Form **990-EZ**

Department of the Treasury
Internal Revenue Service

Short Form
Return of Organization Exempt From Income Tax

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code
(except black lung benefit trust or private foundation)

u Sponsoring organizations of donor advised funds and controlling organizations as defined in section 512(b)(13) must file Form 990. All other organizations with gross receipts less than $1,000,000 and total assets less than $2,500,000 at the end of the year may use this form.
u The organization may have to use a copy of this return to satisfy state reporting requirements.

OMB No. 1545-1150

2008

Open to Public Inspection

A For the 2008 calendar year, or tax year beginning , and ending

B Check if applicable:
- [ ] Address change
- [ ] Name change
- [ ] Initial return
- [ ] Termination
- [ ] Amended return
- [ ] Application pending

Please use IRS label or print or type. See Specific Instructions.

C Name of organization
NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS

Number and street (or P.O. box, if mail is not delivered to street address) | Room/suite
410 EAST MAIN STREET

City or town, state or country, and ZIP + 4
MASCOUTAH IL 62258

D Employer identification number
37-1112496

E Telephone number
618-566-2020

F Group Exemption Number u

● **Section 501(c)(3) organizations and 4947(a)(1) nonexempt charitable trusts must attach a completed Schedule A (Form 990 or 990-EZ).**

G Accounting method: [ ] Cash [X] Accrual
Other (specify) u

H Check u [ ] if the organization is **not** required to attach Schedule B (Form 990, 990-EZ, or 990-PF).

I **Website:** u WWW.NFED.ORG

J **Organization type** (check only one)— [X] 501(c) (3) t (insert no.) [ ] 4947(a)(1) or [ ] 527

K Check u [ ] if the organization is not a section 509(a)(3) supporting organization **and** its gross receipts are normally **not** more than $25,000. A return is not required, but if the organization chooses to file a return, be sure to file a complete return.

L Add lines 5b, 6b, and 7b, to line 9 to determine gross receipts; if $1,000,000 or more, file Form 990 instead of Form 990-EZ u $ 962,915

Part I Revenue, Expenses, and Changes in Net Assets or Fund Balances (See the instructions for Part I.)

Revenue	1	Contributions, gifts, grants, and similar amounts received			1	757,317
	2	Program service revenue including government fees and contracts			2	10,540
	3	Membership dues and assessments			3	
	4	Investment income			4	47,789
	5a	Gross amount from sale of assets other than inventory	5a	22,194		
	b	Less: cost or other basis and sales expenses	5b	22,719		
	c	Gain or (loss) from sale of assets other than inventory (Subtract line 5b from line 5a) (attach sch.) SEE STMT 1			5c	-525
	6	Special events and activities (complete applicable parts of Schedule G). If any amount is from gaming, check here ▶ [ ]				SEE STMT 2
	a	Gross revenue (not including $ 35,059 of contributions reported on line 1)	6a	120,404		
	b	Less: direct expenses other than fundraising expenses	6b	102,251		
	c	Net income or (loss) from special events and activities (Subtract line 6b from line 6a)			6c	18,153
	7a	Gross sales of inventory, less returns and allowances	7a			
	b	Less: cost of goods sold	7b			
	c	Gross profit or (loss) from sales of inventory (Subtract line 7b from line 7a)			7c	
	8	Other revenue (describe ▶ SEE STATEMENT 3)			8	4,671
	9	**Total revenue.** Add lines 1, 2, 3, 4, 5c, 6c, 7c, and 8 ▶			9	837,945
Expenses	10	Grants and similar amounts paid (attach schedule) SEE STATEMENT 4			10	213,911
	11	Benefits paid to or for members			11	
	12	Salaries, other compensation, and employee benefits			12	430,157
	13	Professional fees and other payments to independent contractors			13	
	14	Occupancy, rent, utilities, and maintenance			14	24,630
	15	Printing, publications, postage, and shipping			15	
	16	Other expenses (describe ▶ SEE STATEMENT 5)			16	558,371
	17	**Total expenses.** Add lines 10 through 16 ▶			17	1,227,069
Net Assets	18	Excess or (deficit) for the year (Subtract line 17 from line 9)			18	-389,124
	19	Net assets or fund balances at beginning of year (from line 27, column (A)) (must agree with end-of-year figure reported on prior year's return)			19	1,441,400
	20	Other changes in net assets or fund balances (attach explanation) SEE STATEMENT 6			20	-258,076
	21	Net assets or fund balances at end of year. Combine lines 18 through 20 ▶			21	794,200

Part II Balance Sheets. If Total assets on line 25, column (B) are $2,500,000 or more, file Form 990 instead of Form 990-EZ.

(See the instructions for Part II.)	(A) Beginning of year		(B) End of year
22 Cash, savings, and investments	1,828,989	22	1,246,788
23 Land and buildings	8,800	23	5,411
24 Other assets (describe ▶ SEE STATEMENT 7)	10,449	24	2,507
25 **Total assets**	1,848,238	25	1,254,706
26 **Total liabilities** (describe ▶ SEE STATEMENT 8)	406,838	26	460,506
27 **Net assets or fund balances** (line 27 of column (B) **must** agree with line 21)	1,441,400	27	794,200

Part III Statement of Program Service Accomplishments (See the instructions for Part III.)

