through 3	4		
5	Depreciation and depletion	5		
6	Portion of operating expenses paid or incurred for production or			
u	collection of gross income or for management, conservation, or			
	maintenance of property held for production of income (see instructions)	6		
7	Other expenses (see instructions)	7		
7	Adjusted Net Income (subtract lines 5, 6 and 7 from line 4)	8		
8			(A) Prior Year	(B) Current Year
Sect	on B - Minimum Asset Amount		(A) FIIOI 1 Gai	(optional)
1	Aggregate fair market value of all non-exempt-use assets (see			
•	instructions for short tax year or assets held for part of year):			
а	Average monthly value of securities	1a		
	Average monthly cash balances	1b		
	Fair market value of other non-exempt-use assets	1c		
	Total (add lines 1a, 1b, and 1c)	1d		
	Discount claimed for blockage or other			
	factors (explain in detail in Part VI):			
2	Acquisition indebtedness applicable to non-exempt-use assets	2		
3	Subtract line 2 from line 1d	3		
4	Cash deemed held for exempt use. Enter 1-1/2% of line 3 (for greater amount,			
•	see instructions).	4		
5	Net value of non-exempt-use assets (subtract line 4 from line 3)	5		
6	Multiply line 5 by .035	6		
7	Recoveries of prior-year distributions	7		
8	Minimum Asset Amount (add line 7 to line 6)	8		
Sect	ion C - Distributable Amount			Current Year
1	Adjusted net income for prior year (from Section A, line 8, Column A)	1		
2	Enter 85% of line 1	2		
3	Minimum asset amount for prior year (from Section B, line 8, Column A)	3		
4	Enter greater of line 2 or line 3	4		
5	Income tax imposed in prior year	5		
6	Distributable Amount. Subtract line 5 from line 4, unless subject to			
U	emergency temporary reduction (see instructions)	6		
7	Check here if the current year is the organization's first as a non-functional	ly-integrat	ed Type III supporting or	ganization (see

Schedule A (Form 990 or 990-EZ) 2014

instructions).

	dule A (Form 990 or 990 EZ) 2014 RESEARCH ASSO			.1-2519726 Page 7
Pa	rt V Type III Non-Functionally Integrated 509	(a)(3) Supporting Orga	anizations (continued)	
Sect	ion D - Distributions			Current Year
1	Amounts paid to supported organizations to accomplish exe			
2	Amounts paid to perform activity that directly furthers exempt	ot purposes of supported		
	organizations, in excess of income from activity			
3	Administrative expenses paid to accomplish exempt purpos	es of supported organization	is	
_4	Amounts paid to acquire exempt-use assets			
_5	Qualified set-aside amounts (prior IRS approval required)			
_6	Other distributions (describe in Part VI). See instructions.			
7	Total annual distributions. Add lines 1 through 6.			
8	Distributions to attentive supported organizations to which t	he organization is responsive)	
	(provide details in Part VI). See instructions.			
_9	Distributable amount for 2014 from Section C, line 6			
10	Line 8 amount divided by Line 9 amount			
		(i)	(ii)	(iii)
Coot	ion E - Distribution Allocations (see instructions)	Excess Distributions	Underdistributions	Distributable
Sec.	ion E - Distribution Allocations (see instructions)		Pre-2014	Amount for 2014
1	Distributable amount for 2014 from Section C, line 6			-
2	Underdistributions, if any, for years prior to 2014			
	(reasonable cause required-see instructions)			
3	Excess distributions carryover, if any, to 2014:			
а				
b				
С				
d				
e	From 2013			
f	Total of lines 3a through e			
a	Applied to underdistributions of prior years			
	Applied to 2014 distributable amount			
i	Carryover from 2009 not applied (see instructions)			
i	Remainder. Subtract lines 3g, 3h, and 3i from 3f.			
4	Distributions for 2014 from Section D,			••
-	line 7: \$			
- а	Applied to underdistributions of prior years			
-	Applied to 2014 distributable amount			
	Remainder, Subtract lines 4a and 4b from 4.			
5	Remaining underdistributions for years prior to 2014, if			
-	any. Subtract lines 3g and 4a from line 2 (if amount			
	greater than zero, see instructions).			
6	Remaining underdistributions for 2014. Subtract lines 3h			
_	and 4b from line 1 (if amount greater than zero, see			
	instructions).		•	
7	Excess distributions carryover to 2015. Add lines 3j			
•	and 4c.			•
8	Breakdown of line 7:			
	DIOGRAPHI OF IRIO 1.			
a b				
	Excess from 2013			
	Excess from 2014			
•	EV0000 10(II EQ 1.1			

Schedule A (Form 990 or 990-EZ) 2014

DYSTROPHIC EPIDERMOLYSIS BULLOSA

Schedule A	(Form 990 or 990-EZ)	2014 RESEARCH	ASSOCIATION	OF P	AMERICA	11-2519726 Page 8
Part VI	Supplemental In	2014 RESEARCH Iformation. Provide	the explanations require	ed by Pai	rt II, line 10; Part II, li	ne 17a or 17b; and Part III, line 12.
	Also complete this no	art for any additional info	ormation (See instruction	ons).		
	Wigo combiere mis he	are for any additional line	omidalom (Coo manaca	31.07.		
	······································					
						
		<u></u>				
		<u> </u>				

Schedule B (Form 990, 990-EZ, or 990-PF)

Department of the Treasury Internal Revenue Service

Schedule of Contributors

Attach to Form 990, Form 990-EZ, or Form 990-PF.
 Information about Schedule B (Form 990, 990-EZ, or 990-PF) and its instructions is at www.irs.gov/form990.

