

Return of Organization Exempt From Income Tax

OMB No. 1545-0047

Form 990

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except private foundations)
Do not enter social security numbers on this form as it may be made public.
Go to www.irs.gov/Form990 for instructions and the latest information.

2022

Open to Public Inspection

A For the **2022** calendar year, or tax year beginning and ending

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	C Name of organization NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS		D Employer identification number 37-1112496
	Doing business as		E Telephone number 618-566-2020
	Number and street (or P.O. box if mail is not delivered to street address)	Room/suite	
	6 EXECUTIVE DRIVE, SUITE 2		G Gross receipts \$ 1,514,984.
	City or town, state or province, country, and ZIP or foreign postal code FAIRVIEW HEIGHTS, IL 62208		
F Name and address of principal officer: KARL NELSEN SAME AS C ABOVE		H(a) Is this a group return for subordinates? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No H(b) Are all subordinates included? <input type="checkbox"/> Yes <input type="checkbox"/> No If "No," attach a list. See instructions H(c) Group exemption number	

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

J Website: **WWW.NFED.ORG**

K Form of organization: Corporation Trust Association Other **L** Year of formation: **1981** **M** State of legal domicile: **IL**

Part I Summary		Prior Year	Current Year
Activities & Governance	1 Briefly describe the organization's mission or most significant activities: EMPOWER AND CONNECT PEOPLE TOUCHED BY ECTODERMAL DYSPLASIAS VIA EDUCATION, SUPPORT, & RESEARCH.		
	2 Check this box <input type="checkbox"/> if the organization discontinued its operations or disposed of more than 25% of its net assets.		
	3 Number of voting members of the governing body (Part VI, line 1a)	3	11
	4 Number of independent voting members of the governing body (Part VI, line 1b)	4	11
	5 Total number of individuals employed in calendar year 2022 (Part V, line 2a)	5	8
	6 Total number of volunteers (estimate if necessary)	6	375
	7 a Total unrelated business revenue from Part VIII, column (C), line 12	7a	0.
b Net unrelated business taxable income from Form 990-T, Part I, line 11	7b	0.	
Revenue	8 Contributions and grants (Part VIII, line 1h)	1,500,948.	1,170,684.
	9 Program service revenue (Part VIII, line 2g)	4,580.	24,687.
	10 Investment income (Part VIII, column (A), lines 3, 4, and 7d)	429,476.	254,390.
	11 Other revenue (Part VIII, column (A), lines 5, 6d, 8c, 9c, 10c, and 11e)	33,538.	43,450.
	12 Total revenue - add lines 8 through 11 (must equal Part VIII, column (A), line 12)	1,968,542.	1,493,211.
Expenses	13 Grants and similar amounts paid (Part IX, column (A), lines 1-3)	14,318.	25,103.
	14 Benefits paid to or for members (Part IX, column (A), line 4)	0.	0.
	15 Salaries, other compensation, employee benefits (Part IX, column (A), lines 5-10)	532,591.	641,016.
	16a Professional fundraising fees (Part IX, column (A), line 11e)	0.	0.
	b Total fundraising expenses (Part IX, column (D), line 25)	167,009.	
	17 Other expenses (Part IX, column (A), lines 11a-11d, 11f-24e)	338,445.	417,751.
18 Total expenses. Add lines 13-17 (must equal Part IX, column (A), line 25)	885,354.	1,083,870.	
19 Revenue less expenses. Subtract line 18 from line 12	1,083,188.	409,341.	
Net Assets or Fund Balances	20 Total assets (Part X, line 16)	Beginning of Current Year 4,339,643.	End of Year 3,999,579.
	21 Total liabilities (Part X, line 26)	58,766.	190,948.
	22 Net assets or fund balances. Subtract line 21 from line 20	4,280,877.	3,808,631.

Part II Signature Block

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

Sign Here	Signature of officer	Date			
	KARL NELSEN, PRESIDENT	05/08/23			
Paid Preparer Use Only	Print/Type preparer's name	Preparer's signature	Date	Check if self-employed <input type="checkbox"/>	PTIN
	JEFF PARKER	JEFF PARKER	05/08/23		P00970069
Preparer Use Only	Firm's name	Firm's EIN	Phone no.		
	CLIFTONLARSONALLEN LLP	41-0746749	(618) 233-1200		
Firm's address					
475 REGENCY PARK, SUITE 175					
O'FALLON, IL 62269					