What is the organization's primary exempt purpose?

SEE STATEMENT 9

Describe what was achieved in carrying out the organization's exempt purposes. In a clear and concise manner, describe the services provided, the number of persons benefited, or other relevant information for each program title.

Expenses (Required for 501(c)(3) and (4) organizations and 4947(a)(1) trusts; optional for others.)

28	SEE STATEMENT 10 (Grants $) If this amount includes foreign grants, check here u ☐	28a	188,830
29	SEE STATEMENT 11 (Grants $ 33,321) If this amount includes foreign grants, check here u ☒	29a	275,175
30	TREATMENT - PROVIDES FINANCIAL SUPPORT FOR THE MEDICAL AND DENTAL CARE OF INDIVIDUALS FOR WHOM INSURANCE CARRIERS HAVE DENIED BENEFITS (Grants $ 180,590) If this amount includes foreign grants, check here u ☐	30a	232,913
31	Other program services (attach schedule) SEE STATEMENT 12 (Grants $) If this amount includes foreign grants, check here u ☐	31a	353,396
32	**Total program service expenses** (add lines 28a through 31a) u	32	1,050,314

Part IV List of Officers, Directors, Trustees, and Key Employees. List each one even if not compensated. (See the instructions for Part IV.)

(a) Name and address	(b) Title and average hours per week devoted to position	(c) Compensation (If not paid, enter -0-.)	(d) Contributions to employee benefit plans & deferred compensation	(e) Expense account and other allowances
SEE STATEMENT 13				

Part V Other Information (Note the statement requirements in the instructions for Part VI.)

			Yes	No
33	Did the organization engage in any activity not previously reported to the IRS? If "Yes," attach a detailed description of each activity	33		X
34	Were any changes made to the organizing or governing documents but not reported to the IRS? If "Yes," attach a conformed copy of the changes	34		X
35	If the organization had income from business activities, such as those reported on lines 2, 6a, and 7a (among others), but not reported on Form 990-T, attach a statement explaining your reason for not reporting the income on Form 990-T.			
a	Did the organization have unrelated business gross income of $1,000 or more or section 6033(e) notice, reporting, and proxy tax requirements?	35a		X
b	If "Yes," has it filed a tax return on **Form 990-T** for this year?	35b		
36	Was there a liquidation, dissolution, termination, or substantial contraction during the year? If "Yes," complete applicable parts of Schedule N	36		X
37a	Enter amount of political expenditures, direct or indirect, as described in the instr. u 37a			
b	Did the organization file **Form 1120-POL** for this year?	37b		X
38a	Did the organization borrow from, or make any loans to, any officer, director, trustee, or key employee **or** were any such loans made in a prior year and still unpaid at the start of the period covered by this return?	38a		X
b	If "Yes," complete Schedule L, Part II and enter the total amount involved 38b			
39	Section 501(c)(7) organizations. Enter:			
a	Initiation fees and capital contributions included on line 9 39a			
b	Gross receipts, included on line 9, for public use of club facilities 39b			
40a	Section 501(c)(3) organizations. Enter amount of tax imposed on the organization during the year under: section 4911 u ; section 4912 u ; section 4955 u			
b	Section 501(c)(3) and (4) organizations. Did the organization engage in any section 4958 excess benefit transaction during the year or did it become aware of an excess benefit transaction from a prior year? If "Yes," complete Schedule L, Part I	40b		X
c	Enter amount of tax imposed on organization managers or disqualified persons during the year under sections 4912, 4955, and 4958 u			
d	Enter amount of tax on line 40c reimbursed by the organization u			
e	All organizations. At any time during the tax year, was the organization a party to a prohibited tax shelter transaction? If "Yes," complete Form 8886-T	40e		X

41 List the states with which a copy of this return is filed. u IL

42a The books are in care of u BEVERLY MEIER Telephone no. u 618-566-2020

Located at u 410 EAST MAIN STREET MASCOUTAH, IL ZIP + 4 u 62258

			Yes	No
b	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)?	42b		X
	If "Yes," enter the name of the foreign country: u			
	See the instructions for exceptions and filing requirements for **Form TD F 90-22.1, Report of Foreign Bank and Financial Accounts.**			
c	At any time during the calendar year, did the organization maintain an office outside of the U.S.?	42c		X
	If "Yes," enter the name of the foreign country: u			

43 Section 4947(a)(1) nonexempt charitable trusts filing Form 990-EZ in lieu of **Form 1041—**Check here u ☐
and enter the amount of tax-exempt interest received or accrued during the tax year u 43

			Yes	No
44	Did the organization maintain any donor advised funds? If "Yes," Form 990 must be completed instead of Form 990-EZ	44		X
45	Is any related organization a controlled entity of the organization within the meaning of section 512(b)(13)? If "Yes," Form 990 must be completed instead of Form 990-EZ	45		X

Part VI **Section 501(c)(3) organizations only.** All section 501(c)(3) organizations must answer questions 46–49 and complete the tables for lines 50 and 51.

