

Department of the Treasury
Internal Revenue Service

Do not enter Social Security numbers on this form as it may be made public.
Information about Form 990 and its instructions is at www.irs.gov/form990

Open to Public Inspection

A For the 2013 calendar year, or tax year beginning and ending

B Check if applicable: <input checked="" type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Terminated <input type="checkbox"/> Amended return <input type="checkbox"/> Application pending	C Name of organization DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA		D Employer identification number 11-2519726
	Doing Business As		E Telephone number 212.868.1573
	Number and street (or P.O. box if mail is not delivered to street address)	Room/suite	
	75 BROAD ST		G Gross receipts \$ 1,532,108.
	City or town, state or province, country, and ZIP or foreign postal code NEW YORK, NY 10004		H(a) Is this a group return for subordinates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No H(b) Are all subordinates included? <input type="checkbox"/> Yes <input type="checkbox"/> No If "No," attach a list. (see instructions)

F Name and address of principal officer: BRETT KOPELAN
 SAME AS C ABOVE

I Tax-exempt status: 501(c)(3) 501(c) () (insert no.) 4947(a)(1) or 527

J Website: WWW.DEBRA.ORG

K Form of organization: Corporation Trust Association Other

L Year of formation: 1979 **M State of legal domicile:** NY

Part I Summary		Prior Year	Current Year
Activities & Governance	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		
	2 Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.		
	3 Number of voting members of the governing body (Part VI, line 1a)	3	19
	4 Number of independent voting members of the governing body (Part VI, line 1b)	4	18
	5 Total number of individuals employed in calendar year 2013 (Part V, line 2a)	5	0
	6 Total number of volunteers (estimate if necessary)	6	0
	7a 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	7b	0.	
Revenue	8 Contributions and grants (Part VIII, line 1h)	1,043,787.	757,834.
	9 Program service revenue (Part VIII, line 2g)	0.	0.
	10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	2,892.	3,917.
	11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	119,737.	633,937.
	12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	1,166,416.	1,395,688.
	Expenses	13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)	239,768.
14 Benefits paid to or for members (Part IX, column (A), line 4)		0.	0.
15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)		354,896.	447,983.
16a Professional fundraising fees (Part IX, column (A), line 11e)		0.	0.
b Total fundraising expenses (Part IX, column (D), line 25) 120,085.			
17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)		467,082.	543,817.
18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)		1,061,746.	991,800.
19 Revenue less expenses. Subtract line 18 from line 12	104,670.	403,888.	
Net Assets or Fund Balances	20 Total assets (Part X, line 16)	Beginning of Current Year 1,187,157.	End of Year 1,547,797.
	21 Total liabilities (Part X, line 26)	171,140.	127,892.
	22 Net assets or fund balances. Subtract line 21 from line 20	1,016,017.	1,419,905.

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.

Sign Here	Signature of officer	Date			
	BRETT KOPELAN, EXEC.DIRECTOR				
Paid Preparer Use Only	Print/Type preparer's name	Preparer's signature	Date	Check if self-employed <input type="checkbox"/>	PTIN
	BRIAN C. WHITE				P00058320
Paid Preparer Use Only	Firm's name	Firm's EIN	Phone no.		
	STUDLEY, WHITE & ASSOCIATES, P.C. P.O. BOX 399 DANBURY, CT 06813	06-0990132	203.748.6517		

May the IRS discuss this return with the preparer shown above? (see instructions) Yes No

Part III Statement of Program Service Accomplishments

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

1 Briefly describe the organization's mission:
DEBRA IS DEDICATED TO FINDING A CURE FOR EB, WHICH AFFECTS 1 OUT 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 THE

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 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 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 expenses. Section 501(c)(3) and 501(c)(4) organizations are required to report the amount of grants and allocations to others, the total expenses, and revenue, if any, for each program service reported.

4a (Code:) (Expenses \$ 163,326. including grants of \$) (Revenue \$)
PUBLIC AND PROFESSIONAL EDUCATION - EDUCATE THE PUBLIC & HEALTH PROFESSIONALS ABOUT DYSTROPHIC EPIDERMOLYSIS BULLOSA "EB"

4b (Code:) (Expenses \$ 547,963. including grants of \$) (Revenue \$)
PATIENT & FAMILY SERVICES - PROVIDE SERVICES FOR PEOPLE WITH EB & THEIR FAMILIES THRU NEWSLETTERS, COUNSELING PEER SUPPORT SERVICES, CONFERENCES AND SEMINARS

4c (Code:) (Expenses \$ 24,499. including grants of \$) (Revenue \$)
ADVOCACY - NETWORK WITH OTHER PROFESSIONAL ORGANIZATIONS & MEET KEY LEGISLATORS TO INFORM THEM OF EB AND SECURE RESEARCH FUNDS

4d Other program services (Describe in Schedule O.)
(Expenses \$ 95,093. including grants of \$) (Revenue \$)

4e Total program service expenses **830,881.**

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA**

Form 990 (2013)

11-2519726 Page **3**

Part IV Checklist of Required Schedules

		Yes	No
1	Is the organization described in section 501(c)(3) or 4947(a)(1) (other than a private foundation)? <i>If "Yes," complete Schedule A</i>	X	
2	Is the organization required to complete <i>Schedule B, Schedule of Contributors</i> ?	X	
3	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? <i>If "Yes," complete Schedule C, Part I</i>		X
4	Section 501(c)(3) organizations. Did the organization engage in lobbying activities, or have a section 501(h) election in effect during the tax year? <i>If "Yes," complete Schedule C, Part II</i>		X
5	Is the organization a section 501(c)(4), 501(c)(5), or 501(c)(6) organization that receives membership dues, assessments, or similar amounts as defined in Revenue Procedure 98-19? <i>If "Yes," complete Schedule C, Part III</i>		X
6	Did the organization maintain any donor advised funds or any similar funds or accounts for which donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts? <i>If "Yes," complete Schedule D, Part I</i>		X
7	Did the organization receive or hold a conservation easement, including easements to preserve open space, the environment, historic land areas, or historic structures? <i>If "Yes," complete Schedule D, Part II</i>		X
8	Did the organization maintain collections of works of art, historical treasures, or other similar assets? <i>If "Yes," complete Schedule D, Part III</i>		X
9	Did the organization report an amount in Part X, line 21, for escrow or custodial account liability; serve as a custodian for amounts not listed in Part X; or provide credit counseling, debt management, credit repair, or debt negotiation services? <i>If "Yes," complete Schedule D, Part IV</i>		X
10	Did the organization, directly or through a related organization, hold assets in temporarily restricted endowments, permanent endowments, or quasi-endowments? <i>If "Yes," complete Schedule D, Part V</i>		X
11	If the organization's answer to any of the following questions is "Yes," then complete Schedule D, Parts VI, VII, VIII, IX, or X as applicable.		
a	Did the organization report an amount for land, buildings, and equipment in Part X, line 10? <i>If "Yes," complete Schedule D, Part VI</i>	X	
b	Did the organization report an amount for investments - other securities in Part X, line 12 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VII</i>		X
c	Did the organization report an amount for investments - program related in Part X, line 13 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part VIII</i>		X
d	Did the organization report an amount for other assets in Part X, line 15 that is 5% or more of its total assets reported in Part X, line 16? <i>If "Yes," complete Schedule D, Part IX</i>	X	
e	Did the organization report an amount for other liabilities in Part X, line 25? <i>If "Yes," complete Schedule D, Part X</i>		X
f	Did the organization's separate or consolidated financial statements for the tax year include a footnote that addresses the organization's liability for uncertain tax positions under FIN 48 (ASC 740)? <i>If "Yes," complete Schedule D, Part X</i>		X
12a	Did the organization obtain separate, independent audited financial statements for the tax year? <i>If "Yes," complete Schedule D, Parts XI and XII</i>	X	
b	Was the organization included in consolidated, independent audited financial statements for the tax year? <i>If "Yes," and if the organization answered "No" to line 12a, then completing Schedule D, Parts XI and XII is optional</i>		X
13	Is the organization a school described in section 170(b)(1)(A)(ii)? <i>If "Yes," complete Schedule E</i>		X
14a	Did the organization maintain an office, employees, or agents outside of the United States?		X
b	Did the organization have aggregate revenues or expenses of more than \$10,000 from grantmaking, fundraising, business, investment, and program service activities outside the United States, or aggregate foreign investments valued at \$100,000 or more? <i>If "Yes," complete Schedule F, Parts I and IV</i>		X
15	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of grants or other assistance to or for any foreign organization? <i>If "Yes," complete Schedule F, Parts II and IV</i>	X	
16	Did the organization report on Part IX, column (A), line 3, more than \$5,000 of aggregate grants or other assistance to or for foreign individuals? <i>If "Yes," complete Schedule F, Parts III and IV</i>		X
17	Did the organization report a total of more than \$15,000 of expenses for professional fundraising services on Part IX, column (A), lines 6 and 11e? <i>If "Yes," complete Schedule G, Part I</i>		X
18	Did the organization report more than \$15,000 total of fundraising event gross income and contributions on Part VIII, lines 1c and 8a? <i>If "Yes," complete Schedule G, Part II</i>	X	
19	Did the organization report more than \$15,000 of gross income from gaming activities on Part VIII, line 9a? <i>If "Yes," complete Schedule G, Part III</i>		X
20a	Did the organization operate one or more hospital facilities? <i>If "Yes," complete Schedule H</i>		X
b	If "Yes" to line 20a, did the organization attach a copy of its audited financial statements to this return?		