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

NATIONAL FOUNDATION FOR ECTODERMAL
DYSPLASIAS

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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 \$ 463,508. including grants of \$ 16,694.) (Revenue \$ 24,687.)
**SUPPORT - THE FAMILY SUPPORT TEAMS, COMPRISED OF FAMILY MEMBERS AND
AFFECTED INDIVIDUALS, OVERSEES NFED'S SUPPORT PROGRAMS THAT SEEK TO
EMPOWER AND CONNECT INDIVIDUALS AFFECTED BY ECTODERMAL DYSPLASIAS AND
THEIR FAMILIES. 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 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. NFED**

4b (Code:) (Expenses \$ 251,127. including grants of \$ 8,409.) (Revenue \$ 0.)
**TREATMENT - THE PATIENT CARE COUNCIL, COMPRISED OF MEDICAL AND DENTAL
EXPERTS, OVERSEES THE NFED'S INITIATIVES TO IMPROVE TREATMENT OF
ECTODERMAL DYSPLASIAS. NFED TEACHES CARE PROVIDERS HOW TO DIAGNOSE AND
TREAT THE RARE DISORDERS THROUGH PROFESSIONAL SYMPOSIA AND GRAND ROUNDS
AT UNIVERSITIES. 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. NFED ALSO HELPS FAMILIES PAY FOR NEEDED CARE
THROUGH THE TREATMENT ASSISTANCE PROGRAM AND INSURANCE COACHING.**

4c (Code:) (Expenses \$ 188,054. including grants of \$ 0.) (Revenue \$ 0.)
**RESEARCH - THE SCIENTIFIC ADVISORY COUNCIL OVERSEES NFED'S RESEARCH
INITIATIVES, AIMED TO IMPROVE THE HEALTH AND QUALITY OF LIFE OF
AFFECTED INDIVIDUALS BY FINDING SOLUTIONS AND, EVENTUALLY, FINDING
CURES FOR ECTODERMAL DYSPLASIAS. NFED ADVANCES RESEARCH THROUGH
ADVOCACY AND PARTNERSHIPS WITH ORGANIZATIONS SUCH AS THE NATIONAL
INSTITUTES OF HEALTH. NFED PROVIDES SEED FUNDS TO RESEARCHERS, PROVIDES
THEM WITH ACCESS TO AFFECTED INDIVIDUALS, AND SHARES INFORMATION TO
LAUNCH LARGER PROJECTS. THE ECTODERMAL DYSPLASIAS INTERNATIONAL
REGISTRY SERVES AS A REPOSITORY OF CLINICAL INFORMATION AND FACILITATES
COMMUNICATION AMONG AFFECTED INDIVIDUALS, CLINICIANS INVOLVED IN THEIR
TREATMENT AND SCIENTISTS WHO STRIVE TO ADVANCE RESEARCH ON ECTODERMAL
DYSPLASIAS. NFED ALSO SPONSORS RESEARCH CONFERENCES.**

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

4e Total program service expenses 902,689.

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SEE SCHEDULE O FOR CONTINUATION(S)

**NATIONAL FOUNDATION FOR ECTODERMAL
DYSPLASIAS**

Part IV Checklist of Required Schedules

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

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Part IV Checklist of Required Schedules (continued)

