

Form **990**

# Return of Organization Exempt From Income Tax

OMB No. 1545-0047

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

# 2025

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

Open to Public Inspection

Department of the Treasury  
Internal Revenue Service

Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

**A** For the **2025** calendar year, or tax year beginning and ending

<b>B</b> Check if applicable: <input type="checkbox"/> Address change <input type="checkbox"/> Name change <input type="checkbox"/> Initial return <input type="checkbox"/> Final return/terminated <input type="checkbox"/> Amended return <input type="checkbox"/> Application pending	<b>C</b> Name of organization <b>NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS</b>	<b>D</b> Employer identification number <b>37-1112496</b>
	Doing business as	<b>E</b> Telephone number <b>618-566-2020</b>
	Number and street (or P.O. box if mail is not delivered to street address) Room/suite <b>6 EXECUTIVE DRIVE, SUITE 2</b>	<b>G</b> Gross receipts \$ <b>2,941,767.</b>
	City or town, state or province, country, and ZIP or foreign postal code <b>FAIRVIEW HEIGHTS, IL 62208</b>	<b>H(a)</b> Is this a group return for subordinates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No <b>H(b)</b> Are all subordinates included? <input type="checkbox"/> Yes <input type="checkbox"/> No If "No," attach a list. See instructions <b>H(c)</b> Group exemption number
<b>F</b> Name and address of principal officer: <b>KARL NELSEN</b> <b>SAME AS C ABOVE</b>		
<b>I</b> Tax-exempt status: <input checked="" type="checkbox"/> 501(c)(3) <input type="checkbox"/> 501(c) ( ) (insert no.) <input type="checkbox"/> 4947(a)(1) or <input type="checkbox"/> 527		
<b>J</b> Website: <b>WWW.NFED.ORG</b>		
<b>K</b> Form of organization: <input checked="" type="checkbox"/> Corporation <input type="checkbox"/> Trust <input type="checkbox"/> Association <input type="checkbox"/> Other		<b>L</b> Year of formation: <b>1981</b> <b>M</b> State of legal domicile: <b>IL</b>

Part I Summary		Prior Year	Current Year
Activities & Governance	<b>1</b> Briefly describe the organization's mission or most significant activities: <b>EMPOWER AND CONNECT PEOPLE TOUCHED BY ECTODERMAL DYSPLASIAS VIA EDUCATION, SUPPORT, &amp; RESEARCH.</b>		
	<b>2</b> Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.		
	<b>3</b> Number of voting members of the governing body (Part VI, line 1a)	<b>3</b>	<b>11</b>
	<b>4</b> Number of independent voting members of the governing body (Part VI, line 1b)	<b>4</b>	<b>11</b>
	<b>5</b> Total number of individuals employed in calendar year 2025 (Part V, line 2a)	<b>5</b>	<b>10</b>
	<b>6</b> Total number of volunteers (estimate if necessary)	<b>6</b>	<b>443</b>
	<b>7 a</b> Total unrelated business revenue from Part VIII, column (C), line 12	<b>7a</b>	<b>0.</b>
<b>b</b> Net unrelated business taxable income from Form 990-T, Part I, line 11	<b>7b</b>	<b>0.</b>	
Revenue	<b>8</b> Contributions and grants (Part VIII, line 1h)	<b>971,012.</b>	<b>1,120,585.</b>
	<b>9</b> Program service revenue (Part VIII, line 2g)	<b>10,275.</b>	<b>45,440.</b>
	<b>10</b> Investment income (Part VIII, column (A), lines 3, 4, and 7d)	<b>241,442.</b>	<b>460,376.</b>
	<b>11</b> Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	<b>6,923.</b>	<b>20,723.</b>
	<b>12</b> Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	<b>1,229,652.</b>	<b>1,647,124.</b>
Expenses	<b>13</b> Grants and similar amounts paid (Part IX, column (A), lines 1-3)	<b>14,325.</b>	<b>45,915.</b>
	<b>14</b> Benefits paid to or for members (Part IX, column (A), line 4)	<b>0.</b>	<b>0.</b>
	<b>15</b> Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	<b>628,902.</b>	<b>894,433.</b>
	<b>16a</b> Professional fundraising fees (Part IX, column (A), line 11e)	<b>0.</b>	<b>0.</b>
	<b>b</b> Total fundraising expenses (Part IX, column (D), line 25) <b>219,560.</b>		
<b>17</b> Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	<b>560,156.</b>	<b>619,183.</b>	
<b>18</b> Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	<b>1,203,383.</b>	<b>1,559,531.</b>	
<b>19</b> Revenue less expenses. Subtract line 18 from line 12	<b>26,269.</b>	<b>87,593.</b>	
Net Assets or Fund Balances	<b>20</b> Total assets (Part X, line 16)	<b>Beginning of Current Year</b> <b>4,790,999.</b>	<b>End of Year</b> <b>4,979,793.</b>
	<b>21</b> Total liabilities (Part X, line 26)	<b>98,322.</b>	<b>126,727.</b>
	<b>22</b> Net assets or fund balances. Subtract line 21 from line 20	<b>4,692,677.</b>	<b>4,853,066.</b>

**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 <i>Karl Nelsen</i>	Date <b>5/11/2026</b>
	<b>KARL NELSEN, PRESIDENT</b> Type or print name and title	
Paid Preparer Use Only	Preparer's name <b>JEFF PARKER</b>	Preparer's signature <i>Jeff Parker</i>
	Firm's name <b>CLIFTONLARSONALLEN LLP</b>	Date <b>05/01/26</b>
	Firm's address <b>475 REGENCY PARK, SUITE 175 O'FALLON, IL 62269</b>	Check if self-employed <input type="checkbox"/> PTIN <b>P00970069</b>
		Firm's EIN <b>41-0746749</b>
		Phone no. (618) <b>233-1200</b>

NATIONAL FOUNDATION FOR ECTODERMAL  
DYSPLASIAS

Form 990 (2025)

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:  
TO EMPOWER AND CONNECT PEOPLE TOUCHED BY ECTODERMAL DYSPLASIAS THROUGH  
EDUCATION, SUPPORT, AND RESEARCH.