			Yes	No
46	Did the organization engage in direct or indirect political campaign activities on behalf of or in opposition to candidates for public office? If "Yes," complete Schedule C, Part I	46		X
47	Did the organization engage in lobbying activities? If "Yes," complete Schedule C, Part II	47		X
48	Is the organization operating a school as described in section 170(b)(1)(A)(ii)? If "Yes," complete Schedule E	48		X
49a	Did the organization make any transfers to an exempt non-charitable related organization?	49a		X
b	If "Yes," was the related organization(s) a section 527 organization?	49b		

50 Complete this table for the five highest compensated employees (other than officers, directors, trustees and key employees) who each received more than $100,000 of compensation from the organization. If there is none, enter "None."

(a) Name and address of each employee paid more than $100,000	**(b)** Title and average hours per week devoted to position	**(c)** Compensation	**(d)** Contributions to employee benefit plans & deferred compensation	**(e)** Expense account and other allowances
NONE				

Total number of other employees paid over $100,000 ▶

51 Complete this table for the five highest compensated independent contractors who each received more than $100,000 of compensation from the organization. If there is none, enter "None."

(a) Name and address of each independent contractor paid more than $100,000	**(b)** Type of service	**(c)** Compensation
NONE		

Total number of other independent contractors each receiving over $100,000 ▶

Sign Here

Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than officer) is based on all information of which preparer has any knowledge.

▶ Signature of officer | Date

▶ Type or print name and title.

Paid Preparer's Use Only

Preparer's signature ▶	Date	Check if self-employed ☐	Preparer's Identifying Number (See instr.) P00769718
Firm's name (or yours if self-employed), address, and ZIP + 4 ▶	DIEL & FORGUSON, LLC 852 CAMBRIDGE BLVD STE 100 O FALLON, IL 62269-1957	EIN	37-1372801
		Phone no.	618-632-7574

May the IRS discuss this return with the preparer shown above? See instructions ▶ ☐ Yes ☐ No

SCHEDULE A
(Form 990 or 990-EZ)

Department of the Treasury
Internal Revenue Service

Public Charity Status and Public Support

To be completed by all section 501(c)(3) organizations and section 4947(a)(1) nonexempt charitable trusts.

u Attach to Form 990 or Form 990-EZ. u See separate instructions.

OMB No. 1545-0047
2008
Open to Public Inspection

Name of the organization NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS

Employer identification number 37-1112496

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: (Please check only **one** organization.)

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).** (Attach Schedule H.)

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).** (see instructions)

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–Other

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?

		Yes	No
(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?	11g(i)		
(ii) A family member of a person described in (i) above?	11g(ii)		
(iii) A 35% controlled entity of a person described in (i) or (ii) above?	11g(iii)		

h Provide the following information about the organizations the organization supports.

(i) Name of supported organization	**(ii)** EIN	**(iii)** Type of organization (described on lines 1–9 above or IRC section **(see instructions)**)	(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 support
			Yes	**No**	**Yes**	**No**	**Yes**	**No**	
Total									

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.)

Section A. Public Support

Calendar year (or fiscal year beginning in) u	(a) 2004	(b) 2005	(c) 2006	(d) 2007	(e) 2008	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	564,087	949,488	1,575,854	802,115	757,317	4,648,861
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 1-3	564,087	949,488	1,575,854	802,115	757,317	4,648,861
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)						792,710
6 Public support. Subtract line 5 from line 4						3,856,151

Section B. Total Support

Calendar year (or fiscal year beginning in) u	(a) 2004	(b) 2005	(c) 2006	(d) 2007	(e) 2008	(f) Total
7 Amounts from line 4	564,087	949,488	1,575,854	802,115	757,317	4,648,861
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties and income from similar sources	4,278	33,348	66,578	99,167	47,789	251,160
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.)	5,513	5,650	3,992	3,725	4,671	23,551
11 **Total support.** Add lines 7 through 10						4,923,572

12 Gross receipts from related activities, etc. (see instructions) 12 873,689

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** ▶ ☐

Section C. Computation of Public Support Percentage

14 Public support percentage for 2008 (line 6, column (f) divided by line 11, column (f)) 14 78.3202 %

15 Public support percentage from 2007 Schedule A, Part IV-A, line 26f 15 74.6832 %

16a **33 1/3 % support test—2008.** 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 ▶ ☒

b **33 1/3 % support test—2007.** 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 ▶ ☐

17a **10%-facts-and-circumstances test—2008.** 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 ▶ ☐

b **10%-facts-and-circumstances test—2007.** 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 ▶ ☐

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 ▶ ☐

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.)