	Yes	No
22 Did the organization report more than \$5,000 of grants or other assistance to or for domestic individuals on Part IX, column (A), line 2? <i>If "Yes," complete Schedule I, Parts I and III</i>	X	
23 Did the organization answer "Yes" to Part VII, Section A, line 3, 4, or 5, about compensation of the organization's current and former officers, directors, trustees, key employees, and highest compensated employees? <i>If "Yes," complete Schedule J</i>		X
24a Did the organization have a tax-exempt bond issue with an outstanding principal amount of more than \$100,000 as of the last day of the year, that was issued after December 31, 2002? <i>If "Yes," answer lines 24b through 24d and complete Schedule K. If "No," go to line 25a</i>		X
b Did the organization invest any proceeds of tax-exempt bonds beyond a temporary period exception?		
c Did the organization maintain an escrow account other than a refunding escrow at any time during the year to defease any tax-exempt bonds?		
d Did the organization act as an "on behalf of" issuer for bonds outstanding at any time during the year?		
25a Section 501(c)(3), 501(c)(4), and 501(c)(29) organizations. Did the organization engage in an excess benefit transaction with a disqualified person during the year? <i>If "Yes," complete Schedule L, Part I</i>		X
b Is the organization aware that it engaged in an excess benefit transaction with a disqualified person in a prior year, and that the transaction has not been reported on any of the organization's prior Forms 990 or 990-EZ? <i>If "Yes," complete Schedule L, Part I</i>		X
26 Did the organization report any amount on Part X, line 5 or 22, for receivables from or 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? <i>If "Yes," complete Schedule L, Part II</i>		X
27 Did the organization provide a grant or other assistance to any current or former officer, director, trustee, key employee, creator or founder, substantial contributor or employee thereof, a grant selection committee member, or to a 35% controlled entity (including an employee thereof) or family member of any of these persons? <i>If "Yes," complete Schedule L, Part III</i>		X
28 Was the organization a party to a business transaction with one of the following parties (see the Schedule L, Part IV, instructions for applicable filing thresholds, conditions, and exceptions):		
a A current or former officer, director, trustee, key employee, creator or founder, or substantial contributor? <i>If "Yes," complete Schedule L, Part IV</i>		X
b A family member of any individual described in line 28a? <i>If "Yes," complete Schedule L, Part IV</i>		X
c A 35% controlled entity of one or more individuals and/or organizations described in line 28a or 28b? <i>If "Yes," complete Schedule L, Part IV</i>		X
29 Did the organization receive more than \$25,000 in non-cash contributions? <i>If "Yes," complete Schedule M</i>	X	
30 Did the organization receive contributions of art, historical treasures, or other similar assets, or qualified conservation contributions? <i>If "Yes," complete Schedule M</i>		X
31 Did the organization liquidate, terminate, or dissolve and cease operations? <i>If "Yes," complete Schedule N, Part I</i>		X
32 Did the organization sell, exchange, dispose of, or transfer more than 25% of its net assets? <i>If "Yes," complete Schedule N, Part II</i>		X
33 Did the organization own 100% of an entity disregarded as separate from the organization under Regulations sections 301.7701-2 and 301.7701-3? <i>If "Yes," complete Schedule R, Part I</i>		X
34 Was the organization related to any tax-exempt or taxable entity? <i>If "Yes," complete Schedule R, Part II, III, or IV, and Part V, line 1</i>		X
35a Did the organization have a controlled entity within the meaning of section 512(b)(13)?		X
b If "Yes" to line 35a, did the organization receive any payment from or engage in any transaction with a controlled entity within the meaning of section 512(b)(13)? <i>If "Yes," complete Schedule R, Part V, line 2</i>		
36 Section 501(c)(3) organizations. Did the organization make any transfers to an exempt non-charitable related organization? <i>If "Yes," complete Schedule R, Part V, line 2</i>		X
37 Did the organization conduct more than 5% of its activities through an entity that is not a related organization and that is treated as a partnership for federal income tax purposes? <i>If "Yes," complete Schedule R, Part VI</i>		X
38 Did the organization complete Schedule O and provide explanations on Schedule O for Part VI, lines 11b and 19?	X	

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

Part V Statements Regarding Other IRS Filings and Tax Compliance

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

	Yes	No
1a Enter the number reported in box 3 of Form 1096. Enter -0- if not applicable		
b Enter the number of Forms W-2G included on line 1a. Enter -0- if not applicable		
c Did the organization comply with backup withholding rules for reportable payments to vendors and reportable gaming (gambling) winnings to prize winners?		