OMB No. 1545-0047

2014

Name of the organization

DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA

Employer identification number

11-2519726

Organization type (check one):

Filers of	:	Section:					
Form 990	or 990-EZ	X 501(c)(3) (enter number) organization					
		4947(a)(1) nonexempt charitable trust not treated as a private foundation					
		527 political organization					
Form 990)-PF	501(c)(3) exempt private foundation					
		4947(a)(1) nonexempt charitable trust treated as a private foundation					
		501(c)(3) taxable private foundation					
		covered by the General Rule or a Special Rule . 7), (8), or (10) organization can check boxes for both the General Rule and a Special Rule. See instructions.					
General	Rule						
	For an organization filing Form 990, 990-EZ, or 990-PF that received, during the year, contributions totaling \$5,000 or more (in money or property) from any one contributor. Complete Parts I and II. See instructions for determining a contributor's total contributions.						
Special	Rules						
	For an organization described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33 1/3% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990 or 990-EZ), Part II, line 13, 16a, or 16b, and that received from any one contributor, during the year, total contributions of the greater of (1) \$5,000 or (2) 2% of the amount on (i) Form 990, Part VIII, line 1h, or (ii) Form 990-EZ, line 1. Complete Parts I and II.						
	For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than \$1,000 exclusively for religious, charitable, scientific, literary, or educational purposes, or for the prevention of cruelty to children or animals. Complete Parts I, II, and III.						
	For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions exclusively for religious, charitable, etc., purposes, but no such contributions totaled more than \$1,000. If this box is checked, enter here the total contributions that were received during the year for an exclusively religious, charitable, etc., purpose. Do not complete any of the parts unless the General Rule applies to this organization because it received nonexclusively religious, charitable, etc., contributions totaling \$5,000 or more during the year						
but it mu	st answer "No" on	at is not covered by the General Rule and/or the Special Rules does not file Schedule B (Form 990, 990-EZ, or 990-PF), Part IV, line 2, of its Form 990; or check the box on line H of its Form 990-EZ or on its Form 990-PF, Part I, line 2, to the filing requirements of Schedule B (Form 990, 990-EZ, or 990-PF).					

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990, 990-EZ, or 990-PF. Schedule B (Form 990, 990-EZ, or 990-PF) (2014)

Name of organization
DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA

Employer identification number

11-2519726

Part I Contributors (see instructions). Use duplicate copies of Part I if additional space is needed.

· art i	Continuators (see alstractions). One daplicate copies of all the add		
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
1	J ALEC & CINDI ALEXANDER 3398 HARBOUR POINT PKWY GAINESVILLE, GA 30506	RBOUR POINT PKWY \$ 32,970.	
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
2	JOHN LEE 555 MONTGOMERY ST SAN FRANCISCO, CA 94111	\$\$	Person X Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
3	HOLLISTER 1580 SOUTH MILWAUKEE AVE LIBERTYVILLE, IL 60048	<u>31,440.</u>	Person X Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
4	MOLNLYCKE HEALTH CARE 500 BALDWIN TOWER EDDYSTONE, PA 19022	\$87,373.	Person X Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
5	MCKESSON PATIENT CARE SOLUTIONS 540 LINDBERGH DR MOON TOWNSHIP, PA 15143	\$\$.	Person X Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
6	SHIRE PHARMACEUTICALS 300 SHIRE WAY LEXINGTON, MA 02421	\$\$.	Person X Payroll Noncash (Complete Part II for noncash contributions.)

Name of organization
DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA

Employer identification number

11-2519726

Part I Contributors (see instructions). Use duplicate copies of Part I if additional space is needed.

raiti	Continuators (accommons), one depression copies of the state of		
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
7	RANDALL TRIPP ROTH BENEFIT FUND 111 VALCOUR LANE DESTREHAN, LA 70047	\$40,000.	Person X Payroll
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
8	SCIODERM 1007 SLATER RD DURHAM, NC 217703	\$\$ <u>33,160</u> .	Person X Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
9	FIBROCELL 400 EAGLEVIEW BLVD EXTON, PA 19341	\$ 29,390.	Person X Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
10	EB CARE LLC 75 BROAD ST NEW YORK, NY 10004	\$ 22,500.	Person X Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
110.		\$	Person Payroll Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		\$	Person Payroll Noncash (Complete Part II for noncash contributions.)

Name of organization DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA

Employer identification number

11-2519726

Part II	Noncash Property (see instructions). Use duplicate copies of Pa	Part II if additional space is needed.			
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (see instructions)	(d) Date received		
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (see instructions)	(d) Date received		
		\$			
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (see instructions)	(d) Date received		
Accountable property in a service of the service of		\$			
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (see instructions)	(d) Date received		
		\$			
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (see instructions)	(d) Date received		
		\$			
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (see instructions)	(d) Date received		
		 	990, 990-EZ, or 990-PF) (

Employer identification number

DYSTROPHIC	EPIDERMOLYSIS	BULLOSA

S	EARCH	ASSO	CIATIO	N OF	AMERICA

Part III	CH ASSOCIATION OF AMER Exclusively religious, charitable, etc., contributed the year from any one contributor. Complete completing Part III, enter the total of exclusively religious Use duplicate copies of Part III if additional	ibutions to organizations described i olumns (a) through (e) and the follow s, charitable, etc., contributions of \$1,000 or l	in section 501(c)(7), (8), or (10) that total more than \$1,000 for ring line entry. For organizations less for the year. (Enter this info. once.)			
a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held			
-		(e) Transfer of gift				
-	Transferee's name, address, ar	nd <u>ZIP</u> + 4	Relationship of transferor to transferee			
a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held			
-	Transferee's name, address, ar	(e) Transfer of gift	Relationship of transferor to transferee			
a) No. From	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held			
	Transferee's name, address, ar	(e) Transfer of gift	Relationship of transferor to transferee			
a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held			
-	(e) Transfer of gift					
	Transferee's name, address, a	nd ZIP + 4	Relationship of transferor to transferee			
-						

SCHEDULE D

(Form 990)

Supplemental Financial Statements

Complete if the organization answered "Yes" to Form 990,
Part IV, line 6, 7, 8, 9, 10, 11a, 11b, 11c, 11d, 11e, 11f, 12a, or 12b.

Attach to Form 990.

Information about Schedule D (Form 990) and its instructions is at www.irs.gov/form990.