Section A. Public Support

Calendar year (or fiscal year beginning in) u	(a) 2004	(b) 2005	(c) 2006	(d) 2007	(e) 2008	(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 1-5						
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 1% of the total of lines 9, 10c, 11, and 12 for the year or $5,000						
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) u	(a) 2004	(b) 2005	(c) 2006	(d) 2007	(e) 2008	(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 2008 (line 8, column (f) divided by line 13, column (f))	15	%
16	Public support percentage from 2007 Schedule A, Part IV-A, line 27g	16	%

Section D. Computation of Investment Income Percentage

17	Investment income percentage for **2008** (line 10c, column (f) divided by line 13, column (f))	17	%
18	Investment income percentage from **2007** Schedule A, Part IV-A, line 27h	18	%

19a **33 1/3 % support tests—2008.** 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—2007.** 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.** Complete this part to provide the explanation required by Part II, line 10; Part II, line 17a or 17b; or Part III, line 12. Provide any other additional information. (see instructions)

PART II, LINE 10 - OTHER INCOME DETAIL

PUBLICATIONS $ 23,551

Schedule B
(Form 990, 990-EZ, or 990-PF)
Department of the Treasury
Internal Revenue Service

Schedule of Contributors

u Attach to Form 990, 990-EZ, and 990-PF.

OMB No. 1545-0047

2008

Name of the organization	Employer identification number
NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS	37-1112496

Organization type (check one):

Filers of:	**Section:**
Form 990 or 990-EZ	[X] 501(c)(3) (enter number) organization
	[ ] 4947(a)(1) nonexempt charitable trust **not** treated as a private foundation
	[ ] 527 political organization
Form 990-PF	[ ] 501(c)(3) exempt private foundation
	[ ] 4947(a)(1) nonexempt charitable trust treated as a private foundation
	[ ] 501(c)(3) taxable private foundation

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 organizations 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

[X] For a section 501(c)(3) organization filing Form 990, or Form 990-EZ, that met the 33 1/3% support test of the regulations under sections 509(a)(1)/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 Form 990, Part VIII, line 1h or 2% of the amount on Form 990-EZ, line 1. Complete Parts I and II.

[ ] For a section 501(c)(7), (8), or (10) organization filing Form 990, or Form 990-EZ, that received from any one contributor, during the year, aggregate contributions or bequests 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 Form 990-EZ, that received from any one contributor, during the year, some contributions for use exclusively for religious, charitable, etc., purposes, but these contributions did not aggregate 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. Organizations that are not covered by the General Rule and/or the Special Rules do not file Schedule B (Form 990, 990-EZ, or 990-PF), but they **must** answer "No" on Part IV, line 2 of their Form 990, or check the box in the heading of their Form 990-EZ, or on line 2 of their Form 990-PF, to certify that they do not meet the filing requirements of Schedule B (Form 990, 990-EZ, or 990-PF).

Name of organization
NATIONAL FOUNDATION FOR ECTODERMAL

Employer identification number
37-1112496

Part I **Contributors** (see instructions)

(a) No.	(b) Name, address, and ZIP + 4	(c) Aggregate contributions	(d) Type of contribution
1	STRAUMANN 60 MINUTEMAN ROAD ANDOVER MA 01810	$ 25,000	Person [X] Payroll [ ] Noncash [ ] (Complete Part II if there is a noncash contribution.)
2	THE HUBBARD FOUNDATION 3415 UNIVERSITY AVE., S.E. ST. PAUL MN 55114	$ 25,000	Person [X] Payroll [ ] Noncash [ ] (Complete Part II if there is a noncash contribution.)
3	ETHELYN BOYD 52 WEST MAIN MASCOUTAH IL 62258	$ 17,163	Person [ ] Payroll [ ] Noncash [X] (Complete Part II if there is a noncash contribution.)
4	LOUIS KAY C/O JACK SALOMON, RSM MCGLADRY, INC. 750 THIRD AVENUE, 9TH FLOOR NEW YORK NY 10017	$ 20,000	Person [X] Payroll [ ] Noncash [ ] (Complete Part II if there is a noncash contribution.)
5	ALTARUM INSTITUTE NAOMI TEIN, MPR, SENIOR POLICY ASSOC 1200 18TH STREET, NW WASHINGTON DC 20036	$ 16,962	Person [X] Payroll [ ] Noncash [ ] (Complete Part II if there is a noncash contribution.)
6	MEDICAL UNIVERSITY OF SOUTH CAROLINA 172 ASHLEY AVE, BSB 449 PO BOX 250507 CHARLESTON SC 29426	$ 29,465	Person [X] Payroll [ ] Noncash [ ] (Complete Part II if there is a noncash contribution.)