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

		Yes	No
2a	Enter the number of employees reported on Form W-3, Transmittal of Wage and Tax Statements, filed for the calendar year ending with or within the year covered by this return		
	2a		8
b	If at least one is reported on line 2a, did the organization file all required federal employment tax returns?	X	
3a	Did the organization have unrelated business gross income of \$1,000 or more during the year?		X
b	If "Yes," has it filed a Form 990-T for this year? <i>If "No" to line 3b, provide an explanation on Schedule O</i>		
4a	At any time during the calendar year, did the organization have an interest in, or a signature or other authority over, a financial account in a foreign country (such as a bank account, securities account, or other financial account)?		X
b	If "Yes," enter the name of the foreign country See instructions for filing requirements for FinCEN Form 114, Report of Foreign Bank and Financial Accounts (FBAR).		
5a	Was the organization a party to a prohibited tax shelter transaction at any time during the tax year?		X
b	Did any taxable party notify the organization that it was or is a party to a prohibited tax shelter transaction?		X
c	If "Yes" to line 5a or 5b, did the organization file Form 8886-T?		
6a	Does the organization have annual gross receipts that are normally greater than \$100,000, and did the organization solicit any contributions that were not tax deductible as charitable contributions?		X
b	If "Yes," did the organization include with every solicitation an express statement that such contributions or gifts were not tax deductible?		
7	Organizations that may receive deductible contributions under section 170(c).		
a	Did the organization receive a payment in excess of \$75 made partly as a contribution and partly for goods and services provided to the payor?		X
b	If "Yes," did the organization notify the donor of the value of the goods or services provided?		
c	Did the organization sell, exchange, or otherwise dispose of tangible personal property for which it was required to file Form 8282?		X
d	If "Yes," indicate the number of Forms 8282 filed during the year	7d	
e	Did the organization receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?		X
f	Did the organization, during the year, pay premiums, directly or indirectly, on a personal benefit contract?		X
g	If the organization received a contribution of qualified intellectual property, did the organization file Form 8899 as required?		
h	If the organization received a contribution of cars, boats, airplanes, or other vehicles, did the organization file a Form 1098-C?		
8	Sponsoring organizations maintaining donor advised funds. Did a donor advised fund maintained by the sponsoring organization have excess business holdings at any time during the year?		
9	Sponsoring organizations maintaining donor advised funds.		
a	Did the sponsoring organization make any taxable distributions under section 4966?		
b	Did the sponsoring organization make a distribution to a donor, donor advisor, or related person?		
10	Section 501(c)(7) organizations. Enter:		
a	Initiation fees and capital contributions included on Part VIII, line 12	10a	
b	Gross receipts, included on Form 990, Part VIII, line 12, for public use of club facilities	10b	
11	Section 501(c)(12) organizations. Enter:		
a	Gross income from members or shareholders	11a	
b	Gross income from other sources. (Do not net amounts due or paid to other sources against amounts due or received from them.)	11b	
12a	Section 4947(a)(1) non-exempt charitable trusts. Is the organization filing Form 990 in lieu of Form 1041?	12a	
b	If "Yes," enter the amount of tax-exempt interest received or accrued during the year	12b	
13	Section 501(c)(29) qualified nonprofit health insurance issuers.		
a	Is the organization licensed to issue qualified health plans in more than one state? Note: See the instructions for additional information the organization must report on Schedule O.	13a	
b	Enter the amount of reserves the organization is required to maintain by the states in which the organization is licensed to issue qualified health plans	13b	
c	Enter the amount of reserves on hand	13c	
14a	Did the organization receive any payments for indoor tanning services during the tax year?		X
b	If "Yes," has it filed a Form 720 to report these payments? <i>If "No," provide an explanation on Schedule O</i>	14b	
15	Is the organization subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment(s) during the year? If "Yes," see the instructions and file Form 4720, Schedule N.	15	X
16	Is the organization an educational institution subject to the section 4968 excise tax on net investment income? If "Yes," complete Form 4720, Schedule O.	16	X
17	Section 501(c)(21) organizations. Did the trust, or any disqualified or other person engage in any activities that would result in the imposition of an excise tax under section 4951, 4952 or 4953? If "Yes," complete Form 6069.	17	

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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 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.	1a	11		
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

NATIONAL FOUNDATION FOR ECTODERMAL
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		118,124.	0.	0.	
(2) TIMOTHY MICKELSON DIRECTOR OF DEVELOPMENT	40.00				X		113,461.	0.	0.	
(3) KARL NELSEN PRESIDENT	5.00	X		X			0.	0.	0.	
(4) GEORGE BARBAR DIRECTOR	1.00	X					0.	0.	0.	
(5) KEITH THROM SECRETARY	1.00	X		X			0.	0.	0.	
(6) RICHARD STRATZ DIRECTOR	1.00	X					0.	0.	0.	
(7) KRISTA BASILE DIRECTOR	1.00	X					0.	0.	0.	
(8) ROY MOFFITT DIRECTOR	1.00	X					0.	0.	0.	
(9) MARIANNE VERMEER TREASURER	1.00	X		X			0.	0.	0.	
(10) J. TIMOTHY WRIGHT, DDS, MS DIRECTOR	1.00	X					0.	0.	0.	
(11) ANIL VORA VICE PRESIDENT	10.00	X		X			0.	0.	0.	
(12) RUTH GEISMAR DIRECTOR	1.00	X					0.	0.	0.	
(13) JACK KRIZ DIRECTOR	1.00	X					0.	0.	0.	

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

(A) Name and title	(B) Average hours per week (list any hours for related organizations below line)	(C) Position (do not check more than one box, unless person is both an officer and a director/trustee)						(D) Reportable compensation from the organization (W-2/1099-MISC/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			
1b Subtotal							231,585.	0.	0.	
c Total from continuation sheets to Part VII, Section A							0.	0.	0.	
d Total (add lines 1b and 1c)							231,585.	0.	0.	