Form **990** (2013)

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA**

Form 990 (2013)

11-2519726 Page 4

Part IV Checklist of Required Schedules *(continued)*

	Yes	No
21 Did the organization report more than \$5,000 of grants or other assistance to any domestic organization or government on Part IX, column (A), line 1? <i>If "Yes," complete Schedule I, Parts I and II</i>		X
22 Did the organization report more than \$5,000 of grants or other assistance to individuals in the United States on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>		X
23 Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5 about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i>		X
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? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i>		X
b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		
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?		
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) and 501(c)(4) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>		X
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? <i>If "Yes," complete Schedule L, Part I</i>		X
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 so, complete Schedule L, Part II		X
27 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 of any of these persons? <i>If "Yes," complete Schedule L, Part III</i>		X
28 Was the organization a party to a business transaction with one of the following parties (see Schedule L, Part IV instructions for applicable filing thresholds, conditions, and exceptions):		
a A current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>		X
b A family member of a current or former officer, director, trustee, or key employee? <i>If "Yes," complete Schedule L, Part IV</i>		X
c 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? <i>If "Yes," complete Schedule L, Part IV</i>		X
29 Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>	X	
30 Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i>		X
31 Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>		X
32 Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i>		X
33 Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I</i>		X
34 Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1</i>		X
35a Did the organization have a controlled entity within the meaning of section 512(b)(13)?		X
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)? <i>If "Yes," complete Schedule R, Part V, line 2</i>		
36 Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>		X
37 Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If "Yes," complete Schedule R, Part VI</i>		X
38 Did the organization complete Schedule O and provide explanations in Schedule O for Part VI, lines 11b and 19?	X	

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

Form 990 (2013)

Part V Statements Regarding Other IRS Filings and Tax Compliance

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

		Yes	No
1a	Enter the number reported in Box 3 of Form 1096. Enter -0- if not applicable		
1b	Enter the number of Forms W-2G included in line 1a. Enter -0- if not applicable		
1c	Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?		
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return		
2b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns? Note. If the sum of lines 1a and 2a is greater than 250, you may be required to e-file (see instructions)	X	
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?		X
3b	If "Yes," has it filed a Form 990-T for this year? If "No," to line 3b, provide an explanation in Schedule O		
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?		X
4b	If "Yes," enter the name of the foreign country: See instructions for filing requirements for Form TD F 90-22.1, Report of Foreign Bank and Financial Accounts.		
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?		X
5b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?		X
5c	If "Yes," to line 5a or 5b, did the organization file Form 8886-T?		
6a	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?		X
6b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?		
7	Organizations that may receive deductible contributions under section 170(c).		
7a	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?		X
7b	If "Yes," did the organization notify the donor of the value of the goods or services provided?		
7c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?		X
7d	If "Yes," indicate the number of Forms 8282 filed during the year		
7e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?		
7f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?		
7g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?		
7h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?		
8	Sponsoring organizations maintaining donor advised funds and section 509(a)(3) supporting organizations. Did the supporting organization, or a donor advised fund maintained by a sponsoring organization, have excess business holdings at any time during the year?		
9	Sponsoring organizations maintaining donor advised funds.		
9a	Did the organization make any taxable distributions under section 4966?		
9b	Did the organization make a distribution to a donor, donor advisor, or related person?		
10	Section 501(c)(7) organizations. Enter:		
10a	Initiation fees and capital contributions included on Part VIII, line 12		
10b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities		
11	Section 501(c)(12) organizations. Enter:		
11a	Gross income from members or shareholders		
11b	Gross income from other sources (Do not net amounts due or paid to other sources against amounts due or received from them.)		
12a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?		
12b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year		
13	Section 501(c)(29) qualified nonprofit health insurance issuers.		
13a	Is the organization licensed to issue qualified health plans in more than one state? Note. See the instructions for additional information the organization must report on Schedule O.		
13b	Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans		
13c	Enter the amount of reserves on hand		
14a	Did the organization receive any payments for indoor tanning services during the tax year?		X
14b	If "Yes," has it filed a Form 720 to report these payments? If "No," provide an explanation in Schedule O		

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA**

Form 990 (2013)

11-2519726 Page **6**

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

		Yes	No
1a	Enter the number of voting members of the governing body at the end of the tax year 1a 19 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.		
b	Enter the number of voting members included in line 1a, above, who are independent 1b 18		
2	Did any officer, director, trustee, or key employee have a family relationship or a business relationship with any other officer, director, trustee, or key employee?		X
3	Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors, or trustees, or key employees to a management company or other person?		X
4	Did the organization make any significant changes to its governing documents since the prior Form 990 was filed?		X
5	Did the organization become aware during the year of a significant diversion of the organization's assets?		X
6	Did the organization have members or stockholders?		X
7a	Did the organization have members, stockholders, or other persons who had the power to elect or appoint one or more members of the governing body?		X
b	Are any governance decisions of the organization reserved to (or subject to approval by) members, stockholders, or persons other than the governing body?		X
8	Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:		
a	The governing body?	X	
b	Each committee with authority to act on behalf of the governing body?	X	
9	Is there any officer, director, trustee, or key employee listed in Part VII, Section A, who cannot be reached at the organization's mailing address? If "Yes," provide the names and addresses in Schedule O		X

Section B. Policies (This Section B requests information about policies not required by the Internal Revenue Code.)

		Yes	No
10a	Did the organization have local chapters, branches, or affiliates?		X
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?		
11a	Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form?	X	
b	Describe in Schedule O the process, if any, used by the organization to review this Form 990.		
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?	X	
c	Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe in Schedule O how this was done	X	
13	Did the organization have a written whistleblower policy?		X
14	Did the organization have a written document retention and destruction policy?		X
15	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?		
a	The organization's CEO, Executive Director, or top management official	X	
b	Other officers or key employees of the organization	X	
	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 taxable entity during the year?		X
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

- 17** List the states with which a copy of this Form 990 is required to be filed **▶ NY, MI, MA, NJ, CA,**
- 18** 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.
 Own website Another's website Upon request Other (explain in Schedule O)
- 19** 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.
- 20** State the name, physical address, and telephone number of the person who possesses the books and records of the organization: ▶
BRETT KOPELAN - 212.868.1573
75 BROAD ST SUITE 300, NEW YORK, NY 10004

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.

Check this box if neither the organization nor any related organization compensated any current officer, director, or trustee.

(A) Name and Title	(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)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(1) FAITH DANIELS DIRECTOR	1.00	X					0.	0.	0.	
(2) CHARLEE MILLER TREASURER	1.00	X		X			0.	0.	0.	
(3) J ALEC ALEXANDER DIRECTOR	1.00	X					0.	0.	0.	
(4) FRANK KACMARSKY DIRECTOR	1.00	X					0.	0.	0.	
(5) RICHARD GALLAGHER DIRECTOR	1.00	X					0.	0.	0.	
(6) TOM GILLESPIE DIRECTOR	1.00	X					0.	0.	0.	
(7) DANIEL MARK SIEGEL MD DIRECTOR	1.00	X					0.	0.	0.	
(8) DR. ROBERT MEIROWITZ DIRECTOR	1.00	X					0.	0.	0.	
(9) BRETT KOPELAN EXECUTIVE DIRECTOR	40.00	X		X			116,146.	0.	0.	
(10) DR.LARRY MILLER RESIGNED IN 201 DIRECTOR	1.00	X					0.	0.	0.	
(11) DR.ALAN SHALITA DIRECTOR	1.00	X					0.	0.	0.	
(12) DR.JOUNI UITTO DIRECTOR	1.00	X					0.	0.	0.	
(13) KATHLEEN BROWN DIRECTOR	1.00	X					0.	0.	0.	
(14) SONYA WILANDER DIRECTOR	1.00	X		X			0.	0.	0.	
(15) LESLIE RADER PRESIDENT	1.00	X					0.	0.	0.	
(16) THOMAS MISISCO DIRECTOR	1.00	X					0.	0.	0.	
(17) ANGELA CHRISTIANO PH.D. DIRECTOR	1.00	X					0.	0.	0.	