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 \$ 626,577. including grants of \$ 45,915. ) (Revenue \$ 49,642. )  
SUPPORT - NFED PUBLISHES HIGH QUALITY INFORMATION TO PROVIDE FAMILIES  
WITH KNOWLEDGE THAT WILL INCREASE THEIR QUALITY OF LIFE. INFORMATION  
IS SHARED THROUGH THE FIRST CONNECT PROGRAM, A WEB SITE, MEDICAL/DENTAL  
GUIDE SERIES, AND CONFERENCES. THE NATIONAL FAMILY CONFERENCE IS THE  
NFED'S HALLMARK PROGRAM BRINGING ENTIRE FAMILIES TOGETHER TO LEARN,  
SHARE, AND NETWORK WITH ONE ANOTHER AND WITH EXPERT CARE PROVIDERS.  
AFFECTED CHILDREN AND THEIR SIBLINGS ATTEND KIDS CAMP AT THE  
CONFERENCES WHERE THEY PARTICIPATE IN EDUCATIONAL AND SOCIAL ACTIVITIES  
WITH OTHER CHILDREN LIKE THEM TO DEVELOP SELF-ESTEEM. THE NFED  
PROVIDES FINANCIAL ASSISTANCE TO INDIVIDUALS TO ATTEND THE FAMILY  
CONFERENCE. THE NFED'S FAMILY-TO-FAMILY NETWORK CONNECTS FAMILIES WITH  
A CARING LIAISON IN THEIR REGION WHO CAN PROVIDE MORAL SUPPORT,

4b (Code: ) (Expenses \$ 293,085. including grants of \$ 0. ) (Revenue \$ 0. )  
TREATMENT - NFED'S PATIENT CARE COUNCIL, COMPRISED OF MEDICAL AND  
DENTAL EXPERTS, OVERSEES THE NFED'S INITIATIVES TO IMPROVE TREATMENT OF  
ECTODERMAL DYSPLASIAS. THE NFED TEACHES CARE PROVIDERS HOW TO DIAGNOSE  
AND TREAT THE RARE DISORDERS THROUGH PROFESSIONAL SYMPOSIA AND GRAND  
ROUNDS AT UNIVERSITIES. THE NFED ADVOCATES FOR IMPROVING ACCESS TO  
CARE WITH SPONSORING LEGISLATION TO COVER CONGENITAL ANOMALIES, AND  
COLLABORATING WITH UNIVERSITIES, GOVERNMENT, PATIENT HEALTH  
ORGANIZATIONS. AFFECTED INDIVIDUALS CAN RECEIVE MORE AFFORDABLE CARE  
FROM EXPERIENCED TEAMS OF DENTISTS IN TREATMENT OF ECTODERMAL  
DYSPLASIAS AT NFED DENTAL TREATMENT CENTERS IN THE U.S. THE NFED ALSO  
HELPS FAMILIES PAY FOR NEEDED CARE THROUGH THE TREATMENT ASSISTANCE  
PROGRAM AND INSURANCE COACHING.

4c (Code: ) (Expenses \$ 398,931. including grants of \$ 0. ) (Revenue \$ 0. )  
RESEARCH - NFED'S SCIENTIFIC ADVISORY COUNCIL OVERSEES THE NFED'S  
RESEARCH INITIATIVES, AIMED TO IMPROVE THE HEALTH AND QUALITY OF LIFE  
OF AFFECTED INDIVIDUALS BY FINDING MANAGEMENT SOLUTIONS AND,  
EVENTUALLY, FINDING CURES FOR ECTODERMAL DYSPLASIAS. THE NFED ADVANCES  
RESEARCH THROUGH ADVOCACY AND PARTNERSHIPS WITH ORGANIZATIONS SUCH AS  
THE NATIONAL INSTITUTE OF HEALTH. THE NFED PROVIDES SEEDS FUNDS TO  
RESEARCHERS, PROVIDES THEM WITH ACCESS TO AFFECTED INDIVIDUALS, AND  
SHARES INFORMATION TO LAUNCH LARGER PROJECTS. NFED IS DEVELOPING A  
WEB-BASED ECTODERMAL DYSPLASIAS INTERNATIONAL REGISTRY TO SERVE AS A  
REPOSITORY OF GENETIC AND CLINICAL INFORMATION AND FACILITATES  
COMMUNICATION AMONG SCIENTISTS WHO STRIVE TO ADVANCE RESEARCH ON  
ECTODERMAL DYSPLASIAS. THE NFED ALSO SPONSORS SCIENTIFIC MEETINGS TO

4d Other program services (Describe on Schedule O.)  
(Expenses \$ including grants of \$ ) (Revenue \$ )

4e Total program service expenses 1,318,593.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS

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Part IV Checklist of Required Schedules

Table with 3 columns: Question ID, Yes, No. Contains 21 rows of questions regarding organizational activities, with 'X' marks in the Yes/No columns.

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Part IV Checklist of Required Schedules (continued)

Table with 3 columns: Question number, Yes, No. Rows 22-38 covering various organizational requirements and schedules.

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

Table with 3 columns: Question number, Yes, No. Rows 1a, 1b, 1c regarding IRS filings and gaming.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS

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Part V Statements Regarding Other IRS Filings and Tax Compliance (continued)

Table with columns for question number, question text, and Yes/No response boxes. Includes questions 2a through 17 regarding employee reporting, tax shelter transactions, foreign accounts, and charitable contributions.

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**Part VI Governance, Management, and Disclosure.** For each "Yes" response to lines 2 through 7b below, and for a "No" response to line 8a, 8b, or 10b below, describe the circumstances, processes, or changes on 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 11 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 on Schedule O.		
b Enter the number of voting members included on line 1a, above, who are independent ..... 1b 11		
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? ..... 2		X
3 Did the organization delegate control over management duties customarily performed by or under the direct supervision of officers, directors, trustees, or key employees to a management company or other person? ..... 3		X
4 Did the organization make any significant changes to its governing documents since the prior Form 990 was filed? ..... 4		X
5 Did the organization become aware during the year of a significant diversion of the organization's assets? ..... 5		X
6 Did the organization have members or stockholders? ..... 6		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? ..... 7a		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? ..... 7b		X
8 Did the organization contemporaneously document the meetings held or written actions undertaken during the year by the following:		
a The governing body? ..... 8a	X	
b Each committee with authority to act on behalf of the governing body? ..... 8b	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 on Schedule O ..... 9		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? ..... 10a		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? ..... 10b		
11a Has the organization provided a complete copy of this Form 990 to all members of its governing body before filing the form? ..... 11a	X	
b Describe on 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 ..... 12a	X	
b Were officers, directors, or trustees, and key employees required to disclose annually interests that could give rise to conflicts? ..... 12b	X	
c Did the organization regularly and consistently monitor and enforce compliance with the policy? If "Yes," describe on Schedule O how this was done ..... 12c	X	
13 Did the organization have a written whistleblower policy? ..... 13	X	
14 Did the organization have a written document retention and destruction policy? ..... 14	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 ..... 15a	X	
b Other officers or key employees of the organization ..... 15b	X	
If "Yes" to line 15a or 15b, describe the process on 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? ..... 16a		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? ..... 16b		

**Section C. Disclosure**

- 17 List the states with which a copy of this Form 990 is required to be filed IL
- 18 Section 6104 requires an organization to make its Forms 1023 (1024 or 1024-A, 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 on Schedule O)
- 19 Describe on 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, address, and telephone number of the person who possesses the organization's books and records  
**MARY FETE - 618-566-2020**  
**6 EXECUTIVE DRIVE, STE 2, FAIRVIEW HEIGHTS, IL 62208**

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DYSPLASIAS

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**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 the 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, box 6 of Form 1099-MISC, and/or box 1 of Form 1099-NEC) 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.