Name of organization
NATIONAL FOUNDATION FOR ECTODERMAL

Employer identification number
37-1112496

Part I **Contributors** (see instructions)

(a) No.	(b) Name, address, and ZIP + 4	(c) Aggregate contributions	(d) Type of contribution
7	CONTRIBUTIONS $5,000 OR LESS VARIOUS MASCOUTH IL 62258	$ 450,255	Person [X] Payroll [ ] Noncash [ ] (Complete Part II if there is a noncash contribution.)
		$	Person [ ] Payroll [ ] Noncash [ ] (Complete Part II if there is a noncash contribution.)
		$	Person [ ] Payroll [ ] Noncash [ ] (Complete Part II if there is a noncash contribution.)
		$	Person [ ] Payroll [ ] Noncash [ ] (Complete Part II if there is a noncash contribution.)
		$	Person [ ] Payroll [ ] Noncash [ ] (Complete Part II if there is a noncash contribution.)
		$	Person [ ] Payroll [ ] Noncash [ ] (Complete Part II if there is a noncash contribution.)

Name of organization
NATIONAL FOUNDATION FOR ECTODERMAL

Employer identification number
37-1112496

Part II Noncash Property (see instructions)

(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (see instructions)	(d) Date received
3	300 SHARES ANHEUSER BUSCH	$ 17,163	6/06/08

(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (see instructions)	(d) Date received
		$	

(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (see instructions)	(d) Date received
		$	

(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (see instructions)	(d) Date received
		$	

(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (see instructions)	(d) Date received
		$	

(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (see instructions)	(d) Date received
		$	

Form **990**

Special Events Schedule

2008

For calendar year 2008, or tax year beginning , and ending

Name: NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS

Employer Identification Number: 37-1112496

	(A)	(B)	(C)	Others	Total
Gross receipts	81,530	42,412	31,521	0	155,463
Less contributions	25,625	0	9,434	0	35,059
Gross revenue	55,905	42,412	22,087	0	120,404
Less direct expenses	82,463	4,274	15,514	0	102,251
Net income (loss)	-26,558	38,138	6,573	0	18,153

Description:

(A) HALLOWEEN BASH

(B) OTHER EVENTS

(C) APPLE CLASSIC GOLF TOUR.

Others

Form **4562** Department of the Treasury Internal Revenue Service (99)

Depreciation and Amortization

(Including Information on Listed Property)

▶ See separate instructions. ▶ Attach to your tax return.

OMB No. 1545-0172 **2008** Attachment Sequence No. 67

Name(s) shown on return: NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS

Identifying number: 37-1112496

Business or activity to which this form relates: INDIRECT DEPRECIATION

Part I Election To Expense Certain Property Under Section 179

Note: If you have any listed property, complete Part V before you complete Part I.

1	Maximum amount. See the instructions for a higher limit for certain businesses	1	250,000
2	Total cost of section 179 property placed in service (see instructions)	2	
3	Threshold cost of section 179 property before reduction in limitation (see instructions)	3	800,000
4	Reduction in limitation. Subtract line 3 from line 2. If zero or less, enter -0-	4	
5	Dollar limitation for tax year. Subtract line 4 from line 1. If zero or less, enter -0-. If married filing separately, see instructions	5	

	(a) Description of property	(b) Cost (business use only)	(c) Elected cost
6			
7	Listed property. Enter the amount from line 29	7	

8	Total elected cost of section 179 property. Add amounts in column (c), lines 6 and 7	8	
9	Tentative deduction. Enter the **smaller** of line 5 or line 8	9	
10	Carryover of disallowed deduction from line 13 of your 2007 Form 4562	10	
11	Business income limitation. Enter the smaller of business income (not less than zero) or line 5 (see instructions)	11	
12	Section 179 expense deduction. Add lines 9 and 10, but do not enter more than line 11	12	
13	Carryover of disallowed deduction to 2009. Add lines 9 and 10, less line 12 ▶	13	

Note: Do not use Part II or Part III below for listed property. Instead, use Part V.

Part II Special Depreciation Allowance and Other Depreciation (Do not include listed property.) (See instructions.)

14	Special depreciation allowance for qualified property (other than listed property) placed in service during the tax year (see instructions)	14	
15	Property subject to section 168(f)(1) election	15	
16	Other depreciation (including ACRS)	16	3,032

Part III MACRS Depreciation (Do not include listed property.) (See instructions.)

Section A

17	MACRS deductions for assets placed in service in tax years beginning before 2008	17	0
18	If you are electing to group any assets placed in service during the tax year into one or more general asset accounts, check here ▶ ☐		

Section B—Assets Placed in Service During 2008 Tax Year Using the General Depreciation System

(a) Classification of property	(b) Month and year placed in service	(c) Basis for depreciation (business/investment use only–see instructions)	(d) Recovery period	(e) Convention	(f) Method	(g) Depreciation deduction
19a 3-year property						
b 5-year property						
c 7-year property						
d 10-year property						
e 15-year property						
f 20-year property						
g 25-year property			25 yrs.		S/L	
h Residential rental property			27.5 yrs.	MM	S/L	
			27.5 yrs.	MM	S/L	
i Nonresidential real property			39 yrs.	MM	S/L	
				MM	S/L	

Section C—Assets Placed in Service During 2008 Tax Year Using the Alternative Depreciation System

(a) Classification of property	(b) Month and year placed in service	(c) Basis for depreciation	(d) Recovery period	(e) Convention	(f) Method	(g) Depreciation deduction
20a Class life					S/L	
b 12-year			12 yrs.		S/L	
c 40-year			40 yrs.	MM	S/L	

Part IV Summary (See instructions.)