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA**

Form 990 (2013)

11-2519726 Page **8**

Part VII Section A. Officers, Directors, Trustees, Key Employees, and Highest Compensated Employees (continued)

(A) Name and title	(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)						(D) Reportable compensation from the organization (W-2/1099-MISC)	(E) Reportable compensation from related organizations (W-2/1099-MISC)	(F) Estimated amount of other compensation from the organization and related organizations
		Individual trustee or director	Institutional trustee	Officer	Key employee	Highest compensated employee	Former			
(18) JAMES WETRICH DIRECTOR	1.00	X					0.	0.	0.	
(19) GREGG CUVIN RESIGNED IN 2013 DIRECTOR	1.00	X					0.	0.	0.	
(20) ALEXANDER SILVER DIRECTOR	1.00	X					0.	0.	0.	
(21) JEANNE ROCCON ROHM DIRECTOR	1.00	X					0.	0.	0.	
(22) ROBERT RYAN DIRECTOR	1.00	X					0.	0.	0.	
(23) WILLIAM CORNMAN DIRECTOR	1.00	X					0.	0.	0.	
1b Sub-total							116,146.	0.	0.	
c Total from continuation sheets to Part VII, Section A							0.	0.	0.	
d Total (add lines 1b and 1c)							116,146.	0.	0.	

2 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**

	Yes	No
3 Did the organization list any former officer, director, or trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual</i>		X
4 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? <i>If "Yes," complete Schedule J for such individual</i>		X
5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? <i>If "Yes," complete Schedule J for such person</i>		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	(B) Description of services	(C) Compensation
NONE		

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**

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA**

Form 990 (2013)

11-2519726 Page **9**

Part VIII Statement of Revenue

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

			(A) Total revenue	(B) Related or exempt function revenue	(C) Unrelated business revenue	(D) Revenue excluded from tax under sections 512-514	
Contributions, Gifts, Grants and Other Similar Amounts	1 a Federated campaigns	1a					
	b Membership dues	1b					
	c Fundraising events	1c					
	d Related organizations	1d					
	e Government grants (contributions)	1e					
	f All other contributions, gifts, grants, and similar amounts not included above	1f	757,834.				
	g Noncash contributions included in lines 1a-1f: \$						
	h Total. Add lines 1a-1f		757,834.				
Program Service Revenue	2 a _____		Business Code				
	b _____						
	c _____						
	d _____						
	e _____						
	f All other program service revenue						
	g Total. Add lines 2a-2f						
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)			3,917.		3,917.	
	4 Income from investment of tax-exempt bond proceeds						
	5 Royalties						
	6 a Gross rents	(i) Real	(ii) Personal				
		b Less: rental expenses					
		c Rental income or (loss)					
		d Net rental income or (loss)					
	7 a Gross amount from sales of assets other than inventory	(i) Securities	(ii) Other				
		b Less: cost or other basis and sales expenses					
		c Gain or (loss)					
		d Net gain or (loss)					
	8 a Gross income from fundraising events (not including \$ _____ of contributions reported on line 1c). See Part IV, line 18	a		758,470.			
		b Less: direct expenses	b	136,420.			
		c Net income or (loss) from fundraising events		622,050.			622,050.
	9 a Gross income from gaming activities. See Part IV, line 19	a					
b Less: direct expenses		b					
c Net income or (loss) from gaming activities							
10 a Gross sales of inventory, less returns and allowances	a						
	b Less: cost of goods sold	b					
	c Net income or (loss) from sales of inventory						
Miscellaneous Revenue		Business Code					
11 a MISCELLANEOUS INCOME		900099	11,887.	11,887.			
b _____							
c _____							
d All other revenue							
e Total. Add lines 11a-11d			11,887.				
12 Total revenue. See instructions.			1,395,688.	11,887.	0.	625,967.	

332009
10-29-13

Form **990** (2013)

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA**

Form 990 (2013)

11-2519726 Page **10**

Part IX Statement of Functional Expenses

Section 501(c)(3) and 501(c)(4) organizations must complete all columns. All other organizations must complete column (A).

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

Do not include amounts reported on lines 6b, 7b, 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 governments and organizations in the United States. See Part IV, line 21				
2 Grants and other assistance to individuals in the United States. See Part IV, line 22				
3 Grants and other assistance to governments, organizations, and individuals outside the United States. 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 described in section 4958(c)(3)(B)				
7 Other salaries and wages	375,513.	319,186.	18,776.	37,551.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)				
9 Other employee benefits	38,597.	32,807.	1,930.	3,860.
10 Payroll taxes	33,873.	28,792.	1,694.	3,387.
11 Fees for services (non-employees):				
a Management				
b Legal				
c Accounting	6,000.	3,648.	784.	1,568.
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, column (A) amount, list line 11g expenses on Sch O.)	9,680.	9,680.		
12 Advertising and promotion	24,521.	20,843.	1,226.	2,452.
13 Office expenses	85,233.	72,448.	4,262.	8,523.
14 Information technology				
15 Royalties				
16 Occupancy	89,888.	76,405.	4,494.	8,989.
17 Travel	66,786.	56,768.	3,339.	6,679.
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings				
20 Interest	121.	103.	6.	12.
21 Payments to affiliates				
22 Depreciation, depletion, and amortization	4,139.	3,518.	207.	414.
23 Insurance	9,118.	7,750.	456.	912.
24 Other expenses. Itemize expenses not covered 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 O.)				
a PATIENT ASSISTANCE	136,745.	136,745.		
b BAD DEBTS	38,422.			38,422.
c DUES & SUBSCRIPTIONS	17,431.	14,816.	872.	1,743.
d MISCELLANEOUS	15,472.	13,151.	774.	1,547.
e All other expenses	40,261.	34,221.	2,014.	4,026.
25 Total functional expenses. Add lines 1 through 24e	991,800.	830,881.	40,834.	120,085.
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 <input type="checkbox"/> if following SOP 98-2 (ASC 958-720)				

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA**

Form 990 (2013)

11-2519726 Page **11**

Part 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
Assets	1 Cash - non-interest-bearing	482,210.	1	733,017.
	2 Savings and temporary cash investments	542,067.	2	544,783.
	3 Pledges and grants receivable, net		3	
	4 Accounts receivable, net	131,789.	4	211,259.
	5 Loans and other receivables from current and former officers, directors, trustees, key employees, and highest compensated employees. Complete Part II of Schedule L		5	
	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 employees' beneficiary organizations (see instr). Complete Part II of Sch L		6	
	7 Notes and loans receivable, net		7	
	8 Inventories for sale or use		8	
	9 Prepaid expenses and deferred charges	5,047.	9	10,576.
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	33,350.		
	10b Less: accumulated depreciation	6,436.	10c	26,914.
	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		14	
	15 Other assets. See Part IV, line 11	21,248.	15	21,248.
16 Total assets. Add lines 1 through 15 (must equal line 34)	1,187,157.	16	1,547,797.	
Liabilities	17 Accounts payable and accrued expenses	21,140.	17	27,892.
	18 Grants payable	150,000.	18	100,000.
	19 Deferred revenue		19	
	20 Tax-exempt bond liabilities		20	
	21 Escrow or custodial account liability. Complete Part IV of Schedule D		21	
	22 Loans and other payables to current and former officers, directors, trustees, key employees, highest compensated employees, and disqualified persons. Complete Part II of Schedule L		22	
	23 Secured mortgages and notes payable to unrelated third parties		23	
	24 Unsecured notes and loans payable to unrelated third parties		24	
	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 Schedule D		25	
	26 Total liabilities. Add lines 17 through 25	171,140.	26	127,892.
Net Assets or Fund Balances	Organizations that follow SFAS 117 (ASC 958), check here <input checked="" type="checkbox"/> and complete lines 27 through 29, and lines 33 and 34.			
	27 Unrestricted net assets	911,964.	27	1,310,791.
	28 Temporarily restricted net assets	104,053.	28	109,114.
	29 Permanently restricted net assets		29	
	Organizations that do not follow SFAS 117 (ASC 958), check here <input type="checkbox"/> and complete lines 30 through 34.			
	30 Capital stock or trust principal, or current funds		30	
	31 Paid-in or capital surplus, or land, building, or equipment fund		31	
	32 Retained earnings, endowment, accumulated income, or other funds		32	
33 Total net assets or fund balances	1,016,017.	33	1,419,905.	
34 Total liabilities and net assets/fund balances	1,187,157.	34	1,547,797.	