Open to Public Inspection

Department of the Treasury Internal Revenue Service Name of the organization

DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA

Employer identification number 11-2519726

OMB No. 1545-0047

Par	t I Organizations Maintaining Donor Advised	Funds or Other Similar Fun	ds or Accounts. Complete if the
	organization answered "Yes" to Form 990, Part IV, line		
		(a) Donor advised funds	(b) Funds and other accounts
1	Total number at end of year		
2	Aggregate value of contributions to (during year)		
3	Aggregate value of grants from (during year)		
4	Aggregate value at end of year		
5	Did the organization inform all donors and donor advisors in w	riting that the assets held in donor ad	vised funds
v	are the organization's property, subject to the organization's e		
6	Did the organization inform all grantees, donors, and donor ad	visors in writing that grant funds can	be used only
Ü	for charitable purposes and not for the benefit of the donor or	donor advisor, or for any other purpo	se conferring
	impermissible private benefit?		
Pai		nization answered "Yes" to Form 990), Part IV, line 7.
1	Purpose(s) of conservation easements held by the organization		
•	Preservation of land for public use (e.g., recreation or ed		istorically important land area
	Protection of natural habitat		ertified historic structure
	Preservation of open space		
2	Complete lines 2a through 2d if the organization held a qualifie	ed conservation contribution in the for	rm of a conservation easement on the last
_	day of the tax year.		
	day of the tax your		Held at the End of the Tax Year
а	Total number of conservation easements		2a
b	Total acreage restricted by conservation easements		
c	Number of conservation easements on a certified historic structure.	cture included in (a)	2c
ď	and the second s	fter 8/17/06, and not on a historic stru	ıcture
-	listed in the National Register		2d
3	Number of conservation easements modified, transferred, rele	ased, extinguished, or terminated by	the organization during the tax
	year >		
4	Number of states where property subject to conservation ease	ement is located 🕨	_
5	Does the organization have a written policy regarding the period	odic monitoring, inspection, handling	of
	violations, and enforcement of the conservation easements it	holds?	Yes No
6	Staff and volunteer hours devoted to monitoring, inspecting, a	and enforcing conservation easements	s during the year 🚩
7	Amount of expenses incurred in monitoring, inspecting, and en	nforcing conservation easements dur	ing the year ► \$
8	Does each conservation easement reported on line 2(d) above	e satisfy the requirements of section 1	70(h)(4)(B)(i)
	and section 170(h)(4)(B)(ii)?		Yes No
9	In Part XIII, describe how the organization reports conservatio	n easements in its revenue and exper	nse statement, and balance sheet, and
	include, if applicable, the text of the footnote to the organization	on's financial statements that describ	es the organization's accounting for
	concernation encoments		
Pai	rt III Organizations Maintaining Collections of	Art, Historical Treasures, or	Other Similar Assets.
	Complete if the organization answered "Yes" to Form 9	90, Part IV, line 8.	
1a	If the organization elected, as permitted under SFAS 116 (ASC	C 958), not to report in its revenue sta	tement and balance sheet works of art,
	historical treasures, or other similar assets held for public exhi	bition, education, or research in furth	erance of public service, provide, in Part XIII,
	the text of the footnote to its financial statements that describ	es these items.	
b	If the organization elected, as permitted under SFAS 116 (ASC	C 958), to report in its revenue statem	ent and balance sheet works of art, historical
	treasures, or other similar assets held for public exhibition, ed	ucation, or research in furtherance of	public service, provide the following amounts
	relating to these items:		. .
	(i) Revenue included in Form 990, Part VIII, line 1		
	(ii) Assets included in Form 990, Part X		🕨 \$
2	If the organization received or held works of art, historical trea	sures, or other similar assets for finan	icial gain, provide
	the following amounts required to be reported under SFAS 11	6 (ASC 958) relating to these items:	.
а	Revenue included in Form 990, Part VIII, line 1		
b	Assets included in Form 990, Part X		

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990. 432051 10-01-14

Schedule D (Form 990) 2014

	rt III Organizations Maintaining C	Collections of A				r Othe	r Simila	r Asse	ts/contin	rued)	-95
3	Using the organization's acquisition, accessi										
ن	(check all that apply):	on, and other record	.U. U. 10U	carry or the	. Sho maig trict	a a a a	Garie u				- -
_	Public exhibition	d		l oan or eve	hange prograi	me					
a		e			nange program						
b	Scholarly research	е	, [Vallet						•	
C	Preservation for future generations Provide a description of the organization's co	allostians and avalai	n how th	ov furthar t	ha araanizatia	n'e avon	nt nurno	ea in Pari	· VIII		
4	During the year, did the organization solicit or							se iii i ai	. Alli.		
5	to be sold to raise funds rather than to be ma								Yes	Γ.	□No
Pa	rt IV Escrow and Custodial Arran										
1 4	reported an amount on Form 990, Pa	-	ete ii tile	Organizatio	II alisweieu	163 101	OH 11 000,	i airiv, i	1110 0, 01		
40	Is the organization an agent, trustee, custod		tiany for	contribution	e or other ass	ets not i	actuded				
ıa									Yes		No
	on Form 990, Part X?								_ 103	L	
a	it "Yes," explain the arrangement in Part Alli	and complete the to	niownig i	aoie.				***************************************	Amount		
	Danisulus kalausa						1c		7 WI JOURN		
	Beginning balance										
a	d Additions during the year										
е.	Distributions during the year										
f	Ending balance								Yes		No
	Did the organization include an amount on F								-	<u> </u>	
	b If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided in Part XIII Part V Endowment Funds. Complete if the organization answered "Yes" to Form 990, Part IV, line 10.										
га	TEV Endowment Funds. Complete				(c) Two years			are back	(a) Four	· vaare	hack
		(a) Current year	(a) ⊢	rior year	(c) two years	S DACK (a) Tillee ye	als Dack	(e) 1 out	years	Duon_
1a											
b	b Contributions										
C	c Net investment earnings, gains, and losses										
d	d Grants or scholarships										
е	Other expenditures for facilities										
	and programs										
f	Administrative expenses										
g	End of year balance										
2	Provide the estimated percentage of the curr	rent year end baland	e (line 1	g, column (a	ı)) held as:						
а											
b	b Permanent endowment >%										
¢	c Temporarily restricted endowment										
	The percentages in lines 2a, 2b, and 2c shou	ıld equal 100%.									
3a	Are there endowment funds not in the posse	ssion of the organiz	ation tha	at are held a	nd administer	ed for th	e organiza	ation	r		
	by:									Yes	No
	(i) unrelated organizations								3a(i)		
	(ii) related organizations										
b	b If "Yes" to 3a(ii), are the related organizations listed as required on Schedule R?										
4											
	rt VI Land, Buildings, and Equipm	ent.									
	Complete if the organization answere	d "Yes" to Form 990	, Part IV	, line 11a. S	ee Form 990,	Part X, li	ne 10.				
	Description of property	(a) Cost or o			or other		cumulated	ı	(d) Bool	k valu	ıe
		basis (investr			(other)	depi	eciation				
1a	Land										
b	Buildings										
c	Leasehold improvements										
d	Equipment	•									
	Other	ı		3	2,629.		14,13	0.	1	8,4	99.
	I. Add lines 1a through 1e. (Column (d) must e		X. colun					D			99.
ıvıd	6.7 NO BIDO LA RILOUGIE FO. LOOIGHIEL (G) THUSE E	garant on it over the	,	,			s	chedule			