21	Listed property. Enter amount from line 28	21	
22	**Total.** Add amounts from line 12, lines 14 through 17, lines 19 and 20 in column (g), and line 21. Enter here and on the appropriate lines of your return. Partnerships and S corporations—see instr.	22	3,032
23	For assets shown above and placed in service during the current year, enter the portion of the basis attributable to section 263A costs	23	

For Paperwork Reduction Act Notice, see separate instructions.

DAA

THERE ARE NO AMOUNTS FOR PAGE 2

Federal Statements

Statement 1 - Form 990-EZ, Part I, Line 5c - Sale of Assets Other than Inventory - Securities

Description		Date Acquired	Date Sold	Sale Price	Cost & Expense	Depreciation	Gain / Loss
How Received	Whom Sold						
300 SH ANHEUSER BUSCH							
DONATION		6/06/08	6/09/08	$ 17,191	$ 17,163	$	$ 28
100 SH KANSAS CITY SOUTHERN							
DONATION		9/19/08	9/19/08	5,003	5,197		-194
TOTAL				$ 22,194	$ 22,360	$ 0	$ -166

Statement 2 - Form 990-EZ, Part I, Line 5c - Sale of Assets Other than Inventory - Other

Description		Date Acquired	Date Sold	Sale Price	Cost & Expense	Depreciation	Gain / Loss
How Received	Whom Sold						
COMPUTER (1-138)							
PURCHASE		4/01/03	2/01/08	$	$ 589	$ 540	$ -49
COMPUTER (1-140)							
PURCHASE		4/01/03	2/01/08		589	540	-49
COMPUTER (1-155)							
PURCHASE		4/01/03	2/01/08		589	540	-49
EPSON 1520 PRINTER (2-104)							
PURCHASE		11/18/99	2/01/08		500	500	
COMPUTER (1-159)							
PURCHASE		2/01/04	2/01/08		749	537	-212
TOTAL				$ 0	$ 3,016	$ 2,657	$ -359

Statement 3 - Form 990-EZ, Part I, Line 8 - Other Revenue

Description	Amount
PUBLICATIONS	$ 4,671
TOTAL	$ 4,671

Federal Statements

Statement 4 - Form 990-EZ, Part I, Line 10 - Grants and Similar Amounts Paid

Name and Address		Relationship to Organization		Class of Activity	Date of Gift	
Description of Property	Cash Contribution	Noncash Contribution	Book Value	Book Value Explanation	FMV Explanation	Purpose
MOHAMMED ABDEL-RAHMAN ALI 4 ZOKAK ABE ALHARES HARET EL GAMEA EG 11668						
	550		$			
CLIENT ASSISTANCE						
	180,590					
CLIENT SUPPORT						
	8,721					
SCHOLARSHIP						
	1,000					
SCHOLARSHIP						
	1,250					
SCHOLARSHIP						
	1,000					
SCHOLARSHIP						
	550					
SCHOLARSHIP						
	1,000					

Federal Statements

Statement 4 - Form 990-EZ, Part I, Line 10 - Grants and Similar Amounts Paid (continued)

Name and Address / Description of Property	Cash Contribution	Relationship to Organization / Noncash Contribution	Book Value	Class of Activity / Book Value Explanation	Date of Gift / FMV Explanation	Purpose
SCHOLARSHIP	1,000		$			
SCHOLARSHIP	1,000					
SCHOLARSHIP	550					
SCHOLARSHIP	1,000					
SCHOLARSHIP	1,000					
SCHOLARSHIP	550					
SCHOLARSHIP	1,000					
SCHOLARSHIP	550					
SCHOLARSHIP	550					
SCHOLARSHIP	550					
SCHOLARSHIP	1,000					
SCHOLARSHIP	1,000					

Statement 4 - Form 990-EZ, Part I, Line 10 - Grants and Similar Amounts Paid (continued)

Name and Address		Relationship to Organization		Class of Activity	Date of Gift	
Description of Property	Cash Contribution	Noncash Contribution	Book Value	Book Value Explanation	FMV Explanation	Purpose
SCHOLARSHIP						
	1,000					
SCHOLARSHIP						
	550					
SCHOLARSHIP						
	550					
SCHOLARSHIP						
	1,000					
SCHOLARSHIP						
	1,000					
SCHOLARSHIP						
	550					
SCHOLARSHIP						
	1,250					
SCHOLARSHIP						
	550					
SCHOLARSHIP						
	550					
SCHOLARSHIP						
	1,250					
SCHOLARSHIP						
	550					

Statement 4 - Form 990-EZ, Part I, Line 10 - Grants and Similar Amounts Paid (continued)