Form **990** (2013)

Part 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)	1,395,688.
2	Total expenses (must equal Part IX, column (A), line 25)	991,800.
3	Revenue less expenses. Subtract line 2 from line 1	403,888.
4	Net assets or fund balances at beginning of year (must equal Part X, line 33, column (A))	1,016,017.
5	Net unrealized gains (losses) on investments	
6	Donated services and use of facilities	
7	Investment expenses	
8	Prior period adjustments	
9	Other changes in net assets or fund balances (explain in Schedule O)	0.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 33, column (B))	1,419,905.

Part XII Financial Statements and Reporting

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

	Yes	No
1 Accounting method used to prepare the Form 990: <input type="checkbox"/> Cash <input checked="" type="checkbox"/> Accrual <input type="checkbox"/> Other _____ If the organization changed its method of accounting from a prior year or checked "Other," explain in Schedule O.		
2a Were the organization's financial statements compiled or reviewed by an independent accountant? _____ 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: <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		X
b Were the organization's financial statements audited by an independent accountant? _____ If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both: <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		X
c If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? _____ If the organization changed either its oversight process or selection process during the tax year, explain in Schedule O.		
3a As a result of a federal award, was the organization required to undergo an audit or audits as set forth in the Single Audit Act and OMB Circular A-133? _____		X
b If "Yes," did the organization undergo the required audit or audits? If the organization did not undergo the required audit or audits, explain why in Schedule O and describe any steps taken to undergo such audits _____		

Form **990** (2013)

SCHEDULE A
(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.

OMB No. 1545-0047

2013

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

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

Name of the organization DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA
Employer identification number 11-2519726

Part I Reason for Public Charity Status (All organizations must complete this part.) See instructions.

The organization is not a private foundation because it is: (For lines 1 through 11, check only one box.)

- 1 A church, convention of churches, or association of churches described in section 170(b)(1)(A)(i).
2 A school described in section 170(b)(1)(A)(ii). (Attach Schedule E.)
3 A hospital or a cooperative hospital service organization described in section 170(b)(1)(A)(iii).
4 A medical research organization operated in conjunction with a hospital described in section 170(b)(1)(A)(iii). Enter the hospital's name, city, and state:
5 An organization operated for the benefit of a college or university owned or operated by a governmental unit described in section 170(b)(1)(A)(iv). (Complete Part II.)
6 A federal, state, or local government or governmental unit described in section 170(b)(1)(A)(v).
7 [X] An organization that normally receives a substantial part of its support from a governmental unit or from the general public described in section 170(b)(1)(A)(vi). (Complete Part II.)
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 income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See section 509(a)(2). (Complete Part III.)
10 An organization organized and operated exclusively to test for public safety. See section 509(a)(4).
11 An organization organized and operated exclusively for the benefit of, to perform the functions of, or to carry out the purposes of one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2). See section 509(a)(3). Check the box that describes the type of supporting organization and complete lines 11e through 11h.
a Type I b Type II c Type III - Functionally integrated d Type III - Non-functionally integrated
e By checking this box, I certify that the organization is not controlled directly or indirectly by one or more disqualified persons other than foundation managers and other than one or more publicly supported organizations described in section 509(a)(1) or section 509(a)(2).
f If the organization received a written determination from the IRS that it is a Type I, Type II, or Type III supporting organization, check this box
g Since August 17, 2006, has the organization accepted any gift or contribution from any of the following persons?
(i) A person who directly or indirectly controls, either alone or together with persons described in (ii) and (iii) below, the governing body of the supported organization?
(ii) A family member of a person described in (i) above?
(iii) A 35% controlled entity of a person described in (i) or (ii) above?
h Provide the following information about the supported organization(s).

Table with 3 columns: Question (11g(i), 11g(ii), 11g(iii)), Yes, No

Table with 7 main columns: (i) Name of supported organization, (ii) EIN, (iii) Type of organization, (iv) Is the organization in col. (i) listed in your governing document?, (v) Did you notify the organization in col. (i) of your support?, (vi) Is the organization in col. (i) organized in the U.S., (vii) Amount of monetary support. Includes a Total row.

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

Schedule A (Form 990 or 990-EZ) 2013

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.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	255,540.	489,432.	719,454.	948,110.		2412536.
2 Tax revenues levied for the organization'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	255,540.	489,432.	719,454.	948,110.		2412536.
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.						2412536.

Section B. Total Support

Calendar year (or fiscal year beginning in) ▶	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
7 Amounts from line 4	255,540.	489,432.	719,454.	948,110.		2412536.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	5,254.	974.	2,892.	788.		9,908.
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 IV.)						
11 Total support. Add lines 7 through 10						2422444.
12 Gross receipts from related activities, etc. (see instructions)					12	1,130,148.
13 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and stop here	<input type="checkbox"/>					

Section C. Computation of Public Support Percentage

14 Public support percentage for 2013 (line 6, column (f) divided by line 11, column (f))	14	99.59 %
15 Public support percentage from 2012 Schedule A, Part II, line 14	15	98.90 %
16a 33 1/3% support test - 2013. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization	<input checked="" type="checkbox"/>	
b 33 1/3% support test - 2012. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization	<input type="checkbox"/>	
17a 10% -facts-and-circumstances test - 2013. If the organization did not check a box on line 13, 16a, or 16b, and line 14 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization	<input type="checkbox"/>	
b 10% -facts-and-circumstances test - 2012. If the organization did not check a box on line 13, 16a, 16b, or 17a, and line 15 is 10% or more, and if the organization meets the "facts-and-circumstances" test, check this box and stop here. Explain in Part IV how the organization meets the "facts-and-circumstances" test. The organization qualifies as a publicly supported organization	<input type="checkbox"/>	
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions	<input type="checkbox"/>	

Part III Support Schedule for Organizations Described in Section 509(a)(2)

(Complete only if you checked the box on line 9 of Part I or if the organization failed to qualify under Part II. If the organization fails to qualify under the tests listed below, please complete Part II.)

Section A. Public Support

Calendar year (or fiscal year beginning in) ►	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c Add lines 7a and 7b						
8 Public support. (Subtract line 7c from line 6.)						

Section B. Total Support

Calendar year (or fiscal year beginning in) ►	(a) 2009	(b) 2010	(c) 2011	(d) 2012	(e) 2013	(f) Total
9 Amounts from line 6						
10a Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources						
b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975						
c Add lines 10a and 10b						
11 Net income from unrelated business activities not included in line 10b, whether or not the business is regularly carried on						
12 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part IV.)						
13 Total support. (Add lines 9, 10c, 11, and 12.)						

14 First five years. If the Form 990 is for the organization's first, second, third, fourth, or fifth tax year as a section 501(c)(3) organization, check this box and **stop here**

Section C. Computation of Public Support Percentage

15 Public support percentage for 2013 (line 8, column (f) divided by line 13, column (f))	15	%
16 Public support percentage from 2012 Schedule A, Part III, line 15	16	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2013 (line 10c, column (f) divided by line 13, column (f))	17	%
18 Investment income percentage from 2012 Schedule A, Part III, line 17	18	%

19a 33 1/3% support tests - 2013. If the organization did not check the box on line 14, and line 15 is more than 33 1/3%, and line 17 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization

b 33 1/3% support tests - 2012. If the organization did not check a box on line 14 or line 19a, and line 16 is more than 33 1/3%, and line 18 is not more than 33 1/3%, check this box and **stop here**. The organization qualifies as a publicly supported organization

20 Private foundation. If the organization did not check a box on line 14, 19a, or 19b, check this box and see instructions

Part IV

Supplemental Information. Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; and Part III, line 12.

Also complete this part for any additional information. (See instructions).

Lined area for supplemental information.

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

2013

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 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

Check if your organization is covered by the **General Rule** or a **Special Rule**.

Note. Only a section 501(c)(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, \$5,000 or more (in money or property) from any one contributor. Complete Parts I and II.

Special Rules

- For a section 501(c)(3) organization 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) and received from any one contributor, during the year, a contribution 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 a section 501(c)(7), (8), or (10) organization filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than \$1,000 for use *exclusively* for religious, charitable, scientific, literary, or educational purposes, or the prevention of cruelty to children or animals. Complete Parts I, II, and III.
- For a section 501(c)(7), (8), or (10) organization filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions for use *exclusively* for religious, charitable, etc., purposes, but these contributions did not total to 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 of \$5,000 or more during the year ▶ \$ _____

Caution. An organization that is not covered by the General Rule and/or the Special Rules does not file Schedule B (Form 990, 990-EZ, or 990-PF), but it **must** answer "No" on 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 certify that it does not meet 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) (2013)

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.