2 Total number of individuals (including but not limited to those listed above) who received more than \$100,000 of reportable compensation from the organization 2

	Yes	No
3 Did the organization list any former officer, director, trustee, key employee, or highest compensated employee on line 1a? <i>If "Yes," complete Schedule J for such individual</i>		X
4 For any individual listed on line 1a, is the sum of reportable compensation and other compensation from the organization and related organizations greater than \$150,000? <i>If "Yes," complete Schedule J for such individual</i>		X
5 Did any person listed on line 1a receive or accrue compensation from any unrelated organization or individual for services rendered to the organization? <i>If "Yes," complete Schedule J for such person</i>		X

Section B. Independent Contractors

1 Complete this table for your five highest compensated independent contractors that received more than \$100,000 of compensation from the organization. Report compensation for the calendar year ending with or within the organization's tax year.

(A) Name and business address	(B) Description of services	(C) Compensation
NONE		

2 Total number of independent contractors (including but not limited to those listed above) who received more than \$100,000 of compensation from the organization 0

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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	293,896.				
	d Related organizations	1d					
	e Government grants (contributions)	1e					
	f All other contributions, gifts, grants, and similar amounts not included above ...	1f	876,788.				
	g Noncash contributions included in lines 1a-1f	1g	\$ 114,300.				
	h Total. Add lines 1a-1f		1,170,684.				
Program Service Revenue	2 a NATIONAL FAMILY CONFER	Business Code					
		624100	24,687.	24,687.			
	b _____						
	c _____						
	d _____						
	e _____						
	f All other program service revenue						
g Total. Add lines 2a-2f		24,687.					
Other Revenue	3 Investment income (including dividends, interest, and other similar amounts)		36,066.			36,066.	
	4 Income from investment of tax-exempt bond proceeds						
	5 Royalties						
	6 a Gross rents	6a	(i) Real				
			(ii) Personal				
	b Less: rental expenses ...	6b					
	c Rental income or (loss)	6c					
	d Net rental income or (loss)						
	7 a Gross amount from sales of assets other than inventory	7a	(i) Securities	218,324.			
			(ii) Other				
	b Less: cost or other basis and sales expenses	7b	0.				
	c Gain or (loss)	7c	218,324.				
d Net gain or (loss)		218,324.			218,324.		
8 a Gross income from fundraising events (not including \$ 293,896. of contributions reported on line 1c). See Part IV, line 18	8a		61,437.				
			21,773.				
b Less: direct expenses	8b						
c Net income or (loss) from fundraising events		39,664.			39,664.		
9 a Gross income from gaming activities. See Part IV, line 19	9a						
b Less: direct expenses	9b						
c Net income or (loss) from gaming activities							
10 a Gross sales of inventory, less returns and allowances	10a						
b Less: cost of goods sold	10b						
c Net income or (loss) from sales of inventory							
Miscellaneous Revenue	11 a PROMOTIONAL ITEMS	Business Code					
		624100	3,786.			3,786.	
	b _____						
	c _____						
	d All other revenue						
e Total. Add lines 11a-11d		3,786.					
12 Total revenue. See instructions		1,493,211.	24,687.	0.	297,840.		

**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	25,103.	25,103.		
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	583,754.	472,444.	6,815.	104,495.
8 Pension plan accruals and contributions (include section 401(k) and 403(b) employer contributions)	11,831.	9,575.	138.	2,118.
9 Other employee benefits	967.	783.	11.	173.
10 Payroll taxes	44,464.	35,986.	519.	7,959.
11 Fees for services (nonemployees):				
a Management				
b Legal	1,024.	840.	10.	174.
c Accounting	48,416.	39,701.	484.	8,231.
d Lobbying				
e Professional fundraising services. See Part IV, line 17				
f Investment management fees	2,584.	2,119.	26.	439.
g Other. (If line 11g amount exceeds 10% of line 25, column (A), amount, list line 11g expenses on Sch O.)	41,698.	34,193.	417.	7,088.
12 Advertising and promotion	47,861.	40,681.	957.	6,223.
13 Office expenses	12,063.	9,892.	121.	2,050.
14 Information technology				
15 Royalties				
16 Occupancy	10,985.	9,008.	110.	1,867.
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	23,665.	17,275.	1,657.	4,733.
23 Insurance	6,104.	5,006.	61.	1,037.
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 FAMILY CONFERENCES	86,888.	86,888.		
b ADVOCACY	42,425.	42,425.		
c MEMBERSHIPS	41,046.	33,657.	410.	6,979.
d DEVELOPMENT	23,307.	9,324.	2,331.	11,652.
e All other expenses	29,685.	27,789.	105.	1,791.
25 Total functional expenses. Add lines 1 through 24e	1,083,870.	902,689.	14,172.	167,009.
26 Joint costs. Complete this line only if the organization reported in column (B) joint costs from a combined educational campaign and fundraising solicitation. Check here <input type="checkbox"/> if following SOP 98-2 (ASC 958-720)				