See the instructions for the order in which to list the persons above.

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/1099-NEC)	(E) Reportable compensation from related organizations (W-2/1099-MISC/1099-NEC)	(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) MARY FETE EXECUTIVE DIRECTOR	40.00					X		118,000.	0.	0.
(2) KARL NELSEN PRESIDENT	5.00	X		X				0.	0.	0.
(3) CHARLES RICHTER DIRECTOR	1.00	X						0.	0.	0.
(4) KEITH THROM DIRECTOR	1.00	X						0.	0.	0.
(5) JEANNE WANG DIRECTOR	1.00	X						0.	0.	0.
(6) RICHARD STRATZ TREASURER	1.00	X		X				0.	0.	0.
(7) J. TIMOTHY WRIGHT, DDS, MS DIRECTOR	1.00	X						0.	0.	0.
(8) ANIL VORA VICE PRESIDENT	10.00	X		X				0.	0.	0.
(9) RUTH GEISMAR AD HOC ADVISOR	1.00	X						0.	0.	0.
(10) JACK KRIZ SECRETARY	1.00	X		X				0.	0.	0.
(11) SOREN ROE DIRECTOR	1.00	X						0.	0.	0.
(12) BILL WILKINSON DIRECTOR	1.00	X						0.	0.	0.



NATIONAL FOUNDATION FOR ECTODERMAL  
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**Part VIII** Statement of Revenue

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

				(A)	(B)	(C)	(D)	
				Total revenue	Related or exempt function revenue	Unrelated business revenue	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	268,144.				
	d	Related organizations	1d					
	e	Government grants (contributions)	1e					
	f	All other contributions, gifts, grants, and similar amounts not included above	1f	852,441.				
	g	Noncash contributions included in lines 1a-1f	1g	\$ 110,642.				
	h	Total. Add lines 1a-1f			1,120,585.			
Program Service Revenue				Business Code				
	2 a	NATIONAL AND REGIONAL FAMILY CONF		624100	45,440.	45,440.		
	b							
	c							
	d							
	e							
	f	All other program service revenue						
g	Total. Add lines 2a-2f			45,440.				
Other Revenue	3	Investment income (including dividends, interest, and other similar amounts)			87,290.		87,290.	
	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)			373,086.		373,086.		
8 a	Gross income from fundraising events (not including \$ 268,144. of contributions reported on line 1c). See Part IV, line 18							
b	Less: direct expenses							
c	Net income or (loss) from fundraising events			16,521.		16,521.		
9 a	Gross income from gaming activities. See Part IV, line 19							
b	Less: direct expenses							
c	Net income or (loss) from gaming activities							
10 a	Gross sales of inventory, less returns and allowances							
b	Less: cost of goods sold							
c	Net income or (loss) from sales of inventory							
Miscellaneous Revenue				Business Code				
	11 a	MISC. INCOME		624100	4,202.	4,202.		
	b							
	c							
	d	All other revenue						
e	Total. Add lines 11a-11d				4,202.			
12	Total revenue. See instructions				1,647,124.	49,642.	0.	
							476,897.	

**NATIONAL FOUNDATION FOR ECTODERMAL  
DYSPLASIAS**

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**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 domestic organizations and domestic governments. See Part IV, line 21				
2 Grants and other assistance to domestic individuals. See Part IV, line 22	45,915.	45,915.		
3 Grants and other assistance to foreign organizations, foreign governments, and foreign individuals. See Part IV, lines 15 and 16				
4 Benefits paid to or for members				
5 Compensation of current officers, directors, trustees, and key employees				
6 Compensation not included above to disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B)				
7 Other salaries and wages	796,191.	643,127.	13,198.	139,866.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	18,673.	15,083.	310.	3,280.
9 Other employee benefits	14,893.	12,030.	247.	2,616.
10 Payroll taxes	64,676.	52,242.	1,072.	11,362.
11 Fees for services (nonemployees):				
a Management				
b Legal	12,953.	10,621.	130.	2,202.
c Accounting	54,706.	44,859.	547.	9,300.
d Lobbying				
e Professional fundraising services. See Part IV, line 17				
f Investment management fees	13,600.	11,152.	136.	2,312.
g Other. (If line 11g amount exceeds 10% of line 25, column (A), amount, list line 11g expenses on Sch O.)	87,567.	71,804.	876.	14,887.
12 Advertising and promotion	31,401.	26,691.	628.	4,082.
13 Office expenses	37,872.	31,057.	379.	6,436.
14 Information technology				
15 Royalties				
16 Occupancy	9,066.	7,434.	91.	1,541.
17 Travel				
18 Payments of travel or entertainment expenses for any federal, state, or local public officials				
19 Conferences, conventions, and meetings				
20 Interest				
21 Payments to affiliates				
22 Depreciation, depletion, and amortization				
23 Insurance	10,984.	9,007.	110.	1,867.
24 Other expenses. Itemize expenses not covered above. (List miscellaneous expenses on line 24e. If line 24e amount exceeds 10% of line 25, column (A), amount, list line 24e expenses on Schedule O.)				
a <b>FAMILY CONFERENCES</b>	156,560.	156,560.		
b <b>RESEARCH FUNDING</b>	90,639.	90,639.		
c <b>ADVOCACY</b>	53,368.	53,368.		
d <b>DEVELOPMENT</b>	32,856.	13,139.	3,288.	16,429.
e All other expenses	27,611.	23,865.	366.	3,380.
25 <b>Total functional expenses.</b> Add lines 1 through 24e	1,559,531.	1,318,593.	21,378.	219,560.
26 <b>Joint costs.</b> 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)				

NATIONAL FOUNDATION FOR ECTODERMAL  
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Form 990 (2025)