(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	\$ 30,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
2	JOHN LEE 555 MONTGOMERY ST SAN FRANCISCO, CA 94111	\$ 50,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
3	MOLNLYCKE HEALTH CARE 500 BALDWIN TOWER EDDYSTONE, PA 19022	\$ 80,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
4	NATIONAL REHAB 540 LINDBURGH DR MOON TOWNSHIP, PA 15108	\$ 47,691.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
5	NOEL MARKWELL 2201 RINGLING BLVD SARASOTA, FL 34237	\$ 41,567.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
6	NATIONAL RURAL LETTER CARRIERS AUX 80 WHITE OAK LANE PLYMOUTH, NC 27962	\$ 82,029.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (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.

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
7	MARY LEE JOHNSON RICHARDS CHARITABLE FDN 2318 BALLE LANE POINT PLEASANT, NJ 08742	\$ 25,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
	_____ _____ _____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
	_____ _____ _____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
	_____ _____ _____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
	_____ _____ _____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
	_____ _____ _____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
	_____ _____ _____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (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 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
_____	_____ _____ _____ _____	\$ _____	_____
_____	_____ _____ _____ _____	\$ _____	_____
_____	_____ _____ _____ _____	\$ _____	_____
_____	_____ _____ _____ _____	\$ _____	_____
_____	_____ _____ _____ _____	\$ _____	_____
_____	_____ _____ _____ _____	\$ _____	_____
_____	_____ _____ _____ _____	\$ _____	_____

Name of organization DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA	Employer identification number 11-2519726
---	---

Part III *Exclusively* religious, charitable, etc., individual contributions to section 501(c)(7), (8), or (10) organizations that total more than \$1,000 for the year. Complete columns (a) through (e) and the following line entry. For organizations completing Part III, enter the total of *exclusively* religious, charitable, etc., contributions of \$1,000 or less for the year. (Enter this information once.) ▶ \$ _____
Use duplicate copies of Part III if additional space is needed.

(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, and ZIP + 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

(e) Transfer of gift	
Transferee's name, address, and ZIP + 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

(e) Transfer of gift	
Transferee's name, address, and ZIP + 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

(e) Transfer of gift	
Transferee's name, address, and ZIP + 4	Relationship of transferor to transferee

SCHEDULE D
(Form 990)

Department of the Treasury
Internal Revenue Service

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.**

OMB No. 1545-0047

2013

Open to Public Inspection

Name of the organization DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA **Employer identification number** 11-2519726

Part I Organizations Maintaining Donor Advised Funds or Other Similar Funds or Accounts. Complete if the organization answered "Yes" to Form 990, Part IV, line 6.

	(a) Donor advised funds	(b) Funds and other accounts
1 Total number at end of year		
2 Aggregate contributions to (during year)		
3 Aggregate grants from (during year)		
4 Aggregate value at end of year		
5 Did the organization inform all donors and donor advisors in writing that the assets held in donor advised funds are the organization's property, subject to the organization's exclusive legal control?		<input type="checkbox"/> Yes <input type="checkbox"/> No
6 Did the organization inform all grantees, donors, and donor advisors in writing that grant funds can be used only for charitable purposes and not for the benefit of the donor or donor advisor, or for any other purpose conferring impermissible private benefit?		<input type="checkbox"/> Yes <input type="checkbox"/> No

Part II Conservation Easements. Complete if the organization answered "Yes" to Form 990, Part IV, line 7.

- Purpose(s) of conservation easements held by the organization (check all that apply).

<input type="checkbox"/> Preservation of land for public use (e.g., recreation or education)	<input type="checkbox"/> Preservation of an historically important land area
<input type="checkbox"/> Protection of natural habitat	<input type="checkbox"/> Preservation of a certified historic structure
<input type="checkbox"/> Preservation of open space	
- Complete lines 2a through 2d if the organization held a qualified conservation contribution in the form of a conservation easement on the last day of the tax year.

	Held at the End of the Tax Year
a Total number of conservation easements	2a
b Total acreage restricted by conservation easements	2b
c Number of conservation easements on a certified historic structure included in (a)	2c
d Number of conservation easements included in (c) acquired after 8/17/06, and not on a historic structure listed in the National Register	2d
- Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year ▶ _____
- Number of states where property subject to conservation easement is located ▶ _____
- Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds?
- Staff and volunteer hours devoted to monitoring, inspecting, and enforcing conservation easements during the year ▶ _____
- Amount of expenses incurred in monitoring, inspecting, and enforcing conservation easements during the year ▶ \$ _____
- Does each conservation easement reported on line 2(d) above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)?
- In Part XIII, describe how the organization reports conservation easements in its revenue and expense statement, and balance sheet, and include, if applicable, the text of the footnote to the organization's financial statements that describes the organization's accounting for conservation easements.

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets. Complete if the organization answered "Yes" to Form 990, Part IV, line 8.

- If the organization elected, as permitted under SFAS 116 (ASC 958), not to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide, in Part XIII, the text of the footnote to its financial statements that describes these items.
 - If the organization elected, as permitted under SFAS 116 (ASC 958), to report in its revenue statement and balance sheet works of art, historical treasures, or other similar assets held for public exhibition, education, or research in furtherance of public service, provide the following amounts relating to these items:

(i) Revenues included in Form 990, Part VIII, line 1	▶ \$ _____
(ii) Assets included in Form 990, Part X	▶ \$ _____
- If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under SFAS 116 (ASC 958) relating to these items:

a Revenues included in Form 990, Part VIII, line 1	▶ \$ _____
b Assets included in Form 990, Part X	▶ \$ _____

Part III Organizations Maintaining Collections of Art, Historical Treasures, or Other Similar Assets (continued)

3 Using the organization's acquisition, accession, and other records, check any of the following that are a significant use of its collection items (check all that apply):

- a Public exhibition
- b Scholarly research
- c Preservation for future generations
- d Loan or exchange programs
- e Other _____

4 Provide a description of the organization's collections and explain how they further the organization's exempt purpose in Part XIII.

5 During the year, did the organization solicit or receive donations of art, historical treasures, or other similar assets to be sold to raise funds rather than to be maintained as part of the organization's collection? Yes No

Part IV Escrow and Custodial Arrangements. Complete if the organization answered "Yes" to Form 990, Part IV, line 9, or reported an amount on Form 990, Part X, line 21.

1a Is the organization an agent, trustee, custodian or other intermediary for contributions or other assets not included on Form 990, Part X? Yes No

b If "Yes," explain the arrangement in Part XIII and complete the following table:

	Amount
c Beginning balance	1c
d Additions during the year	1d
e Distributions during the year	1e
f Ending balance	1f

2a Did the organization include an amount on Form 990, Part X, line 21? Yes No

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.

	(a) Current year	(b) Prior year	(c) Two years back	(d) Three years back	(e) Four years back
1a Beginning of year balance					
b Contributions					
c Net investment earnings, gains, and losses					
d Grants or scholarships					
e Other expenditures for facilities and programs					
f Administrative expenses					
g End of year balance					

2 Provide the estimated percentage of the current year end balance (line 1g, column (a)) held as:

- a Board designated or quasi-endowment ▶ _____ %
- b Permanent endowment ▶ _____ %
- c Temporarily restricted endowment ▶ _____ %

The percentages in lines 2a, 2b, and 2c should equal 100%.

3a Are there endowment funds not in the possession of the organization that are held and administered for the organization by:

	Yes	No
(i) unrelated organizations	3a(i)	
(ii) related organizations	3a(ii)	

b If "Yes" to 3a(ii), are the related organizations listed as required on Schedule R?

4 Describe in Part XIII the intended uses of the organization's endowment funds.

Part VI Land, Buildings, and Equipment.

Complete if the organization answered "Yes" to Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

Description of property	(a) Cost or other basis (investment)	(b) Cost or other basis (other)	(c) Accumulated depreciation	(d) Book value
1a Land				
b Buildings				
c Leasehold improvements				
d Equipment				
e Other		33,350.	6,436.	26,914.
Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, column (B), line 10(c).)				26,914.

Part VII Investments - Other Securities.

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

Complete if the organization answered "Yes" to Form 990, Part IV, line 11c. See Form 990, Part X, line 13.

(a) Description of investment	(b) Book value	(c) Method of valuation: Cost or end-of-year market value
(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.