RESEARCH ASSOCIATION OF AMERICA

Part VII Investments - Other Securities.			
Complete if the organization answered "Yes"		e 11b. See Form 990, Part X, line 12.	
(a) Description of security or category (including name of security)	(b) Book value	(c) Method of valuation: Cost	or end-of-year market value
(1) Financial derivatives			
(2) Closely-held equity interests			
(3) Other			
(A)			
(B)			
(C)			
(D)			
(E)			
(F)			
(G)			
(H)			
Total. (Col. (b) must equal Form 990, Part X, col. (B) line 12.) Part VIII Investments - Program Related.			
	to Form 000 Dort IV lin	a 11a Cas Earm 800 Bart V line 12	
Complete if the organization answered "Yes" (a) Description of investment	(b) Book value	(c) Method of valuation: Cost	or end-of-vear market value
	(B) Book raido	(o) monios or manancia o car	
(1)			
(2)			
(3)			
(4)			
(5) (6)			
(7)			
(8)			
(9)			
Total. (Col. (b) must equal Form 990, Part X, col. (B) line 13.)			
Part IX Other Assets.	<u> </u>		
Complete if the organization answered "Yes"	to Form 990, Part IV, lin	e 11d. See Form 990, Part X, line 15.	
	Description		(b) Book value
(1)			
(2)			
(3)			
(4)			
(5)			
(6)			
(7)			
(8)			
(9)			
Total. (Column (b) must equal Form 990, Part X, col. (B) line Part X Other Liabilities.	e 15.)		▶
Complete if the organization answered "Yes"	to Form 990, Part IV, lin	e 11e o <u>r 11f. S</u> ee Form 990, Part X, li	ne 25.
1. (a) Description of liability		(b) Book value	
(1) Federal income taxes			
(2)			
(3)			
(4)			
(5)			
(6)			
(7)			
(8)			
(9)			
Total. (Column (b) must equal Form 990, Part X, col. (B) line	e 25.)		
2 Liability for uncertain tay positions. In Part XIII provide		to the organization's financial statem	nents that reports the

432053 10-01-14

^{2.} Liability for uncertain tax positions. In Part XIII, provide the text of the footnote to the organization's financial statements that reports the organization's liability for uncertain tax positions under FIN 48 (ASC 740). Check here if the text of the footnote has been provided in Part XIII X

Schedule D (Form 990) 2014

RESEARCH ASSOCIATION OF AMERICA

Pa	Complete if the organization answered "Yes" to Form 990, Part IV, line		Revenue per i	neturi	l•
	Total revenue, gains, and other support per audited financial statements			1	1,986,290.
1	**				<u> </u>
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12: Net unrealized gains (losses) on investments	2a	<3,764	.	
a	Donated services and use of facilities		436,926		
b	Recoveries of prior year grants			1	
c	Other (Describe in Part XIII.)			┦	
d e	Add lines 2a through 2d			2e	433,162.
3	Subtract line 2e from line 1				1,553,128.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:				-
ъ	Investment expenses not included on Form 990, Part VIII, line 7b	4a			
b	Other (Describe in Part XIII.)				
C				4c	0.
5	Total revenue. Add lines 3 and 4c. (This must equal Form 990, Part I, line 12.			5	1,553,128.
Рa	rt XII Reconciliation of Expenses per Audited Financial St	atements Witl	n Expenses pe	r Retu	rn.
	Complete if the organization answered "Yes" to Form 990, Part IV, line				
1	Total expenses and losses per audited financial statements			1	<u>1,745,746.</u>
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:				
а	Donated services and use of facilities	2a	436,927	<u>.</u>	
b	Prior year adjustments	1 1		_	
C	Other losses	_		_	
d	Other (Describe in Part XIII.)			_	
е				2e	<u>436,927.</u>
3	Subtract line 2e from line 1				1,308,819.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:				
а	Investment expenses not included on Form 990, Part VIII, line 7b	4a		-	
b	Other (Describe in Part XIII.)	4b		_	•
С	Add lines 4a and 4b			4c	0.
5	Total expenses. Add lines 3 and 4c. (This must equal Form 990, Part I, line 1	8.)		5_	1,308,819.
Pa	rt XIII Supplemental Information.				
Prov	ide the descriptions required for Part II, lines 3, 5, and 9; Part III, lines 1a and	4; Part IV, lines 1b	and 2b; Part V, line	4; Part	X, line 2; Part XI,
lines	2d and 4b; and Part XII, lines 2d and 4b. Also complete this part to provide a	ny additional infor	nation.		
PA.	RT X, LINE 2:				
	- CD CONTEST ON DEGOCALIZED BUT REFERED OF	שאע פרפד	TTONG ONL	V WH	EN THEY ARE
TH.	E ORGANIZATION RECOGNIZES THE EFFECT OF	TAA PUSI	TIONS ONL	T AATT	DIA TITUT STEED
	DE TAKETH MUNN NOW OF DETMC CHCENTNED	MANTA CEMEN	и нус реф.	тияя	ико тнат
MO.	RE LIKELY THAN NOT OF BEING SUSTAINED.	MAMADAMEN	I HAD DEL	131414.	IVIII IIII
m TT	E ORGANIZATION HAD NO UNCERTAIN TAX POS	TTTONS TH	י תיוווטש ייבו	REOU	TRE
<u>1H.</u>	E URGANIZATION HAD NO UNCERTAIN TAX FOR	TITOMP TI	HIL MOODE	<u></u> 20	
13 T 1	NANCIAL STATEMENT RECOGNITION. TAX YEAR	S DATTNG	BACK TO 2	011	REMAIN OPEN
ĽΙ.	NANCIAL STATEMENT RECOGNITION: TAX TEAM	DHIIMO	Differ 10 2	<u> </u>	
шΔ	EXAMINATION BY FEDERAL AND STATE AUTHO	RTTTES.			
TO	EXAMINATION BY FEDERAL AND STATE ACTIO	WITTED.			
י א כד ד אי כד	RT XII, LINE 2D - OTHER ADJUSTMENTS:				
rA.	MI VII' HIME VD - OLHEW ADOODIMEMID.				
тът	KIND EXPENSES				
TT/	KTIAD DIVERBORD				
-					

Cahadula D (Carm 000) 2014	DYSTROPHIC	EPIDERMOL	YSIS BULLOSA OF AMERICA	11-2519726 Page 5
Schedule D (Form 990) 2014 Part XIII Supplemental Inform	mation (continued)	POOCTVITOIA	OF AMBRICA	11 2515/20 rugos
Cupplemental inter-	Traction (continued)			
1				

SCHEDULE F (Form 990)

Statement of Activities Outside the United States

Complete if the organization answered "Yes" on Form 990, Part IV, line 14b, 15, or 16.