NATIONAL FOUNDATION FOR ECTODERMAL
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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	609,178.	1	772,544.
	2 Savings and temporary cash investments	125,505.	2	1.
	3 Pledges and grants receivable, net	25,963.	3	21,575.
	4 Accounts receivable, net	45,724.	4	0.
	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	8,123.	9	23,467.
	10a Land, buildings, and equipment: cost or other basis. Complete Part VI of Schedule D	10a 41,323.		
	b Less: accumulated depreciation	10b 41,323.	10c	0.
	11 Investments - publicly traded securities	3,525,150.	11	3,060,702.
	12 Investments - other securities. See Part IV, line 11		12	
	13 Investments - program-related. See Part IV, line 11		13	
	14 Intangible assets		14	121,290.
	15 Other assets. See Part IV, line 11		15	
16 Total assets. Add lines 1 through 15 (must equal line 33)	4,339,643.	16	3,999,579.	
Liabilities	17 Accounts payable and accrued expenses	49,589.	17	63,558.
	18 Grants payable	9,177.	18	6,100.
	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	0.	25	121,290.
	26 Total liabilities. Add lines 17 through 25	58,766.	26	190,948.
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	4,223,557.	27	3,655,423.
	28 Net assets with donor restrictions	57,320.	28	153,208.
	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 Total net assets or fund balances	4,280,877.	32	3,808,631.
33 Total liabilities and net assets/fund balances	4,339,643.	33	3,999,579.	

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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	1,493,211.
2	Total expenses (must equal Part IX, column (A), line 25)	2	1,083,870.
3	Revenue less expenses. Subtract line 2 from line 1	3	409,341.
4	Net assets or fund balances at beginning of year (must equal Part X, line 32, column (A))	4	4,280,877.
5	Net unrealized gains (losses) on investments	5	-877,198.
6	Donated services and use of facilities	6	-4,389.
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	3,808,631.

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? _____ If "Yes," check a box below to indicate whether the financial statements for the year were compiled or reviewed on a separate basis, consolidated basis, or both: <input type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis		X
b Were the organization's financial statements audited by an independent accountant? _____ If "Yes," check a box below to indicate whether the financial statements for the year were audited on a separate basis, consolidated basis, or both: <input checked="" type="checkbox"/> Separate basis <input type="checkbox"/> Consolidated basis <input type="checkbox"/> Both consolidated and separate basis	X	
c If "Yes" to line 2a or 2b, does the organization have a committee that assumes responsibility for oversight of the audit, review, or compilation of its financial statements and selection of an independent accountant? _____ If the organization changed either its oversight process or selection process during the tax year, explain on Schedule O.	X	
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 (2022)

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

2022

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 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).

(i) Name of supported organization	(ii) EIN	(iii) Type of organization (described on lines 1-10 above (see instructions))	(iv) Is the organization listed in your governing document?		(v) Amount of monetary support (see instructions)	(vi) Amount of other support (see instructions)
			Yes	No		
Total						

NATIONAL FOUNDATION FOR ECTODERMAL
DYSPLASIAS

Part II Support Schedule for Organizations Described in Sections 170(b)(1)(A)(iv) and 170(b)(1)(A)(vi)

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

Section A. Public Support

Calendar year (or fiscal year beginning in)	(a) 2018	(b) 2019	(c) 2020	(d) 2021	(e) 2022	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")	685,752.	823,099.	793,549.	1500948.	1170684.	4974032.
2 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
3 The value of services or facilities furnished by a governmental unit to the organization without charge						
4 Total. Add lines 1 through 3	685,752.	823,099.	793,549.	1500948.	1170684.	4974032.
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)						55,633.
6 Public support. Subtract line 5 from line 4.						4918399.

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2018	(b) 2019	(c) 2020	(d) 2021	(e) 2022	(f) Total
7 Amounts from line 4	685,752.	823,099.	793,549.	1500948.	1170684.	4974032.
8 Gross income from interest, dividends, payments received on securities loans, rents, royalties, and income from similar sources	26,206.	26,429.	24,326.	25,780.	36,066.	138,807.
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.)	783.	3,652.	207.	803.	3,786.	9,231.
11 Total support. Add lines 7 through 10						5122070.
12 Gross receipts from related activities, etc. (see instructions)					12	259,414.
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						<input type="checkbox"/>