Complete if the organization answered "Yes" to Form 990, Part IV, line 11d. See Form 990, Part X, line 15.

(a) 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 15.) ▶	

Part X Other Liabilities.

Complete if the organization answered "Yes" to Form 990, Part IV, line 11e or 11f. See Form 990, Part X, line 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 25.) ▶	

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

Part XI Reconciliation of Revenue per Audited Financial Statements With Revenue per Return.

Complete if the organization answered "Yes" to Form 990, Part IV, line 12a.

1	Total revenue, gains, and other support per audited financial statements	1	1,765,957.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:		
a	Net unrealized gains on investments	2a	
b	Donated services and use of facilities	2b	370,269.
c	Recoveries of prior year grants	2c	
d	Other (Describe in Part XIII.)	2d	
e	Add lines 2a through 2d	2e	370,269.
3	Subtract line 2e from line 1	3	1,395,688.
4	Amounts included on Form 990, Part VIII, line 12, but not on line 1:		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIII.)	4b	
c	Add lines 4a and 4b	4c	0.
5	Total revenue. Add lines 3 and 4c . (This must equal Form 990, Part I, line 12.)	5	1,395,688.

Part XII Reconciliation of Expenses per Audited Financial Statements With Expenses per Return.

Complete if the organization answered "Yes" to Form 990, Part IV, line 12a.

1	Total expenses and losses per audited financial statements	1	1,362,069.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:		
a	Donated services and use of facilities	2a	370,269.
b	Prior year adjustments	2b	
c	Other losses	2c	
d	Other (Describe in Part XIII.)	2d	
e	Add lines 2a through 2d	2e	370,269.
3	Subtract line 2e from line 1	3	991,800.
4	Amounts included on Form 990, Part IX, line 25, but not on line 1:		
a	Investment expenses not included on Form 990, Part VIII, line 7b	4a	
b	Other (Describe in Part XIII.)	4b	
c	Add lines 4a and 4b	4c	0.
5	Total expenses. Add lines 3 and 4c . (This must equal Form 990, Part I, line 18.)	5	991,800.

Part XIII Supplemental Information.

Provide 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 any additional information.

PART XII, LINE 2D - OTHER ADJUSTMENTS:

IN KIND EXPENSES

**SCHEDULE F
(Form 990)**

Statement of Activities Outside the United States

OMB No. 1545-0047

2013

Department of the Treasury
Internal Revenue Service

► Complete if the organization answered "Yes" on Form 990, Part IV, line 14b, 15, or 16.
► Attach to Form 990. ► See separate instructions.
► Information about Schedule F (Form 990) and its instructions is at www.irs.gov/form990.

Open to Public
Inspection

Name of the organization
**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA**

Employer identification number
11-2519726

Part I General Information on Activities Outside the United States. Complete if the organization answered "Yes" on Form 990, Part IV, line 14b.

1 For grantmakers. Does the organization maintain records to substantiate the amount of its grants and other assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? Yes No

2 For grantmakers. Describe in Part V the organization's procedures for monitoring the use of its grants and other assistance outside the United States.

3 Activities per Region. (The following Part I, line 3 table can be duplicated if additional space is needed.)

(a) Region	(b) Number of offices in the region	(c) Number of employees, agents, and independent contractors in region	(d) Activities conducted in region (by type) (e.g., fundraising, program services, investments, grants to recipients located in the region)	(e) If activity listed in (d) is a program service, describe specific type of service(s) in region	(f) Total expenditures for and investments in region
3 a Sub-total	0	0			0.
b Total from continuation sheets to Part I	0	0			0.
c Totals (add lines 3a and 3b)	0	0			0.

332071
10-03-13

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA**

11 - 2519726

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	(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	TO FUND INTERNATIONAL RESEARCH TO FIND A CURE FOR EPIDERMOLYSIS BULLOSA	1,243,000	CASH TRANSFER	0.		FMV

2 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 ▲

3 Enter total number of other organizations or entities ▲

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA**

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.

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

Part IV 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 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)* Yes 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 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 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 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)* Yes No

Schedule F (Form 990) 2013

Part V Supplemental Information

Provide the information required by Part I, line 2 (monitoring of funds); Part I, line 3, column (f) (accounting method; amounts of investments vs. expenditures per region); Part II, line 1 (accounting method); Part III (accounting method); and Part III, column (c) (estimated number of recipients), as applicable. Also complete this part to provide any additional information.

Multiple horizontal lines for supplemental information.

SCHEDULE G
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

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.

OMB No. 1545-0047

2013

Open To Public Inspection

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

Name of the organization **DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA**

Employer identification number
11-2519726

Part I

Fundraising Activities. Complete if the organization answered "Yes" to Form 990, Part IV, line 17. Form 990-EZ filers are not required to complete this part.

1 Indicate whether the organization raised funds through any of the following activities. Check all that apply.

- a Mail solicitations
- b Internet and email solicitations
- c Phone solicitations
- d In-person solicitations
- e Solicitation of non-government grants
- f Solicitation of government grants
- g Special fundraising events

2 a Did the organization have a written or oral agreement with any individual (including officers, directors, trustees or key employees listed in Form 990, Part VII) or entity in connection with professional fundraising services? **Yes** **No**

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.

(i) Name and address of individual or entity (fundraiser)	(ii) Activity	(iii) Did fundraiser have custody or control of contributions?		(iv) Gross receipts from activity	(v) Amount paid to (or retained by) fundraiser listed in col. (i)	(vi) Amount paid to (or retained by) organization
		Yes	No			
Total				▶		

3 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.

DYSTROPHIC EPIDERMOLYSIS BULLOSA

Part II 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.

		(a) Event #1	(b) Event #2	(c) Other events	(d) Total events (add col. (a) through col. (c))
		ANNUAL GOLF / TENNIS (event type)	(event type)	(total number)	
Revenue	1	Gross receipts			
	2	Less: Contributions			
	3	Gross income (line 1 minus line 2)			
Direct Expenses	4	Cash prizes			
	5	Noncash prizes			
	6	Rent/facility costs			
	7	Food and beverages			
	8	Entertainment			
	9	Other direct expenses			
	10	Direct expense summary. Add lines 4 through 9 in column (d)			
	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.

		(a) Bingo	(b) Pull tabs/instant bingo/progressive bingo	(c) Other gaming	(d) Total gaming (add col. (a) through col. (c))
		1	Gross revenue		
Direct Expenses	2	Cash prizes			
	3	Noncash prizes			
	4	Rent/facility costs			
	5	Other direct expenses			
	6	Volunteer labor	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No
7	Direct expense summary. Add lines 2 through 5 in column (d)				
8	Net gaming income summary. Subtract line 7 from line 1, column (d)				

9 Enter the state(s) in which the organization operates gaming activities: _____

a Is the organization licensed to operate gaming activities in each of these states? Yes No

b If "No," explain: _____

10a Were any of the organization's gaming licenses revoked, suspended or terminated during the tax year? Yes No

b If "Yes," explain: _____

DYSTROPHIC EPIDERMOLYSIS BULLOSA

- 11 Does the organization operate gaming activities with nonmembers? Yes No
- 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? Yes No
- 13 Indicate the percentage of gaming activity operated in:

13a		%
13b		%
- 14 Enter the name and address of the person who prepares the organization's gaming/special events books and records:

Name ► _____

Address ► _____

- 15a Does the organization have a contract with a third party from whom the organization receives gaming revenue? Yes No
- 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 ► _____

16 Gaming manager information:

Name ► _____

Gaming manager compensation ► \$ _____

Description of services provided ► _____

Director/officer Employee Independent contractor

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? Yes No
- 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 ► \$ _____

Part IV **Supplemental Information.** Provide the explanations required by Part I, line 2b, columns (iii) and (v), and Part III, lines 9, 9b, 10b, 15b, 15c, 16, and 17b, as applicable. Also complete this part to provide any additional information (see instructions).

Part IV Supplemental Information (continued)

Multiple horizontal lines for supplemental information.

**SCHEDULE I
(Form 990)**

Department of the Treasury
Internal Revenue Service

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

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

▶ Attach to Form 990.

OMB No. 1545-0047

2013

Open to Public
Inspection

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

Name of the organization **DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA** Employer identification number
11-2519726

Part I General Information on Grants and Assistance

- 1** Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? Yes No
- 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 Governments and Organizations in the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed.