OMB No. 1545-0047

Department of the Treasury

Attach to Form 990. Information about Schedule F (Form 990) and its instructions is at www.irs.gov/form990. Open to Public Inspection

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	ne of the organization					Employer identi	fication number
	STROPHIC EPID					11 05107	26
	SEARCH ASSOCI	ATION OF	AMERICA	tside the United States. Comple	4 - # 4b	11-251972	
Pa			ctivities Out	tside the United States. Comple	te if the organ	ization answered	res on
	Form 990, Part IV		maintain recor	ds to substantiate the amount of its gra	nts and other	assistance.	
1	the grantage' eligibility for	or the grante or a	riidiiidaii record	the selection criteria used to award the	grants or assi	stance?	Yes X No
	the grantees engineer to	or the grants or a	assistance, and	ing account official asset to award in	granto or door		
2	For grantmakers, Desc	ribe in Part V the	organization's	procedures for monitoring the use of its	grants and o	ther assistance out	tside the
_	United States.				-		
3		ne following Part	I, line 3 table ca	an be duplicated if additional space is n	eeded.)		
	(a) Region	(b) Number of	(c) Number of	(d) Activities conducted in region	(e) If activ	vity listed in (d)	(f) Total
		offices	employees, agents, and independent contractors	(by type) (e.g., fundraising, program	,	gram service,	expenditures for and
		in the region	independent	services, investments, grants to recipients located in the region)		specific type ce(s) in region	investments
			in region	recipients located in the region)	OI SEIVIC	e(s) iii region	in region

3 a	Sub-total	0	0				0.
h	Total from continuation						

and 3b) LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990.

Schedule F (Form 990) 2014

sheets to Part I c Totals (add lines 3a

DYSTROPHIC EPIDERMOLYSIS BULLOSA

RESEARCH ASSOCIATION OF AMERICA

Schedule F (Form 990) 2014

Part II Grants and Other Assistance to Organizations or Entities Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 15, for any recipient who received more than \$5,000. Part II can be duplicated if additional space is needed.

1 (a) Name of organization	(b) IRS code section and EIN (if applicable)	(c) Region	(d) Purpose of grant TO FUND INTERNATIONAL	(e) Amount of cash grant	(f) Manner of cash disbursement	(g) Amount of non-cash assistance	(h) Description of non-cash assistance	(i) Method of valuation (book, FMV, appraisal, other)
		EUROPE	** ~ U	Ó	CASH TRANSFER	0) M
ber of which t ber of	Enter total number of recipient organizations listed a the IRS, or for which the grantee or counsel has pro Enter total number of other organizations or entities	ins listed above that are lel has provided a sectic or entities	Enter total number of recipient organizations listed above that are recognized as charities by the foreign country, recognized as tax-exempt by the IRS, or for which the grantee or counsel has provided a section 501(c)(3) equivalency letter Enter total number of other organizations or entities	foreign country,	recognized as tax-e	kempt by		
							Schec	Schedule F (Form 990) 2014

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11-2519726

Schedule F (Form 990) 2014

Part III Grants and Other Assistance to Individuals Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 16.

Part III can be duplicated if additional space is needed.

(h) Method of valuation (book, FMV, appraisal, other)					en en en en en en en en en en en en en e	Schedule F (Form 990) 2014
						Schedule F (F
(g) Description of non-cash assistance						
(f) Amount of non-cash assistance						
(e) Manner of cash disbursement						
(d) Amount of cash grant						
(c) Number of recipients						
(b) Region						
(a) Type of grant or assistance						

Schedule F (Form 990) 2014 RESEARCH ASSOCIATION OF AMERICA Part IV Foreign Forms

I GIL	Foreign Forms		
1	Was the organization a U.S. transferor of property to a foreign corporation during the tax year? If "Yes," the organization may be required to file Form 926, Return by a U.S. Transferor of Property to a Foreign Corporation (see Instructions for Form 926)	Yes	X No
2	Did the organization have an interest in a foreign trust during the tax year? If "Yes," the organization may be required to file Form 3520, Annual Return To Report Transactions With Foreign Trusts and Receipt of Certain Foreign Gifts, and/or Form 3520-A, Annual Information Return of Foreign Trust With a U.S. Owner (see Instructions for Forms 3520 and 3520-A; do not file with Form 990)	Yes	X No
3	Did the organization have an ownership interest in a foreign corporation during the tax year? If "Yes," the organization may be required to file Form 5471, Information Return of U.S. Persons With Respect To Certain Foreign Corporations (see Instructions for Form 5471)	Yes	X No
4	Was the organization a direct or indirect shareholder of a passive foreign investment company or a qualified electing fund during the tax year? If "Yes," the organization may be required to file Form 8621, Information Return by a Shareholder of a Passive Foreign Investment Company or Qualified Electing Fund (see Instructions for Form 8621)	Yes	X No
5	Did the organization have an ownership interest in a foreign partnership during the tax year? If "Yes," the organization may be required to file Form 8865, Return of U.S. Persons With Respect to Certain Foreign Partnerships (see Instructions for Form 8865)	Yes	X No
6	Did the organization have any operations in or related to any boycotting countries during the tax year? If "Yes," the organization may be required to file Form 5713, International Boycott Report (see Instructions for Form 5713; do not file with Form 990)	Yes	X No

Schedule F (Form 990) 2014

SCHEDULE G

Department of the Treasury

(Form 990 or 990-EZ)

Supplemental Information Regarding Fundraising or Gaming Activities

Complete if the organization answered "Yes" to Form 990, Part IV, lines 17, 18, or 19, or if the organization entered more than \$15,000 on Form 990-EZ, line 6a. Attach to Form 990 or Form 990-EZ.

Information about Schedule G (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form 990.

OMB No. 1545-0047

Open to Public Inspection

Internal Revenue Service Name of the organization

DYSTROPHIC EPIDERMOLYSIS BULLOSA

Employer identification number

11-2519726 RESEARCH ASSOCIATION OF AMERICA Fundraising Activities. Complete if the organization answered "Yes" to Form 990, Part IV, line 17. Form 990-EZ filers are not Part I required to complete this part. 1 Indicate whether the organization raised funds through any of the following activities. Check all that apply. Solicitation of non-government grants Mail solicitations Solicitation of government grants Internet and email solicitations b Special fundraising events Phone solicitations C d In-person solicitations 2 a Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or □ No Yes key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services? b If "Yes," list the ten highest paid individuals or entities (fundraisers) pursuant to agreements under which the fundraiser is to be compensated at least \$5,000 by the organization. (iii) Did fundraiser have custody or control of contributions? (v) Amount paid (vi) Amount paid (iv) Gross receipts (i) Name and address of individual to (or retained by) to (or retained by) (ii) Activity fundraiser from activity or entity (fundraiser) organization listed in col. (i) Yes No List all states in which the organization is registered or licensed to solicit contributions or has been notified it is exempt from registration or licensing.