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	363,991.	1	290,386.
	2	Savings and temporary cash investments	628,166.	2	950,037.
	3	Pledges and grants receivable, net		3	
	4	Accounts receivable, net		4	
	5	Loans and other receivables from any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		5	
	6	Loans and other receivables from other disqualified persons (as defined under section 4958(f)(1)), and persons described in section 4958(c)(3)(B)		6	
	7	Notes and loans receivable, net		7	
	8	Inventories for sale or use		8	
	9	Prepaid expenses and deferred charges	19,447.	9	18,059.
	10a	Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	41,323.		
	10b	Less: accumulated depreciation	41,323.		
			0.	10c	0.
	11	Investments - publicly traded securities	3,740,384.	11	3,698,005.
	12	Investments - other securities. See Part IV, line 11		12	
	13	Investments - program-related. See Part IV, line 11		13	
	14	Intangible assets	39,011.	14	23,306.
15	Other assets. See Part IV, line 11		15		
16	<b>Total assets.</b> Add lines 1 through 15 (must equal line 33)	4,790,999.	16	4,979,793.	
Liabilities	17	Accounts payable and accrued expenses	37,182.	17	48,025.
	18	Grants payable	22,129.	18	55,395.
	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 any current or former officer, director, trustee, key employee, creator or founder, substantial contributor, or 35% controlled entity or family member of any of these persons		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	39,011.	25	23,307.
	26	<b>Total liabilities.</b> Add lines 17 through 25	98,322.	26	126,727.
Net Assets or Fund Balances	Organizations that follow FASB ASC 958, check here <input checked="" type="checkbox"/> and complete lines 27, 28, 32, and 33.				
	27	Net assets without donor restrictions	4,674,445.	27	4,853,066.
	28	Net assets with donor restrictions	18,232.	28	0.
	Organizations that do not follow FASB ASC 958, check here <input type="checkbox"/> and complete lines 29 through 33.				
	29	Capital stock or trust principal, or current funds		29	
	30	Paid-in or capital surplus, or land, building, or equipment fund		30	
	31	Retained earnings, endowment, accumulated income, or other funds		31	
32	<b>Total net assets or fund balances</b>	4,692,677.	32	4,853,066.	
33	<b>Total liabilities and net assets/fund balances</b>	4,790,999.	33	4,979,793.	

Form 990 (2025)

NATIONAL FOUNDATION FOR ECTODERMAL  
DYSPLASIAS

Form 990 (2025)

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**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	1,647,124.
2	Total expenses (must equal Part IX, column (A), line 25)	2	1,559,531.
3	Revenue less expenses. Subtract line 2 from line 1	3	87,593.
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	4,692,677.
5	Net unrealized gains (losses) on investments	5	82,958.
6	Donated services and use of facilities	6	-10,162.
7	Investment expenses	7	
8	Prior period adjustments	8	
9	Other changes in net assets or fund balances (explain on Schedule O)	9	0.
10	Net assets or fund balances at end of year. Combine lines 3 through 9 (must equal Part X, line 32, column (B))	10	4,853,066.

**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 on Schedule O.			
2a	Were the organization's financial statements compiled or reviewed by an independent accountant?		X
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			
b	Were the organization's financial statements audited by an independent accountant?	X	
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 checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis			
c	If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant?	X	
If the organization changed either its oversight process or selection process during the tax year, explain on 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 Uniform Guidance, 2 C.F.R. Part 200, Subpart F?		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 on Schedule O and describe any steps taken to undergo such audits		

Form 990 (2025)

SCHEDULE A (Form 990)

Department of the Treasury Internal Revenue Service

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.
Go to www.irs.gov/Form990 for instructions and the latest information.

OMB No. 1545-0047

2025 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: (For lines 1 through 12, 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 (Form 990).)
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 agricultural research organization described in section 170(b)(1)(A)(ix) operated in conjunction with a land-grant college or university or a non-land-grant college of agriculture (see instructions). Enter the name, city, and state of the college or university:
10 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.)
11 An organization organized and operated exclusively to test for public safety. See section 509(a)(4).
12 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 on lines 12a through 12d that describes the type of supporting organization and complete lines 12e, 12f, and 12g.
a Type I. A supporting organization operated, supervised, or controlled by its supported organization(s), typically by giving the supported organization(s) the power to regularly appoint or elect a majority of the directors or trustees of the supporting organization. You must complete Part IV, Sections A and B.
b Type II. A supporting organization supervised or controlled in connection with its supported organization(s), by having control or management of the supporting organization vested in the same persons that control or manage the supported organization(s). You must complete Part IV, Sections A and C.
c Type III functionally integrated. A supporting organization operated in connection with, and functionally integrated with, its supported organization(s) (see instructions). You must complete Part IV, Sections A, D, and E.
d Type III non-functionally integrated. A supporting organization operated in connection with its supported organization(s) that is not functionally integrated. The organization generally must satisfy a distribution requirement and an attentiveness requirement (see instructions). You must complete Part IV, Sections A and D, and Part V.
e Check this box if the organization received a written determination from the IRS that it is a Type I, Type II, Type III functionally integrated, or Type III non-functionally integrated supporting organization.
f Enter the number of supported organizations
g Provide the following information about the supported organization(s).

Table with 6 columns: (i) Name of supported organization, (ii) EIN, (iii) Type of organization, (iv) Is the organization listed in your governing document?, (v) Amount of monetary support, (vi) Amount of other support. Includes a Total row at the bottom.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS

Schedule A (Form 990) 2025

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

Table with 7 columns: (a) 2021, (b) 2022, (c) 2023, (d) 2024, (e) 2025, (f) Total. Rows include: 1 Gifts, grants, contributions, and membership fees received; 2 Tax revenues levied for the organization's benefit; 3 The value of services or facilities furnished by a governmental unit; 4 Total. Add lines 1 through 3; 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.

Section B. Total Support

Table with 7 columns: (a) 2021, (b) 2022, (c) 2023, (d) 2024, (e) 2025, (f) Total. Rows include: 7 Amounts from line 4; 8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources; 9 Net income from unrelated business activities, whether or not the business is regularly carried on; 10 Other income. Do not include gain or loss from the sale of capital assets (Explain in Part VI); 11 Total support. Add lines 7 through 10; 12 Gross receipts from related activities, etc. (see instructions); 13 First 5 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

Table with 3 columns: Line number, Percentage, and Unit (%). Rows include: 14 Public support percentage for 2025 (line 6, column (f), divided by line 11, column (f)) - 93.27%; 15 Public support percentage from 2024 Schedule A, Part II, line 14 - 90.38%; 16a 33 1/3% support test - 2025. 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 [X]; b 33 1/3% support test - 2024. 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 - 2025. 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 VI how the organization meets the facts-and-circumstances test. The organization qualifies as a publicly supported organization [ ]; b 10% -facts-and-circumstances test - 2024. 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 VI 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 [ ].