Name and Address		Relationship to Organization		Class of Activity	Date of Gift	
Description of Property	**Cash Contribution**	**Noncash Contribution**	**Book Value**	**Book Value Explanation**	**FMV Explanation**	**Purpose**
SCHOLARSHIP						
	1,000		$			
SCHOLARSHIP REFUND						
	-300					
TOTAL	213,911					

Federal Statements

Statement 5 - Form 990-EZ, Part I, Line 16 - Other Expenses

Description	Amount
EXPENSES	$
MEETINGS / TRAVEL	1,810
MEETINGS / TRAVEL	770
MEETINGS / TRAVEL	7,277
MEETINGS / TRAVEL	2,903
MEETINGS / TRAVEL	122,708
MEETINGS / TRAVEL	4,066
MEMBERSHIPS	2,558
MEMBERSHIPS	993
MEMBERSHIPS	44
MEMBERSHIPS	87
MEMBERSHIPS	967
MEMBERSHIPS	27
OFFICE SUPPLIES	2,722
OFFICE SUPPLIES	4,793
OFFICE SUPPLIES	1,030
POSTAGE	4,650
POSTAGE	5,712
POSTAGE	1,204
OFFICE EQUIPMENT	4,315
OFFICE EQUIPMENT	4,877
OFFICE EQUIPMENT	1,501
REPAIRS & MAINTENANCE	928
REPAIRS & MAINTENANCE	1,049
REPAIRS & MAINTENANCE	310
PRINTED / ELECTRONIC INFO	8,453
PRINTED / ELECTRONIC INFO	2,848
PRINTED / ELECTRONIC INFO	611
CONTINUING EDUCATION	873
UTILITIES	1,054
UTILITIES	1,192
UTILITIES	367
FAMILY SUPPORT NETWORK	1,919
BOARD OF DIRECTORS	4,581
BOARD OF DIRECTORS	4,654
PROFESSIONAL FEES	8,855
INSURANCE	848
INSURANCE	959
INSURANCE	295
NEWSLETTER	28,863
PUBLIC RELATIONS	3,665
PUBLIC RELATIONS	81
NATIONAL FAMILY CONFERENC	73,178
REGIONAL FAMILY CONFERENC	10,847
COMMUNICATIONS	860
COMMUNICATIONS	969
COMMUNICATIONS	296
CONTINUING EDUCATION	155
BOARD OF DIRECTORS	2,901
PROFESSIONAL FEES	530
CONTINUING EDUCATION	48
PROFESSIONAL FEES	226
PROMOTIONAL ITEMS	273
CONTINUING EDUCATION	90

Federal Statements

Statement 5 - Form 990-EZ, Part I, Line 16 - Other Expenses (continued)

Description	Amount
UTILITIES	$ 458
BOARD OF DIRECTORS	1,010
PROFESSIONAL FEES	21,414
BANK / CREDIT CARD FEES	4,256
INVESTMENT COMMISSIONS /	248
INSURANCE	369
OFFICE SUPPLIES	1,237
OFFICE EQUIPMENT	1,906
PROMOTIONAL ITEMS	2,477
POSTAGE	585
PRINTED / ELECTRONIC INFO	1,261
PUBLIC RELATIONS	1,710
REPAIRS & MAINTENANCE	403
COMMUNICATIONS	404
CONTINUING EDUCATION	78
UTILITIES	596
STRATEGIC PLAN	2,749
PROFESSIONAL FEES	368
INSURANCE	479
OFFICE SUPPLIES	1,977
OFFICE EQUIPMENT	2,439
POSTAGE	892
PRINTED / ELECTRONIC INFO	1,068
PUBLIC RELATIONS	41
REPAIRS & MAINTENANCE	524
COMMUNICATIONS	481
THIRD PARTY SPONSORED EVE	2,123
MISCELLANEOUS FUND RAISIN	1,285
DIRECT MAIL	24,401
EMPLOYEE CAMPAIGNS	50
CONTINUING EDUCATION	119
UTILITIES	917
STRATEGIC PLAN	2,115
STRATEGIC PLAN	4,864
STRATEGIC PLAN	5,499
STRATEGIC PLAN	4,230
STRATEGIC PLAN	1,692
PROFESSIONAL FEES	565
INSURANCE	738
OFFICE SUPPLIES	3,700
OFFICE EQUIPMENT	3,752
POSTAGE	2,629
PRINTED / ELECTRONIC INFO	6,934
PUBLIC RELATIONS	62
PUBLIC RELATIONS	25
NATIONAL FAMILY CONFERENC	1,372
REGIONAL FAMILY CONFERENC	33
REGIONAL FAMILY CONFERENC	13
REPAIRS & MAINTENANCE	774
DIRECT FUNDING	102,500
COMMUNICATIONS	757
TOTAL	$ 558,371

Federal Statements

Statement 6 - Form 990-EZ, Part I, Line 20 - Other Changes in Net Assets or Fund Balances