1 (a) Name and address of organization or government	(b) EIN	(c) IRC section if applicable	(d) Amount of cash grant	(e) Amount of non-cash assistance	(f) Method of valuation (book, FMV, appraisal, other)	(g) Description of non-cash assistance	(h) Purpose of grant or assistance

- 2** Enter total number of section 501(c)(3) and government organizations listed in the line 1 table
- 3** Enter total number of other organizations listed in the line 1 table

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

Schedule I (Form 990) (2013)

**DYSTROPHIC EPIDERMOLYSIS BULLOSA
RESEARCH ASSOCIATION OF AMERICA**

Schedule I (Form 990) (2013)

11 - 2519726

Page 2

Part III Grants and Other Assistance to Individuals in the United States. Complete if the organization answered "Yes" to Form 990, Part IV, line 22.
Part III can be duplicated if additional space is needed.

(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

Part IV Supplemental Information. Provide the information required in Part I, line 2, Part III, column (b), and any other additional information.

PART I, LINE 2:

EXPLANATION: THE BOARD OF DIRECTORS REVIEWS AND APPROVES ALL REQUEST FOR

RESEARCH FUNDS. THE ENTITY RECEIVING RESEARCH FUNDS PROVIDES WRITTEN

UPDATES ON THE USE OF THE FUNDS.

**SCHEDULE M
(Form 990)**

Noncash Contributions

OMB No. 1545-0047

2013

Open to Public Inspection

Department of the Treasury
Internal Revenue Service

- ▶ 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.

Name of the organization **DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA** Employer identification number **11-2519726**

Part I Types of Property

	(a) Check if applicable	(b) Number of contributions or items contributed	(c) Noncash contribution amounts reported on Form 990, Part VIII, line 1g	(d) Method of determining noncash contribution amounts
1 Art - Works of art				
2 Art - Historical treasures				
3 Art - Fractional interests				
4 Books and publications				
5 Clothing and household goods				
6 Cars and other vehicles				
7 Boats and planes				
8 Intellectual property				
9 Securities - Publicly traded				
10 Securities - Closely held stock				
11 Securities - Partnership, LLC, or trust interests				
12 Securities - Miscellaneous				
13 Qualified conservation contribution - Historic structures				
14 Qualified conservation contribution - Other				
15 Real estate - Residential				
16 Real estate - Commercial				
17 Real estate - Other				
18 Collectibles				
19 Food inventory				
20 Drugs and medical supplies	X	5	349,021.	FMV
21 Taxidermy				
22 Historical artifacts				
23 Scientific specimens				
24 Archeological artifacts				
25 Other ▶ (<u>LEGAL SERVICE</u>)	X	1	21,428.	FAIR MARKET VALUE
26 Other ▶ (_____)				
27 Other ▶ (_____)				
28 Other ▶ (_____)				

29 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 **29**

	Yes	No
30a During the year, did the organization receive by contribution any property reported in Part I, lines 1 - 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 exempt purposes for the entire holding period?		X
b If "Yes," describe the arrangement in Part II.		
31 Does the organization have a gift acceptance policy that requires the review of any non-standard contributions?		X
32a Does the organization hire or use third parties or related organizations to solicit, process, or sell noncash contributions?		X
b If "Yes," describe in Part II.		
33 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.

Schedule M (Form 990) (2013)

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.

Multiple horizontal lines for supplemental information.

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.

OMB No. 1545-0047

2013

Open to Public
Inspection

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

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.

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 \$ 95,093. INCLUDING GRANTS OF \$ 0. REVENUE \$ 0.

FORM 990, PART VI, SECTION B, LINE 11:

EXPLANATION: THE BOARD OF DIRECTORS MEETS WITH THE CERTIFIED PUBLIC
ACCOUNTANT TO REVIEW THE ANNUAL AUDITED FINANCIAL STATEMENTS, MANAGEMENT

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

Schedule O (Form 990 or 990-EZ) (2013)

332211
09-04-13

Name of the organization DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA	Employer identification number 11-2519726
---	--

LETTER AND FORM 990.

FORM 990, PART VI, SECTION B, LINE 12C:

EXPLANATION: THERE IS AN ANNUAL REVIEW PERFORMED OF ALL BOARD MEMBERS TO DETERMINE IF THERE ARE ANY CONFLICTS OF INTERESTS.

FORM 990, PART VI, SECTION B, LINE 15:

EXPLANATION: THE BOARD OF DIRECTORS REVIEWS THE EXECUTIVE DIRECTORS SALARY ON AN ANNUAL BASIS. A STUDY IS PERFORMED OF OTHER NOT FOR PROFIT AGENCY'S IN THE NEW YORK AREA AS WELL AS OTHER AGENCIES THAT PROVIDE A SIMILAR SERVICE TO DETERMINE IF THE SALARY PAID IS COMPETITIVE AND WITHIN ACCEPTABLE LIMITS.

FORM 990, PART VI, SECTION C, LINE 19:

EXPLANATION: THE ORGANIZATION'S ORGANIZING DOCUMENTS, ANNUAL AUDIT REPORT AND FORM 990 ARE AVAILABLE FOR PUBLIC INSPECTION UPON A WRITTEN REQUEST TO THE EXECUTIVE DIRECTOR.

2013 DEPRECIATION AND AMORTIZATION REPORT
FORM 990 PAGE 10

990

Asset No.	Description	Date Acquired	Method	Life	Line No.	Unadjusted Cost Or Basis	Bus % Excl	* Reduction In Basis	Basis For Depreciation	Accumulated Depreciation	Current Sec 179	Current Year Deduction
23	DELL COMPUTER	040111	SL	3.00	16	1,420.			1,420.	708.		473.
24	COMPUTER	011012	SL	3.00	16	2,162.			2,162.	721.		721.
25	COMPUTER	042712	SL	3.00	16	640.			640.	213.		213.
26	COMPUTER	050412	SL	3.00	16	594.			594.	198.		198.
27	FURNITURE	121912	SL	5.00	16	2,279.			2,279.	456.		456.
28	SWITCH	010713	SL	3.00	16	430.			430.			143.
29	LENOVO LAPTOP	043013	SL	3.00	16	1,555.			1,555.			346.
30	FIREWALL	110713	SL	3.00	16	500.			500.			28.
31	SWITCH	110713	SL	3.00	16	320.			320.			18.
32	FURNITURE	082013	SL	5.00	16	21,249.			21,249.			1,417.
33	REFRIGERATOR	100113	SL	5.00	16	1,734.			1,734.			87.
34	SHELVES	101513	SL	3.00	16	468.			468.			39.
	* 990 PAGE 10 TOTAL											
	OTHER					33,351.		0.	33,351.	2,296.	0.	4,139.
	PROGRAM SERVICES											
	10OTHER	010110	SL	5.00	16	<1.>			<1.>	1.		0.

Asset No.	Description	Date Acquired	Method	Life	Line No.	Unadjusted Cost Or Basis	Bus % Excl	* Reduction In Basis	Basis For Depreciation	Accumulated Depreciation	Current Sec 179	Current Year Deduction
	* 990 PAGE 10 TOTAL PROGRAM SERVICES MANAGEMENT AND GENERAL					<1.>		0.	<1.>	1.	0.	0.
	* 990 PAGE 10 TOTAL MANAGEMENT AND GEN					0.		0.	0.	0.	0.	0.
	* GRAND TOTAL 990 PAGE 10 DEPR					33,350.		0.	33,350.	2,297.	0.	4,139.

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

(D) - Asset disposed
40.2

Application for Extension of Time To File an Exempt Organization Return

Department of the Treasury
Internal Revenue Service

▶ **File a separate application for each return.**
▶ **Information about Form 8868 and its instructions is at www.irs.gov/form8868.**

- If you are filing for an **Automatic 3-Month Extension**, complete only **Part I** and check this box
- If you are filing for an **Additional (Not Automatic) 3-Month Extension**, complete only **Part II** (on page 2 of this form).

Do not complete Part II unless you have already been granted an automatic 3-month extension on a previously filed Form 8868.

Electronic filing (e-file). You can electronically file Form 8868 if you need a 3-month automatic extension of time to file (6 months for a corporation required to file Form 990-T), or an additional (not automatic) 3-month extension of time. You can electronically file Form 8868 to request an extension of time to file any of the forms listed in Part I or Part II with the exception of Form 8870, Information Return for Transfers Associated With Certain Personal Benefit Contracts, which must be sent to the IRS in paper format (see instructions). For more details on the electronic filing of this form, visit www.irs.gov/efile and click on *e-file for Charities & Nonprofits*.

Part I Automatic 3-Month Extension of Time. Only submit original (no copies needed).

A corporation required to file Form 990-T and requesting an automatic 6-month extension - check this box and complete

Part I only

All other corporations (including 1120-C filers), partnerships, REMICs, and trusts must use Form 7004 to request an extension of time to file income tax returns.