NATIONAL FOUNDATION FOR ECTODERMAL

DYSPLASIAS

Schedule A (Form 990) 2025

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

(Complete only if you checked the box on line 10 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

Table with 7 columns: (a) 2021, (b) 2022, (c) 2023, (d) 2024, (e) 2025, (f) Total. Rows include: 1 Gifts, grants, contributions, and membership fees received; 2 Gross receipts from admissions, merchandise sold or services performed; 3 Gross receipts from activities that are not an unrelated trade or business; 4 Tax revenues levied for the organization's benefit; 5 The value of services or facilities furnished by a governmental unit; 6 Total. Add lines 1 through 5; 7a Amounts included on lines 1, 2, and 3 received from disqualified persons; 7b Amounts included on lines 2 and 3 received from other than disqualified persons; 8 Public support. (Subtract line 7c from line 6.)

Section B. Total Support

Table with 7 columns: (a) 2021, (b) 2022, (c) 2023, (d) 2024, (e) 2025, (f) Total. Rows include: 9 Amounts from line 6; 10a Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources; 10b Unrelated business taxable income (less section 511 taxes) from businesses acquired after June 30, 1975; 11 Net income from unrelated business activities not included on line 10b; 12 Other income. Do not include gain or loss from the sale of capital assets; 13 Total support. (Add lines 9, 10c, 11, and 12.)

14 First 5 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

Table with 2 columns: Line number, Percentage. Row 15: Public support percentage for 2025 (line 8, column (f), divided by line 13, column (f)) 15 %; Row 16: Public support percentage from 2024 Schedule A, Part III, line 15 16 %

Section D. Computation of Investment Income Percentage

Table with 2 columns: Line number, Percentage. Row 17: Investment income percentage for 2025 (line 10c, column (f), divided by line 13, column (f)) 17 %; Row 18: Investment income percentage from 2024 Schedule A, Part III, line 17 18 %

19a 33 1/3% support tests - 2025. 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 - 2024. 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

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS

Schedule A (Form 990) 2025

Part IV Supporting Organizations

(Complete only if you checked a box on line 12 of Part I. If you checked box 12a, Part I, complete Sections A and B. If you checked box 12b, Part I, complete Sections A and C. If you checked box 12c, Part I, complete Sections A, D, and E. If you checked box 12d, Part I, complete Sections A and D, and complete Part V.)

Section A. All Supporting Organizations

Table with 3 columns: Question, Yes, No. Rows include questions 1 through 10b regarding supported organizations, including their status, control, and support.

NATIONAL FOUNDATION FOR ECTODERMAL

Schedule A (Form 990) 2025

DYSPLASIAS

Part IV Supporting Organizations (continued)

Table with 3 columns: Question, Yes, No. Row 11: Has the organization accepted a gift or contribution from any of the following persons? Sub-rows 11a, 11b, 11c.

Section B. Type I Supporting Organizations

Table with 3 columns: Question, Yes, No. Row 1: Did the governing body, members of the governing body, officers acting in their official capacity, or membership of one or more supported organizations have the power to regularly appoint or elect at least a majority of the organization's officers, directors, or trustees at all times during the tax year? Row 2: Did the organization operate for the benefit of any supported organization other than the supported organization(s) that operated, supervised, or controlled the supporting organization?

Section C. Type II Supporting Organizations

Table with 3 columns: Question, Yes, No. Row 1: Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)?

Section D. All Type III Supporting Organizations

Table with 3 columns: Question, Yes, No. Row 1: Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (i) a written notice describing the type and amount of support provided during the prior tax year, (ii) a copy of the Form 990 that was most recently filed as of the date of notification, and (iii) copies of the organization's governing documents in effect on the date of notification, to the extent not previously provided? Row 2: Were any of the organization's officers, directors, or trustees either (i) appointed or elected by the supported organization(s) or (ii) serving on the governing body of a supported organization? Row 3: By reason of the relationship described on line 2, above, did the organization's supported organizations have a significant voice in the organization's investment policies and in directing the use of the organization's income or assets at all times during the tax year?

Section E. Type III Functionally Integrated Supporting Organizations

Table with 3 columns: Question, Yes, No. Row 1: Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions). Sub-rows a, b, c. Row 2: Activities Test. Answer lines 2a and 2b below. Sub-rows a, b. Row 3: Parent of Supported Organizations. Answer lines 3a, 3b, and 3c below. Sub-rows a, b, c.

NATIONAL FOUNDATION FOR ECTODERMAL  
DYSPLASIAS

Schedule A (Form 990) 2025

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**Part V Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations**

1  Check here if the organization satisfied the Integral Part Test as a qualifying trust on Nov. 20, 1970 ( *explain in Part VI*). See instructions.  
All other Type III non-functionally integrated supporting organizations must complete Sections A through E.

Section A - Adjusted Net Income		(A) Prior Year	(B) Current Year (optional)
1	Net short-term capital gain	1	
2	Recoveries of prior-year distributions	2	
3	Other gross income (see instructions)	3	
4	Add lines 1 through 3.	4	
5	Depreciation and depletion	5	
6	Portion of operating expenses paid or incurred for production or collection of gross income or for management, conservation, or maintenance of property held for production of income (see instructions)	6	
7	Other expenses (see instructions)	7	
8	<b>Adjusted Net Income</b> (subtract lines 5, 6, and 7 from line 4)	8	
Section B - Minimum Asset Amount		(A) Prior Year	(B) Current Year (optional)
1	Aggregate fair market value of all non-exempt-use assets (see instructions for short tax year or assets held for part of year):		
a	Average monthly value of securities	1a	
b	Average monthly cash balances	1b	
c	Fair market value of other non-exempt-use assets	1c	
d	<b>Total</b> (add lines 1a, 1b, and 1c)	1d	
e	<b>Discount</b> claimed for blockage or other factors ( <i>explain in detail in Part VI</i> ):		
2	Acquisition indebtedness applicable to non-exempt-use assets	2	
3	Subtract line 2 from line 1d.	3	
4	Cash deemed held for exempt use. Enter 0.015 of line 3 (for greater amount, see instructions).	4	
5	Net value of non-exempt-use assets (subtract line 4 from line 3)	5	
6	Multiply line 5 by 0.035.	6	
7	Recoveries of prior-year distributions	7	
8	<b>Minimum Asset Amount</b> (add line 7 to line 6)	8	
Section C - Distributable Amount			Current Year
1	Adjusted net income for prior year (from Section A, line 8, column A)	1	
2	Enter 0.85 of line 1.	2	
3	Minimum asset amount for prior year (from Section B, line 8, column A)	3	
4	Enter greater of line 2 or line 3.	4	
5	Income tax imposed in prior year	5	
6	<b>Distributable Amount.</b> Subtract line 5 from line 4, unless subject to emergency temporary reduction (see instructions).	6	
7	<input type="checkbox"/> Check here if the current year is the organization's first as a non-functionally integrated Type III supporting organization (see instructions).		