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.

Schedule G (Form 990 or 990-EZ) 2014

DYSTROPHIC EPIDERMOLYSIS BULLOSA Schedule G (Form 990 or 990-EZ) 2014 RESEARCH ASSOCIATION OF AMERICA 11-2519726 Page 2 Fundraising Events. Complete if the organization answered "Yes" to Form 990, Part IV, line 18, or reported more than \$15,000 of fundraising event contributions and gross income on Form 990-EZ, lines 1 and 6b. List events with gross receipts greater than \$5,000. (c) Other events (b) Event #2 (a) Event #1 (d) Total events NONE ANNUAL (add col. (a) through GOLF/TENNIS col. (c)) (event type) (total number) (event type) 648,365. 648,365 Gross receipts Less: Contributions <u>648,365.</u> 648,365. Gross income (line 1 minus line 2) 4 Cash prizes Noncash prizes Direct Expenses Rent/facility costs Food and beverages Entertainment 162,254. Other direct expenses 10 Direct expense summary. Add lines 4 through 9 in column (d) 486,111 11 Net income summary. Subtract line 10 from line 3, column (d) Part III | Gaming. Complete if the organization answered "Yes" to Form 990, Part IV, line 19, or reported more than \$15,000 on Form 990-EZ, line 6a. (d) Total gaming (add (b) Pull tabs/instant (c) Other gaming (a) Bingo venue col. (a) through col. (c)) bingo/progressive bingo æ Gross revenue Cash prizes Direct Expenses Noncash prizes Rent/facility costs Other direct expenses Yes Yes No No Volunteer labor Direct expense summary. Add lines 2 through 5 in column (d) Net gaming income summary. Subtract line 7 from line 1, column (d) 9 Enter the state(s) in which the organization conducts gaming activities: a Is the organization licensed to conduct gaming activities in each of these states? b If "No," explain: 10a Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year? Yes

Schedule G (Form 990 or 990-EZ) 2014

b If "Yes," explain:

432082 08-28-14

DYSTROPHIC EPIDERMOLYSIS BULLOSA Schedule G (Form 990 or 990-EZ) 2014 RESEARCH ASSOCIATION OF AMERICA 11 Does the organization conduct gaming activities with nonmembers? 12 Is the organization a grantor, beneficiary or trustee of a trust or a member of a partnership or other entity formed to administer charitable gaming? 13 Indicate the percentage of gaming activity conducted in: b An outside facility 14 Enter the name and address of the person who prepares the organization's gaming/special events books and records: b If "Yes," enter the amount of gaming revenue received by the organization ▶ \$______ and the amount of gaming revenue retained by the third party > \$ c If "Yes," enter name and address of the third party: Name 🕨 Address > Gaming manager information: Name > Gaming manager compensation > \$_____ Description of services provided Independent contractor __ Director/officer 17 Mandatory distributions: a Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license? b Enter the amount of distributions required under state law to be distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year > \$ Supplemental Information. Provide the explanations required by Part I, line 2b, columns (iii) and (v), and Part III, lines 9, 9b, 10b, 15b, Part IV 15c, 16, and 17b, as applicable. Also provide any additional information (see instructions).

Schedule G (Form 990 or 990-EZ) 2014

*:		DYSTROPHIC		OLYSIS BU	LLOSA		
Schedule G	(Form 990 or 990-EZ) Supplemental Infor	RESEARCH A	SSOCIATIO	ON OF AME	RICA	11-2519726	Page 4
Part IV	Supplemental Infor	mation (continued)					
						-	
							<u> </u>

SCHEDULE (Form 990)

Internal Revenue Service | PInformation about Schedule I (Form 990) and its instructions is at www.irs.gov/form990.

Name of the organization DYSTROPHIC EPIDERMOLYSIS BULLOSA Department of the Treasury Internal Revenue Service

Governments, and Individuals in the United States Grants and Other Assistance to Organizations,

Complete if the organization answered "Yes" to Form 990, Part IV, line 21 or 22.

▶ Attach to Form 990.

Open to Public

Inspection

OMB No. 1545-0047

Employer identification number 11-2519726		X Yes No		ne 21, for any	(h) Purpose of grant or assistance	and the control of th			7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7 7	*****		- Company of the Comp	**************************************	A	Schedule I (Form 990) (2014)
E E	***************************************	the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection		Domestic Governments. Complete if the organization answered "Yes" to Form 990, Part IV, line 21, for any	(g) Description of non-cash assistance	100000000000000000000000000000000000000		against a control of the control of		A THE STATE OF THE	 TO THE PARTY OF TH				
		for the grants or ass		nization answered "Y	(f) Method of valuation (book, EMV)	other)		7.77							
		grantees' eligibility	d States.	omplete if the orga		assistance				-					
osa Ca		or assistance, the	funds in the United	Governments.	onal space is need (d) Amount of cash grant								isted in the line 1 table		
OLYSIS BULLOSA ON OF AMERICA			oring the use of grant	ations and Domestic	(c) IRC section if applicable								nanizations listed in th		ons for Form 990.
S EPIDERM(ASSOCIATIO	nd Assistance	o substantiate the tance?	cedures for monito	Somestic Organiz	5,000. Part II can (b) EIN						The state of the s		nd government or	s listed in the line 1	see the Instructi
Name of the organization DYSTROPHIC EPIDERMOLYSIS RESEARCH ASSOCIATION OF	Part I General Information on Grants and Assistance	Does the organization maintain records to substantiate the amount of criteria used to award the grants or assistance?	2 Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States	Part II Grants and Other Assistance to Domestic Organizations and	1 (a) Name and address of organization or government or government or government or grown and address of organization or government or governm					***************************************			2 Enter total number of section 501(c)(3) and government organizations		a

DYSTROPHIC EPIDERMOLYSIS BULLOSA

Page 2

11-2519726

Schedule I (Form 990) (2014)

(Form 990) (2014) RESEARCH ASSOCIATION OF AMERICA Grants and Other Assistance to Domestic Individuals. Complete if the organization answered "Yes" to Form 990, Part IV, line 22. Part III can be duplicated if additional space is needed.