Description	Amount
DONATED SERVICES AND USE OF FACILITIES	$ 23,184
NET UNREALIZED GAINS ON INVESTMENTS	-281,258
BOOK / TAX DEPREC DIFFERENCE	-2
TOTAL	$ -258,076

Statement 7 - Form 990-EZ, Part II, Line 24 - Other Assets

Description	Beginning of Year	End of Year
PLEDGES RECEIVABLE	$ 8,400	$
PREPAID EXPENSES AND DEFERRED CHARGES	2,049	2,507
TOTAL	$ 10,449	$ 2,507

Statement 8 - Form 990-EZ, Part II, Line 26 - Total Liabilities

Description	Beginning of Year	End of Year
ACCOUNTS PAYABLE AND ACCRUED EXPENSES	$ 27,433	$ 46,599
GRANTS PAYABLE	379,405	413,907
TOTAL	$ 406,838	$ 460,506

Federal Statements

Statement 9 - Form 990-EZ, Part III - Organization's Primary Exempt Purpose

Description

TO PROVIDE PATIENT SUPPORT AND FINANCIAL ASSISTANCE FOR FAMILIES AFFECTED BY A GENETIC DISORDER AND ON-GOING EDUCATION TO THE MEDICAL/DENTAL COMMUNITY. 5,470 PERSONS WERE SERVED DURING THE YEAR.

Statement 10 - Form 990-EZ, Part III, Line 28 - Statement of Program Service Accomplishments

Description

EDUCATION - PROVIDES ON-GOING EDUCATION TO ED FAMILIES, DOCTORS & DENTISTS BY PROVIDING SPEAKERS & DISPLAYS AT CONVENTIONS, PUBLISHING A MONTHLY NEWSLETTER, PREPARING PAMPHLETS, BOOKLETS AND VIDEOTAPES AND ALERTING THE MEDIA TO NEW DEVELOPMENTS.

Statement 11 - Form 990-EZ, Part III, Line 29 - Statement of Program Service Accomplishments

Description

FAMILY SUPPORT - PROVIDES SUPPORT TO INDIVIDUALS AFFECTED BY ED SYNDROMES BY SPONSORING AN ANNUAL FAMILY CONFERENCE AND DIRECTING INDIVIDUALS TO TREATMENT CENTERS AND GIVE EMOTIONAL SUPPORT.

Statement 12 - Form 990-EZ, Part III, Line 31 - Statement of Program Service Accomplishments

Description

RESEARCH - PROVIDES GRANTS FOR RESEARCH OF FEDERAL AND STATE STATUTES AND GENERAL HEALTH INSURANCE PRACTICES AND POLICIES REGARDING COVERAGE AND DELIVERY OF DENTAL CARE FOR INDIVIDUALS WITH A GENETIC SYNDROME SUCH AS ED

Statement 13 - Form 990EZ, Part IV - List of Officers, Directors, Trustees and Key Employees

Name and Address	Title	Average Hours	Compensation	Benefits	Expenses
KEVIN PAWLOW	PRESIDENT	1	0	0	0
RICHARD R. CAIN, JR.	VICE-PRES.	1	0	0	0
GARRETT C. REUTER	SECRETARY	1	0	0	0
CATHERINE M. KLINGELHOEFER	DIRECTOR	1	0	0	0
KEITH THROM	DIRECTOR	1	0	0	0
BRIAN F. RANDALL	TREASURER	1	0	0	0
ANIL VORA	DIRECTOR	1	0	0	0
FRANK H. FARRINGTON, DDS	DIRECTOR	1	0	0	0
DAVID FREESTONE, MD	DIRECTOR	1	0	0	0
JAMES L. GEHRS, DDS	DIRECTOR	1	0	0	0
KEITH S. GEISMAR	DIRECTOR	1	0	0	0
JERRY F. COSTELLO	DIRECTOR	1	0	0	0
DONALD HUEBENER, DDS, MS	DIRECTOR	1	0	0	0
JACK KRIZ	DIRECTOR	1	0	0	0
RICHARD F. MOSS	DIRECTOR	1	0	0	0
BETH POND	DIRECTOR	1	0	0	0
JOHN A. STITH, MD	DIRECTOR	1	0	0	0
SARAH A. TEVIS, DDS	DIRECTOR	1	0	0	0

Statement 13 - Form 990EZ, Part IV - List of Officers, Directors, Trustees and Key Employees (continued)

Name and Address	Title	Average Hours	Compensation	Benefits	Expenses
JACK SALOMON	DIRECTOR	1	0	0	0
MARY K. RICHTER (EDUCATION)	EXEC DIR	11	14,694	435	0
MARY K. RICHTER (FAMILY SERVICES	EXEC DIR	12	16,268	482	0
MARY K. RICHTER (G&A)	EXEC DIR	9	11,545	342	0
MARY K. RICHTER (TREATMENT)	EXEC DIR	1	1,574	47	0
MARY K. RICHTER (RESEARCH)	EXEC DIR	4	5,248	155	0
MARY K. RICHTER (FUNDRAISING)	EXEC DIR	3	3,149	93	0