Schedule A (Form 990) 2025

NATIONAL FOUNDATION FOR ECTODERMAL

Schedule A (Form 990) 2025

DYSPLASIAS

**Part V** Type III Non-Functionally Integrated 509(a)(3) Supporting Organizations (continued)

Section D - Distributions		Current Year
1	Amounts paid to supported organizations to accomplish exempt purposes	1
2	Amounts paid to perform activity that directly furthers exempt purposes of supported organizations, in excess of income from activity	2
3	Administrative expenses paid to accomplish exempt purposes of supported organizations	3
4	Amounts paid to acquire exempt-use assets	4
5	Qualified set-aside amounts (prior IRS approval required - provide details in Part VI)	5
6	<b>Total annual distributions.</b> Add lines 1 through 5.	6
7	Distributions to attentive supported organizations to which the organization is responsive (provide details in Part VI). See instructions.	7
8	Distributable amount for 2025 from Section C, line 6	8
9	Line 7 amount divided by line 8 amount	9

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2025	(iii) Distributable Amount for 2025
1	Distributable amount for 2025 from Section C, line 6		
2	Underdistributions, if any, for years prior to 2025 (reasonable cause required - explain in Part VI). See instructions.		
3	Excess distributions carryover, if any, to 2025		
a	From 2020		
b	From 2021		
c	From 2022		
d	From 2023		
e	From 2024		
f	<b>Total</b> of lines 3a through 3e		
g	Applied to under distributions of prior years		
h	Applied to 2025 distributable amount		
i	Carryover from 2020 not applied (see instructions)		
j	Remainder. Subtract lines 3g, 3h, and 3i from line 3f.		
4	Distributions for 2025 from Section D, line 6: \$		
a	Applied to underdistributions of prior years		
b	Applied to 2025 distributable amount		
c	Remainder. Subtract lines 4a and 4b from line 4.		
5	Remaining underdistributions for years prior to 2025, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, explain in Part VI. See instructions.		
6	Remaining underdistributions for 2025. Subtract lines 3h and 4b from line 1. For result greater than zero, explain in Part VI. See instructions.		
7	Excess distributions carryover to 2026. Add lines 3j and 4c.		
8	Breakdown of line 7:		
a	Excess from 2021		
b	Excess from 2022		
c	Excess from 2023		
d	Excess from 2024		
e	Excess from 2025		

Schedule A (Form 990) 2025

NATIONAL FOUNDATION FOR ECTODERMAL  
DYSPLASIAS

Schedule A (Form 990) 2025

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**Part VI** **Supplemental Information.** Provide the explanations required by Part II, line 10; Part II, line 17a or 17b; Part III, line 12; Part IV, Section A, lines 1, 2, 3b, 3c, 4b, 4c, 5a, 6, 9a, 9b, 9c, 11a, 11b, and 11c; Part IV, Section B, lines 1 and 2; Part IV, Section C, line 1; Part IV, Section D, lines 2 and 3; Part IV, Section E, lines 1c, 2a, 2b, 3a, 3b, and 3c; Part V, line 1; Part V, Section B, line 1e; Part V, Section D, lines 5 and 7; and Part V, Section E, lines 2, 5, and 6. Also complete this part for any additional information. (See instructions.)

SCHEDULE A, PART II, LINE 10, EXPLANATION FOR OTHER INCOME:

MISCELLANEOUS

2021 AMOUNT: \$ 803.

2022 AMOUNT: \$ 3,786.

2023 AMOUNT: \$ 2,879.

2024 AMOUNT: \$ 718.

2025 AMOUNT: \$ 4,202.

**Schedule B  
(Form 990)**  
(Rev. December 2024)  
Department of the Treasury  
Internal Revenue Service

### Schedule of Contributors

OMB No. 1545-0047

Attach to Form 990, 990-EZ, or 990-PF.  
Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for the latest information.

Name of the organization <b>NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS</b>	Employer identification number <b>37-1112496</b>
--	---

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, contributions totaling \$5,000 or more (in money or property) from any one contributor. Complete Parts I and II. See instructions for determining a contributor's total contributions.

#### Special Rules

For an organization described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33 1/3% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990), Part II, line 13, 16a, or 16b, and that received from any one contributor, during the year, total contributions of the greater of (1) \$5,000; or (2) 2% of the amount on (i) Form 990, Part VIII, line 1h; or (ii) Form 990-EZ, line 1. Complete Parts I and II.

For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than \$1,000 *exclusively* for religious, charitable, scientific, literary, or educational purposes, or for the prevention of cruelty to children or animals. Complete Parts I (entering "N/A" in column (b) instead of the contributor name and address), II, and III.

For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions *exclusively* for religious, charitable, etc., purposes, but no such contributions totaled more than \$1,000. If this box is checked, enter here the total contributions that were received during the year for an *exclusively* religious, charitable, etc., purpose. Don't complete any of the parts unless the **General Rule** applies to this organization because it received *nonexclusively* religious, charitable, etc., contributions totaling \$5,000 or more during the year ..... \$ \_\_\_\_\_

**Caution:** An organization that isn't covered by the General Rule and/or the Special Rules doesn't file Schedule B (Form 990), 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 doesn't meet the filing requirements of Schedule B (Form 990).

Name of organization <b>NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS</b>	Employer identification number <b>37-1112496</b>
--	---

**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		\$ <u>51,000.</u>	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
2		\$ <u>107,561.</u>	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input checked="" type="checkbox"/> (Complete Part II for noncash contributions.)
3		\$ <u>50,000.</u>	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
4		\$ <u>25,000.</u>	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
5		\$ <u>75,000.</u>	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
6		\$ <u>25,000.</u>	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)

Name of organization <b>NATIONAL FOUNDATION FOR ECTODERMAL                  DYSPLASIAS</b>	Employer identification number <b>37-1112496</b>
---	---

**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		\$ 25,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
8		\$ 25,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
9		\$ 27,552.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
10		\$ 54,000.	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.)