Enter filer's identifying number

Type or print	Name of exempt organization or other filer, see instructions. DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA	Employer identification number (EIN) or 11-2519726
File by the due date for filing your return. See instructions.	Number, street, and room or suite no. If a P.O. box, see instructions. 75 BROAD ST, NO. 300	Social security number (SSN)
	City, town or post office, state, and ZIP code. For a foreign address, see instructions. NEW YORK, , NY 10004	

Enter the Return code for the return that this application is for (file a separate application for each return) 011

Application Is For	Return Code	Application Is For	Return Code
Form 990 or Form 990-EZ	01	Form 990-T (corporation)	07
Form 990-BL	02	Form 1041-A	08
Form 4720 (individual)	03	Form 4720 (other than individual)	09
Form 990-PF	04	Form 5227	10
Form 990-T (sec. 401(a) or 408(a) trust)	05	Form 6069	11
Form 990-T (trust other than above)	06	Form 8870	12

BRETT KOPELAN

- The books are in the care of ▶ **75 BROAD ST SUITE 300 - NEW YORK, NY 10004**

Telephone No. ▶ **212.868.1573** Fax No. ▶ _____

- If the organization does not have an office or place of business in the United States, check this box
- If this is for a Group Return, enter the organization's four digit Group Exemption Number (GEN) _____. If this is for the whole group, check this box . If it is for part of the group, check this box and attach a list with the names and EINs of all members the extension is for.

1 I request an automatic 3-month (6 months for a corporation required to file Form 990-T) extension of time until **AUGUST 15, 2014**, to file the exempt organization return for the organization named above. The extension is for the organization's return for:
▶ calendar year **2013** or
▶ tax year beginning _____, and ending _____.

2 If the tax year entered in line 1 is for less than 12 months, check reason: Initial return Final return
 Change in accounting period

3a If this application is for Forms 990-BL, 990-PF, 990-T, 4720, or 6069, enter the tentative tax, less any nonrefundable credits. See instructions.	3a	\$	0.
b If this application is for Forms 990-PF, 990-T, 4720, or 6069, enter any refundable credits and estimated tax payments made. Include any prior year overpayment allowed as a credit.	3b	\$	0.
c Balance due. Subtract line 3b from line 3a. Include your payment with this form, if required, by using EFTPS (Electronic Federal Tax Payment System). See instructions.	3c	\$	0.

Caution. If you are going to make an electronic funds withdrawal (direct debit) with this Form 8868, see Form 8453-EO and Form 8879-EO for payment instructions.

Form CHAR500	Annual Filing for Charitable Organizations New York State Department of Law (Office of the Attorney General) Charities Bureau - Registration Section 120 Broadway New York, NY 10271 http://www.charitiesnys.com	2013
This form used for Article 7-A, EPTL and dual filers (replaces forms CHAR 497, CHAR 010 and CHAR 006)		Open to Public Inspection

1. General Information			
a. For the fiscal year beginning (mm/dd/yyyy) 01/01/2013 and ending (mm/dd/yyyy) 12/31/2013			
b. Check if applicable for NYS: <input checked="" type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial filing <input type="checkbox"/> Final filing <input type="checkbox"/> Amended filing <input type="checkbox"/> NY registration pending	c. Name of organization DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA Number and street (or P.O. box if mail not delivered to street address) 75 BROAD ST Room/suite 300 City or town, state or country and ZIP + 4 NEW YORK, , NY 10004	d. Fed. employer ID no. (EIN) 11-2519726	e. NY State registration no. 02-82-71
		f. Telephone number 212 868.1573	g. Email STAFF@DEBRA.ORG

2. Certification - Two Signatures Required			
We certify under penalties of perjury that we reviewed this report, including all attachments, and to the best of our knowledge and belief, they are true, correct and complete in accordance with the laws of the State of New York applicable to this report.			
a. President or Authorized Officer	BRETT KOPELAN	EXEC. DIRECTOR	
Signature	Printed Name	Title	Date
b. Chief Financial Officer or Treas.			
Signature	Printed Name	Title	Date

3. Annual Report Exemption Information	
a. Article 7-A annual report exemption (Article 7-A registrants and dual registrants) Check <input type="checkbox"/> if total contributions from NY State (including residents, foundations, corporations, government agencies, etc.) did not exceed \$25,000 and the organization did not engage a professional fund raiser (PFR) or fund raising counsel (FRC) to solicit contributions during this fiscal year. NOTE: An organization may claim this exemption if no PFR or FRC was used and either: 1) it received an allocation from a federated fund, United Way or incorporated community appeal and contributions from other sources did not exceed \$25,000 or 2) it received all or substantially all of its contributions from one government agency to which it submitted an annual report similar to that required by Article 7-A.	
b. EPTL annual report exemption (EPTL registrants and dual registrants) Check <input type="checkbox"/> if gross receipts did not exceed \$25,000 and assets (market value) did not exceed \$25,000 at any time during this fiscal year.	
For EPTL or Article 7-A registrants claiming the annual report exemption under the one law under which they are registered and for dual registrants claiming the annual report exemptions under both laws, simply complete part 1 (General Information), part 2 (Certification) and part 3 (Annual Report Exemption Information) above. <i>Do not submit a fee, do not complete the following schedules and do not submit any attachments to this form.</i>	

4. Article 7-A Schedules	
If you did not check the Article 7-A annual report exemption above, complete the following for this fiscal year:	
a. Did the organization use a professional fund raiser, fund raising counsel or commercial co-venturer for fund raising activity in NY State? ... <input type="checkbox"/> Yes* <input checked="" type="checkbox"/> No * If "Yes", complete Schedule 4a.	
b. Did the organization receive government contributions (grants)? <input type="checkbox"/> Yes* <input checked="" type="checkbox"/> No * If "Yes", complete Schedule 4b.	

5. Fee Submitted: See last page for summary of fee requirements.	
Indicate the filing fee(s) you are submitting along with this form:	
a. Article 7-A filing fee \$ <u>25.</u>	Submit only one check or money order for the total fee, payable to "NYS Department of Law"
b. EPTL filing fee \$ _____	
c. Total fee \$ <u>25.</u>	

6. Attachments - For organizations that are not claiming annual report exemptions under both laws, see last page for required attachments ▶▶▶

DYSTROPHIC EPIDERMOLYSIS BULLOSA RESEARCH ASSOCIATION OF AMERICA

5. Fee Instructions

The filing fee depends on the organization's Registration Type. For details on Registration Type and filing fees, see the Instructions for Form CHAR500.

Organization's Registration Type Fee Instructions

- Article 7-A Calculate the Article 7-A filing fee using the table in part a below. The EPTL filing fee is \$0.
EPTL Calculate the EPTL filing fee using the table in part b below. The Article 7-A filing fee is \$0.
Dual Calculate both the Article 7-A and EPTL filing fees using the tables in parts a and b below. Add the Article 7-A and EPTL filing fees together to calculate the total fee. Submit a single check or money order for the total fee.

a) Article 7-A filing fee

Table with 2 columns: Total Support & Revenue, Article 7-A Fee. Rows: more than \$250,000 (\$25), up to \$250,000* (\$10).

* Any organization that contracted with or used the services of a professional fund raiser (PFR) or fund raising counsel (FRC) during the reporting period must pay an Article 7-A filing fee of \$25, regardless of total support and revenue.

b) EPTL filing fee

Table with 2 columns: Net Worth at End of Year, EPTL Fee. Rows: Less than \$50,000 (\$25), \$50,000 or more, but less than \$250,000 (\$50), \$250,000 or more, but less than \$1,000,000 (\$100), \$1,000,000 or more, but less than \$10,000,000 (\$250), \$10,000,000 or more, but less than \$50,000,000 (\$750), \$50,000,000 or more (\$1500).

6. Attachments - Document Attachment Check-List

Check the boxes for the documents you are attaching.

For All Filers
Filing Fee
[X] Single check or money order payable to "NYS Department of Law"
Copies of Internal Revenue Service Forms
[X] IRS Form 990
[X] All required schedules (including Schedule B)
[] IRS Form 990-T
[] IRS Form 990-EZ
[] All required schedules (including Schedule B)
[] IRS Form 990-T
[] IRS Form 990-PF
[] All required schedules (including Schedule B)
[] IRS Form 990-T

Additional Article 7-A Document Attachment Requirement
Independent Accountant's Report
[X] Audit Report (total support & revenue more than \$250,000)
[] Review Report (total support & revenue \$100,001 to \$250,000)
[] No Accountant's Report Required (total support & revenue not more than \$100,000)