Part III

(a) Type of grant or assistance	(b) Number of recipients	(c) Amount of cash grant	(d) Amount of non- cash assistance	(e) Method of valuation (book, FMV, appraisal, other)	(f) Description of non-cash assistance
					The supplication of the su
Part IV Supplemental Information, Provide the information required in	tuired in Part I, line	2, Part III, column	Part I, line 2, Part III, column (b), and any other additional information.	ditional information.	
PART I, LINE 2:	***************************************				THEORETON
THE BOARD OF DIRECTORS REVIEWS AND APPROVES ALL REQUEST FOR RESEARCH FUNDS.	APPROVE	S ALL REQU	EST FOR RE	SEARCH FUNDS.	
THE ENTITY RECEIVING RESEARCH FUNDS PR	S PROVIDI	SS WRITTEN	UPDATES O	OVIDES WRITTEN UPDATES ON THE USE OF	and the second s
THE FUNDS.					

41

SCHEDULE M (Form 990)

Noncash Contributions

OMB No. 1545-0047

Inspection

Department of the Treasury Internal Revenue Service

Name of the organization

Complete if the organizations answered "Yes" on Form 990, Part IV, lines 29 or 30.

Attach to Form 990.

Information about Schedule M (Form 990) and its instructions is at www.irs.gov/form990. DYSTROPHIC EPIDERMOLYSIS BULLOSA

Employer identification number

Schedule M (Form 990) (2014)

11-2519726 RESEARCH ASSOCIATION OF AMERICA Types of Property (d) (b) (c) (a) Noncash contribution Method of determining Number of Check if contributions or amounts reported on noncash contribution amounts applicable tems contributed Form 990, Part VIII, line 1a Art - Works of art Art - Historical treasures 2 Art - Fractional interests Books and publications Clothing and household goods 5 Cars and other vehicles 6 Boats and planes _____ 7 Intellectual property _____ 8 Securities - Publicly traded 9 Securities - Closely held stock 10 Securities - Partnership, LLC, or 11 trust interests Securities · Miscellaneous 12 Qualified conservation contribution -13 Historic structures Qualified conservation contribution - Other... 14 Real estate - Residential 15 Real estate - Commercial 16 17 Real estate - Other 18 Collectibles Food inventory 19 418,727. FMV Х 20 Drugs and medical supplies 21 Taxidermy 22 Historical artifacts Scientific specimens 23 Archeological artifacts 24 18,200. FAIR MARKET VALUE (LEGAL SERVICE) 25 Other Other 26 27 Other Other 28 Number of Forms 8283 received by the organization during the tax year for contributions for which the organization completed Form 8283, Part IV, Donee Acknowledgement ______ Yes No 30a During the year, did the organization receive by contribution any property reported in Part I, lines 1 through 28, that it must hold for at least three years from the date of the initial contribution, and which is not required to be used for Х exempt purposes for the entire holding period? 30a b If "Yes," describe the arrangement in Part II. Does the organization have a gift acceptance policy that requires the review of any non-standard contributions? 31 X 32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash X contributions? b If "Yes," describe in Part II. If the organization did not report an amount in column (c) for a type of property for which column (a) is checked, describe in Part II.

LHA

For Paperwork Reduction Act Notice, see the Instructions for Form 990.

DYSTROPHIC EPIDERMOLYSIS BULLOSA

Part II	Supplemental Information. Provide the information required by Part I, lines 30b, 32b, and 33, and whether the organization is reporting in Part I, column (b), the number of contributions, the number of items received, or a combination of both. Also complete this part for any additional information.
	

Schedule M (Form 990) (2014)

SCHEDULE O

(Form 990 or 990-EZ)

Department of the Treasury Internal Revenue Service

Supplemental Information to Form 990 or 990-EZ

Complete to provide information for responses to specific questions on Form 990 or 990-EZ or to provide any additional information.

Attach to Form 990 or 990-EZ.

Information about Schedule O (Form 990 or 990-EZ) and its instructions is at www.irs.gov/form990.

Open to Public Inspection

OMB No. 1545-0047

Name of the organization

DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA

Employer identification number 11-2519726

FORM 990, PART I, LINE 1, DESCRIPTION OF ORGANIZATION MISSION:
UNITED STATES TODAY, EB IS A GENETICALLY BASED DISEASE CHARACTERIZED BY
CHRONIC, PAINFUL BLISTERING. THE SKIN AND MUCOUS MEMBRANES ARE SO
FRAGILE THAT THE SLIGHTEST TOUCH CAN CAUSE SEVERE BLISTERING INSIDE AND
OUTSIDE THE BODY. PRESENT AT BIRTH, EB AFFECTS MEN AND WOMEN OF ALL
RACES AND ETHNIC GROUPS AND SOMETIMES, WHEN THERE IS NO FAMILY HISTORY,
IT OCCURS AS THE RESULT OF A SPONTANEOUS GENETIC MUTATION. TODAY, THERE
IS NO CURE OR TREATMENT FOR EB, EXCEPT DAILY WOUND CARE AND BANDAGING.
GENETIC RESEARCH IS MAKING PROGRESS TOWARDS TREATMENTS AND A CURE.
r
FORM 990, PART III, LINE 1, DESCRIPTION OF ORGANIZATION MISSION:
SLIGHTEST TOUCH CAN CAUSE SEVERE BLISTERING INSIDE AND OUTSIDE THE
BODY. PRESENT AT BIRTH, EB AFFECTS MEN AND WOMEN OF ALL RACES AND
ETHNIC GROUPS AND SOMETIMES, WHEN THERE IS NO FAMILY HISTORY, IT OCCURS
AS THE RESULT OF A SPONTANEOUS GENETIC MUTATION. TODAY, THERE IS NO
CURE OR TREATMENT FOR EB, EXCEPT DAILY WOUND CARE AND BANDAGING.
GENETIC RESEARCH IS MAKING PROGRESS TOWARDS TREATMENTS AND A CURE.
FORM 990, PART III, LINE 4D, OTHER PROGRAM SERVICES:
RESEARCH - PROVIDE GRANTS FOR RESEARCH INTO THE CAUSES, TREATMENT &
PREVENTION OF EB AND ITS COMPLICATIONS
EXPENSES \$ 117,803. INCLUDING GRANTS OF \$ 0. REVENUE \$ 0.
FORM 990, PART VI, SECTION B, LINE 11:
THE BOARD OF DIRECTORS MEETS WITH THE CERTIFIED PUBLIC ACCOUNTANT TO REVIEW
THE ANNUAL AUDITED FINANCIAL STATEMENTS, MANAGEMENT LETTER AND FORM 990.