Section C. Computation of Public Support Percentage

14 Public support percentage for 2022 (line 6, column (f), divided by line 11, column (f))	14	96.02	%
15 Public support percentage from 2021 Schedule A, Part II, line 14	15	93.67	%
16a 33 1/3% support test - 2022. If the organization did not check the box on line 13, and line 14 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization			<input checked="" type="checkbox"/>
b 33 1/3% support test - 2021. If the organization did not check a box on line 13 or 16a, and line 15 is 33 1/3% or more, check this box and stop here. The organization qualifies as a publicly supported organization			<input type="checkbox"/>
17a 10% -facts-and-circumstances test - 2022. 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			<input type="checkbox"/>
b 10% -facts-and-circumstances test - 2021. 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			<input type="checkbox"/>
18 Private foundation. If the organization did not check a box on line 13, 16a, 16b, 17a, or 17b, check this box and see instructions			<input type="checkbox"/>

NATIONAL FOUNDATION FOR ECTODERMAL
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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

Calendar year (or fiscal year beginning in)	(a) 2018	(b) 2019	(c) 2020	(d) 2021	(e) 2022	(f) Total
1 Gifts, grants, contributions, and membership fees received. (Do not include any "unusual grants.")						
2 Gross receipts from admissions, merchandise sold or services performed, or facilities furnished in any activity that is related to the organization's tax-exempt purpose						
3 Gross receipts from activities that are not an unrelated trade or business under section 513						
4 Tax revenues levied for the organization's benefit and either paid to or expended on its behalf						
5 The value of services or facilities furnished by a governmental unit to the organization without charge						
6 Total. Add lines 1 through 5						
7a Amounts included on lines 1, 2, and 3 received from disqualified persons						
b Amounts included on lines 2 and 3 received from other than disqualified persons that exceed the greater of \$5,000 or 1% of the amount on line 13 for the year						
c Add lines 7a and 7b						
8 Public support. (Subtract line 7c from line 6.)						

Section B. Total Support

Calendar year (or fiscal year beginning in)	(a) 2018	(b) 2019	(c) 2020	(d) 2021	(e) 2022	(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 on 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 VI.)						
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

15 Public support percentage for 2022 (line 8, column (f), divided by line 13, column (f))	15	%
16 Public support percentage from 2021 Schedule A, Part III, line 15	16	%

Section D. Computation of Investment Income Percentage

17 Investment income percentage for 2022 (line 10c, column (f), divided by line 13, column (f))	17	%
18 Investment income percentage from 2021 Schedule A, Part III, line 17	18	%

19a 33 1/3% support tests - 2022. 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 - 2021. 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
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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

	Yes	No
1 Are all of the organization's supported organizations listed by name in the organization's governing documents? <i>If "No," describe in Part VI how the supported organizations are designated. If designated by class or purpose, describe the designation. If historic and continuing relationship, explain.</i>		
2 Did the organization have any supported organization that does not have an IRS determination of status under section 509(a)(1) or (2)? <i>If "Yes," explain in Part VI how the organization determined that the supported organization was described in section 509(a)(1) or (2).</i>		
3a Did the organization have a supported organization described in section 501(c)(4), (5), or (6)? <i>If "Yes," answer lines 3b and 3c below.</i>		
b Did the organization confirm that each supported organization qualified under section 501(c)(4), (5), or (6) and satisfied the public support tests under section 509(a)(2)? <i>If "Yes," describe in Part VI when and how the organization made the determination.</i>		
c Did the organization ensure that all support to such organizations was used exclusively for section 170(c)(2)(B) purposes? <i>If "Yes," explain in Part VI what controls the organization put in place to ensure such use.</i>		
4a Was any supported organization not organized in the United States ("foreign supported organization")? <i>If "Yes," and if you checked box 12a or 12b in Part I, answer lines 4b and 4c below.</i>		
b Did the organization have ultimate control and discretion in deciding whether to make grants to the foreign supported organization? <i>If "Yes," describe in Part VI how the organization had such control and discretion despite being controlled or supervised by or in connection with its supported organizations.</i>		
c Did the organization support any foreign supported organization that does not have an IRS determination under sections 501(c)(3) and 509(a)(1) or (2)? <i>If "Yes," explain in Part VI what controls the organization used to ensure that all support to the foreign supported organization was used exclusively for section 170(c)(2)(B) purposes.</i>		
5a Did the organization add, substitute, or remove any supported organizations during the tax year? <i>If "Yes," answer lines 5b and 5c below (if applicable). Also, provide detail in Part VI, including (i) the names and EIN numbers of the supported organizations added, substituted, or removed; (ii) the reasons for each such action; (iii) the authority under the organization's organizing document authorizing such action; and (iv) how the action was accomplished (such as by amendment to the organizing document).</i>		
b Type I or Type II only. Was any added or substituted supported organization part of a class already designated in the organization's organizing document?		
c Substitutions only. Was the substitution the result of an event beyond the organization's control?		
6 Did the organization provide support (whether in the form of grants or the provision of services or facilities) to anyone other than (i) its supported organizations, (ii) individuals that are part of the charitable class benefited by one or more of its supported organizations, or (iii) other supporting organizations that also support or benefit one or more of the filing organization's supported organizations? <i>If "Yes," provide detail in Part VI.</i>		
7 Did the organization provide a grant, loan, compensation, or other similar payment to a substantial contributor (as defined in section 4958(c)(3)(C)), a family member of a substantial contributor, or a 35% controlled entity with regard to a substantial contributor? <i>If "Yes," complete Part I of Schedule L (Form 990).</i>		
8 Did the organization make a loan to a disqualified person (as defined in section 4958) not described on line 7? <i>If "Yes," complete Part I of Schedule L (Form 990).</i>		
9a Was the organization controlled directly or indirectly at any time during the tax year by one or more disqualified persons, as defined in section 4946 (other than foundation managers and organizations described in section 509(a)(1) or (2))? <i>If "Yes," provide detail in Part VI.</i>		
b Did one or more disqualified persons (as defined on line 9a) hold a controlling interest in any entity in which the supporting organization had an interest? <i>If "Yes," provide detail in Part VI.</i>		
c Did a disqualified person (as defined on line 9a) have an ownership interest in, or derive any personal benefit from, assets in which the supporting organization also had an interest? <i>If "Yes," provide detail in Part VI.</i>		
10a Was the organization subject to the excess business holdings rules of section 4943 because of section 4943(f) (regarding certain Type II supporting organizations, and all Type III non-functionally integrated supporting organizations)? <i>If "Yes," answer line 10b below.</i>		
b Did the organization have any excess business holdings in the tax year? <i>(Use Schedule C, Form 4720, to determine whether the organization had excess business holdings.)</i>		