Name of organization <b>NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS</b>	Employer identification number <b>37-1112496</b>
--	---

**Part III** Exclusively religious, charitable, etc., contributions to organizations described in section 501(c)(7), (8), or (10) that total more than \$1,000 for the year from any one contributor. 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 info. 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)**  
**(Rev. December 2024)**  
Department of the Treasury  
Internal Revenue Service

**Supplemental Financial Statements**

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

OMB No. 1545-0047

Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

**Open to Public Inspection**

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

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

	(a) Donor advised funds	(b) Funds and other accounts
1 Total number at end of year .....		
2 Aggregate value of contributions to (during year) .....		
3 Aggregate value of grants from (during year) .....		
4 Aggregate value at end of year .....		
5 Did the organization inform all donors and donor advisors in 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" on Form 990, Part IV, line 7.

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

<input type="checkbox"/> Preservation of land for public use (for example, recreation or education)	<input type="checkbox"/> Preservation of a 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	
- 2 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 on line 2a .....	2c
d Number of conservation easements included on line 2c acquired after July 25, 2006, and not on a historic structure listed in the National Register .....	2d
- 3 Number of conservation easements modified, transferred, released, extinguished, or terminated by the organization during the tax year \_\_\_\_\_
- 4 Number of states where property subject to conservation easement is located \_\_\_\_\_
- 5 Does the organization have a written policy regarding the periodic monitoring, inspection, handling of violations, and enforcement of the conservation easements it holds? .....
- 6 Staff and volunteer hours devoted to monitoring, inspecting, handling of violations, and enforcing conservation easements during the year \_\_\_\_\_
- 7 Amount of expenses incurred in monitoring, inspecting, handling of violations, and enforcing conservation easements during the year \_\_\_\_\_
- 8 Does each conservation easement reported on line 2d above satisfy the requirements of section 170(h)(4)(B)(i) and section 170(h)(4)(B)(ii)? .....
- 9 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" on Form 990, Part IV, line 8.

- 1a If the organization elected, as permitted under FASB 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.
- b If the organization elected, as permitted under FASB 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) Revenue included on Form 990, Part VIII, line 1 .....	\$ _____
(ii) Assets included in Form 990, Part X .....	\$ _____
- 2 If the organization received or held works of art, historical treasures, or other similar assets for financial gain, provide the following amounts required to be reported under FASB ASC 958 relating to these items:
 

a Revenue included on Form 990, Part VIII, line 1 .....	\$ _____
b Assets included in Form 990, Part X .....	\$ _____

NATIONAL FOUNDATION FOR ECTODERMAL

Schedule D (Form 990) (Rev. 12-2024) DYSPLASIAS

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 make 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 program
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?

Part IV Escrow and Custodial Arrangements Complete if the organization answered "Yes" on 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?
b If "Yes," explain the arrangement in Part XIII and complete the following table:
c Beginning balance
d Additions during the year
e Distributions during the year
f Ending balance
2a Did the organization include an amount on Form 990, Part X, line 21, for escrow or custodial account liability?
b If "Yes," explain the arrangement in Part XIII. Check here if the explanation has been provided in Part XIII

Table with 2 columns: Description, Amount. Rows: 1c Beginning balance, 1d Additions during the year, 1e Distributions during the year, 1f Ending balance.

Part V Endowment Funds Complete if the organization answered "Yes" on Form 990, Part IV, line 10.

Table with 6 columns: Description, (a) Current year, (b) Prior year, (c) Two years back, (d) Three years back, (e) Four years back. Rows: 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 Term endowment %

The percentages on 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:

- (i) Unrelated organizations?
(ii) Related organizations?

Table with 3 columns: Question, Yes, No. Rows: 3a(i) Unrelated organizations?, 3a(ii) Related organizations?, 3b If "Yes" on line 3a(ii), are the related organizations listed as required on Schedule R?

b If "Yes" on line 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" on Form 990, Part IV, line 11a. See Form 990, Part X, line 10.

Table with 5 columns: Description of property, (a) Cost or other basis (investment), (b) Cost or other basis (other), (c) Accumulated depreciation, (d) Book value. Rows: 1a Land, b Buildings, c Leasehold improvements, d Equipment, e Other, Total. Add lines 1a through 1e. (Column (d) must equal Form 990, Part X, line 10c, column (B)).

NATIONAL FOUNDATION FOR ECTODERMAL

Schedule D (Form 990) (Rev. 12-2024) **DYSPLASIAS**

**Part VII Investments - Other Securities**

Complete if the organization answered "Yes" on 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, line 12, col. (B))

**Part VIII Investments - Program Related.**

Complete if the organization answered "Yes" on 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, line 13, col. (B))

**Part IX Other Assets**

Complete if the organization answered "Yes" on 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, line 15, col. (B))

**Part X Other Liabilities**

Complete if the organization answered "Yes" on 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) <b>LEASE LIABILITY</b>	<b>23,307.</b>
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	

Total. (Column (b) must equal Form 990, Part X, line 25, col. (B)) **23,307.**

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 FASB ASC 740. Check here if the text of the footnote has been provided in Part XIII

NATIONAL FOUNDATION FOR ECTODERMAL

Schedule D (Form 990) (Rev. 12-2024) **DYSPLASIAS**

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

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

1	Total revenue, gains, and other support per audited financial statements		1	1,738,756.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains (losses) on investments	2a	82,958.	
b	Donated services and use of facilities	2b		
c	Recoveries of prior year grants	2c		
d	Other (Describe in Part XIII.)	2d	8,674.	
e	Add lines 2a through 2d	2e		91,632.
3	Subtract line 2e from line 1	3		1,647,124.
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		1,647,124.

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

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

1	Total expenses and losses per audited financial statements		1	1,578,367.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
a	Donated services and use of facilities	2a	10,162.	
b	Prior year adjustments	2b		
c	Other losses	2c		
d	Other (Describe in Part XIII.)	2d	8,674.	
e	Add lines 2a through 2d	2e		18,836.
3	Subtract line 2e from line 1	3		1,559,531.
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		1,559,531.