Schedule O (Form 990 or 990-EZ) (2014)

432211 08-27-14

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990 or 990-EZ.

Current Current Year Sec 179 Deduction	239	720	213	198	456	143	518	167	107	3,913	347	156	517	0. 7,694		•	
Accumulated Depreciation	1,181	1,442	426	396	912	143	346	28	18	1,417	87	39		6,435			
Basis For Depreciation	1,420.	2,162.	640.	594.	2,279.	430	1,555.	500.	320.	19,567.	1,734.	468.	1,861,	33,530.		<901,	
Reduction In Basis														.:			
Bus % Excl		1										: +				^	
Unadjusted Cost Or Basis	1,420.	2,162.	640.	594.	2,279.	430.	1,555.	500.	320.	19,567.	1,734.	468.	1,861.	33,530.		<901.	
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Life	3.00	3.00	3.00	3.00	5.00	3.00	3.00	3.00	3.00	5.00	5.00	3.00	3.00			5.00	
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Description	23DELL COMPUTER	24COMPUTER	25COMPUTER	26COMPUTER	27FURNITURE	28SWITCH	29LENOVO LAPTOP	30FIREWALL	31 <mark>SWITCH</mark>	32FURNITURE	33REFRIGERATOR	34SHELVES	COMPUTER	OTHER	PROGRAM SERVICES	10тнек	-
Asset No.	23	24	25	26	27	28	29	30	31	32	33	34	35			₩	

428102 05-01-14

(D) - Asset disposed

* ITC, Section 179, Salvage, Bonus, Commercial Revitalization Deduction

Current Year Deduction				° °	7,694.		
Current Sec 179				· 0	0 0		
Accumulated Depreciation			100 mm (100 mm) (100		6,436.	<u>.</u>	
Basis For Depreciation				<901	32,629.		
* Reduction In Basis				0	0 0		
Bus % Excl				Α.			
Unadjusted Cost Or Basis	1.73			<901.>	32,629.		
No.							
Life							
Method		:		. N.		·	
Date Acquired	·						
Description				* 990 PAGE 10 TOTAL PROGRAM SERVICES MANAGEMENT AND GENERAL	* 990 PAGE 10 TOTAL MANAGEMENT AND GEN * GRAND TOTAL 990 PAGE 10 DEPR		
Asset No.	٠.						

(D) - Asset disposed

428102 05-01-14

* ITC, Section 179, Salvage, Bonus, Commercial Revitalization Deduction

Form **8868**

(Rev. January 2014)

Department of the Treasury Internal Revenue Service

Application for Extension of Time To File an Exempt Organization Return

File a separate application for each return.

Information about Form 8868 and its instructions is at www.irs.gov/form8868 .

OMB No. 1545-1709

	re filing for an Automatic 3-Month Extension, comple					▶ X			
	re filing for an Additional (Not Automatic) 3-Month Ex								
	mplete Part II unless you have already been granted								
	c filing (e-file) . You can electronically file Form 8868 if	-							
	o file Form 990-T), or an additional (not automatic) 3-mo								
	file any of the forms listed in Part I or Part II with the ex								
	Benefit Contracts, which must be sent to the IRS in par		(see instructions). For more details of	on the elec	tronic filing of t	his form,			
Part I	irs.gov/efile and click on e-file for Charities & Nonprofits Automatic 3-Month Extension of Time	s. e. Only s	submit original (no copies ne	eded).					
A corpora	tion required to file Form 990·T and requesting an autor								
Part I only	/					▶ 🔲			
	corporations (including 1120-C filers), partnerships, REN ome tax returns.	IICs, and t	rusts must use Form 7004 to reques						
		4:			er's identifying				
Type or	Name of exempt organization or other filer, see instru		7	Employer	dentification r	iumber (EIN) oi			
print	DYSTROPHIC EPIDERMOLYSIS B		A		11-2519	1726			
File by the	RESEARCH ASSOCIATION OF AM			0					
due date for filing your	Ming your 75 BROAD ST NO. 300								
osturin. See Instructions. City, town or post office, state, and ZIP code. For a foreign address, see instructions.									
iisai dollona.	NEW YORK,, NY 10004	oreign auc	ness, see instructions.						
	NEW TORK,, NI 1000±								
Enter the	Return code for the return that this application is for (file	e a senara	te application for each return)			0 1			
Littor tino	Total 1 oods (of the folds) that the approach to for (in	o w oopaa.		*************	***************************************	1			
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ls For	511	Is For			Code				
	or Form 990-EZ	Code 01	Form 990-T (corporation)			07			
Form 990-		02	Form 1041-A			08			
	0 (individual)	03	Form 4720 (other than individual)			09			
Form 990-		03	Form 5227			10			
	T (sec. 401(a) or 408(a) trust)	05	Form 6069			11			
	T (trust other than above)	06	Form 8870			12			
. 0.111 000	BRETT KOPELAN	1 95							
• The ho	oks are in the care of > 75 BROAD ST SU	ITE 3	00 - NEW YORK, NY	10004					
	one No. > 212.868.1573		Fax No.						
	rganization does not have an office or place of business	s in the Ur							
	s for a Group Return, enter the organization's four digit					up, check this			
oox 🕨 🗌	. If it is for part of the group, check this box								
	uest an automatic 3-month (6 months for a corporation								
			tion return for the organization name		The extension				
	r the organization's return for:	J	ū						
_	X calendar year 2014 or								
•	tax year beginning	, an	d ending						
		 •			_				
2 If the	e tax year entered in line 1 is for less than 12 months, c	heck reas	on: Initial return I	inal retur	n				
	Change in accounting period								
3a If thi	is application is for Forms 990·BL, 990·PF, 990·T, 4720,	or 6069,	enter the tentative tax, less any						
	refundable credits. See instructions.		•	За	\$	0.			
	is application is for Forms 990-PF, 990-T, 4720, or 6069	, enter an	y refundable credits and						
	mated tax payments made. Include any prior year overp			3b	\$	0.			
	ance due. Subtract line 3b from line 3a. Include your pa								
	sing EFTPS (Electronic Federal Tax Payment System).			3с	\$	0.			
	f you are going to make an electronic funds withdrawal								
	or Privacy Act and Paperwork Reduction Act Notice,	sae instru	ictions		Form 886	8 (Rev. 1-2014)			
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