**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 X, LINE 2:**

**NFED IS TAX-EXEMPT UNDER SECTION 501(C)(3) OF THE INTERNAL REVENUE CODE AND, THEREFORE, IS EXEMPT FROM BOTH FEDERAL AND STATE INCOME TAXES. ACCORDINGLY, NO PROVISION HAS BEEN MADE FOR INCOME TAXES IN THE ACCOMPANYING FINANCIAL STATEMENTS.**

**PART XI, LINE 2D - OTHER ADJUSTMENTS:**

**SPECIAL EVENT EXPENSE NETTED WITH REVENUE ON 990 8,674.**

**PART XII, LINE 2D - OTHER ADJUSTMENTS:**

**SPECIAL EVENT EXPENSE NETTED WITH REVENUE ON FORM 990 8,674.**





NATIONAL FOUNDATION FOR ECTODERMAL

Schedule G (Form 990) (Rev. 12-2024) DYSPLASIAS

37-1112496 Page 2

**Part II Fundraising Events.** Complete if the organization answered "Yes" on 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))
		HALLOWEEN BASH		5	
		(event type)	(event type)	(total number)	
Revenue	1	Gross receipts	101,434.	191,905.	293,339.
	2	Less: Contributions	82,334.	185,810.	268,144.
	3	Gross income (line 1 minus line 2)	19,100.	6,095.	25,195.
Direct Expenses	4	Cash prizes			
	5	Noncash prizes			
	6	Rent/facility costs			
	7	Food and beverages			
	8	Entertainment			
	9	Other direct expenses	8,299.	375.	8,674.
	10	Direct expense summary. Add lines 4 through 9 in column (d)			8,674.
	11	Net income summary. Subtract line 10 from line 3, column (d)			16,521.

**Part III Gaming.** Complete if the organization answered "Yes" on 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))
Revenue	1	Gross revenue			
	2	Cash prizes			
Direct Expenses	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 conducts gaming activities: \_\_\_\_\_

a Is the organization licensed to conduct 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: \_\_\_\_\_  
\_\_\_\_\_







**NATIONAL FOUNDATION FOR ECTODERMAL**

37-1112496 Page 2

Schedule I (Form 990) (Rev. 12-2024) **DYSPLASIAS**

**Part III** Grants and Other Assistance to Domestic Individuals. Complete if the organization answered "Yes" on 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 noncash assistance
FAMILY CONFERENCE SCHOLARSHIPS	16	15,018.	0.		
STIPENDS AND TRAVEL ASSISTANCE - ADVOCACY DAY	23	13,350.	0.		
TREATMENT FUNDING	15	17,547.	0.		

**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:**

**FOR CLIENT ASSISTANCE, FUNDS ARE SENT DIRECTLY TO CARE PROVIDERS.**

**SCHEDULE M  
(Form 990)**

**Noncash Contributions**

OMB No. 1545-0047

**2025**

Open to Public Inspection

Department of the Treasury  
Internal Revenue Service

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

Attach to Form 990.

Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

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

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	X	1	110,642.	STOCK MARKET VALUE
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				
21	Taxidermy				
22	Historical artifacts				
23	Scientific specimens				
24	Archeological artifacts				
25	Other ( )				
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 V, Donee Acknowledgment **29**

	Yes	No
30a During the year, did the organization receive by contribution any property reported in Part I, lines 1 through 28, that it must hold for at least 3 years from the date of the initial contribution, and which isn't 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 nonstandard 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 didn't report an amount in column (c) for a type of property for which column (a) is checked, describe in Part II.		

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

Schedule M (Form 990) 2025 Created 12/29/25



**SCHEDULE O  
(Form 990)**

(Rev. December 2024)  
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 Form 990-EZ.  
Go to [www.irs.gov/Form990](http://www.irs.gov/Form990) for instructions and the latest information.

OMB No. 1545-0047

Open to Public  
Inspection

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

**FORM 990, PART III, LINE 4A, PROGRAM SERVICE ACCOMPLISHMENTS:  
INFORMATION AND PRACTICAL ADVICE, GUIDANCE, AND RESOURCES.**

**FORM 990, PART III, LINE 4C, PROGRAM SERVICE ACCOMPLISHMENTS:  
INCREASE UNDERSTANDING OF THE DISORDERS.**

**FORM 990, PART VI, SECTION B, LINE 11B:  
THE ORGANIZATION PROVIDES A COPY OF FORM 990 TO EVERY BOARD MEMBER. IT IS  
REVIEWED IN DETAIL BY THE ORGANIZATION'S EXECUTIVE DIRECTOR AND BOARD  
PRESIDENT AND VICE-PRESIDENT OR TREASURER OR FINANCIAL ADVISOR.**

**FORM 990, PART VI, SECTION B, LINE 12C:  
THE AUDIT, BUDGET AND FINANCE COMMITTEE ANNUALLY REVIEWS THE DISCLOSURE  
PROCESS AND REPORTS TO THE BOARD OF DIRECTORS ON THE SUBMISSION OF ALL  
REQUIRED DISCLOSURE STATEMENTS.**

**FORM 990, PART VI, SECTION B, LINE 15:  
THE BOARD OF DIRECTORS REGULARLY ASSESSES THE PERFORMANCE AND EFFECTIVENESS  
OF THE EXECUTIVE DIRECTOR AND DETERMINES FUTURE ACTIONS TO INCLUDE AMOUNT  
OF COMPENSATION BASED ON THAT ASSESSMENT. THE BOARD OF DIRECTORS PROVIDE  
GUIDANCE TO THE EXECUTIVE DIRECTOR IN DETERMINING THE COMPENSATION OF THE  
ORGANIZATION'S STAFF. THE MEMBERS OF THE BOARD OF DIRECTORS ARE NOT  
COMPENSATED.**

**FORM 990, PART VI, SECTION C, LINE 19:  
THE ORGANIZATION MAKES ITS GOVERNING DOCUMENTS, CONFLICT OF INTEREST POLICY  
AND FINANCIAL STATEMENTS AVAILABLE TO THE PUBLIC. THE FINANCIAL STATEMENTS  
AND FORM 990 ARE POSTED ON THE ORGANIZATION'S WEBSITE AND COPIES OF OTHER  
GOVERNING DOCUMENTS SUCH AS FORM 1023 AND CONFLICT OF INTEREST POLICY ARE  
AVAILABLE UPON WRITTEN REQUEST.**

**FORM 990, PART XII, LINE 2C: AUDIT PROCESS -  
THERE WERE NO CHANGES IN THE OVERSIGHT PROCESS OR SELECTION PROCESS  
DURING THE YEAR.**

**FORM 990, PART VI, PAGE 6, QUESTION 20 - BOOKS IN CARE OF  
THE ORGANIZATION EXTERNALLY CONTRACTS FOR BOOKKEEPING SERVICES.**