NATIONAL FOUNDATION FOR ECTODERMAL
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Part IV Supporting Organizations (continued)

	Yes	No
11 Has the organization accepted a gift or contribution from any of the following persons?		
a A person who directly or indirectly controls, either alone or together with persons described on lines 11b and 11c below, the governing body of a supported organization?		
b A family member of a person described on line 11a above?		
c A 35% controlled entity of a person described on line 11a or 11b above? <i>If "Yes" to line 11a, 11b, or 11c, provide detail in Part VI.</i>		

Section B. Type I Supporting Organizations

	Yes	No
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? <i>If "No," describe in Part VI how the supported organization(s) effectively operated, supervised, or controlled the organization's activities. If the organization had more than one supported organization, describe how the powers to appoint and/or remove officers, directors, or trustees were allocated among the supported organizations and what conditions or restrictions, if any, applied to such powers during the tax year.</i>		
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? <i>If "Yes," explain in Part VI how providing such benefit carried out the purposes of the supported organization(s) that operated, supervised, or controlled the supporting organization.</i>		

Section C. Type II Supporting Organizations

	Yes	No
1 Were a majority of the organization's directors or trustees during the tax year also a majority of the directors or trustees of each of the organization's supported organization(s)? <i>If "No," describe in Part VI how control or management of the supporting organization was vested in the same persons that controlled or managed the supported organization(s).</i>		

Section D. All Type III Supporting Organizations

	Yes	No
1 Did the organization provide to each of its supported organizations, by the last day of the fifth month of the organization's tax year, (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?		
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? <i>If "No," explain in Part VI how the organization maintained a close and continuous working relationship with the supported organization(s).</i>		
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? <i>If "Yes," describe in Part VI the role the organization's supported organizations played in this regard.</i>		

Section E. Type III Functionally Integrated Supporting Organizations

1 Check the box next to the method that the organization used to satisfy the Integral Part Test during the year (see instructions).		
a <input type="checkbox"/> The organization satisfied the Activities Test. Complete line 2 below.		
b <input type="checkbox"/> The organization is the parent of each of its supported organizations. Complete line 3 below.		
c <input type="checkbox"/> The organization supported a governmental entity. Describe in Part VI how you supported a governmental entity (see instructions).		
2 Activities Test. Answer lines 2a and 2b below.		
a Did substantially all of the organization's activities during the tax year directly further the exempt purposes of the supported organization(s) to which the organization was responsive? <i>If "Yes," then in Part VI identify those supported organizations and explain how these activities directly furthered their exempt purposes, how the organization was responsive to those supported organizations, and how the organization determined that these activities constituted substantially all of its activities.</i>		
b Did the activities described on line 2a, above, constitute activities that, but for the organization's involvement, one or more of the organization's supported organization(s) would have been engaged in? <i>If "Yes," explain in Part VI the reasons for the organization's position that its supported organization(s) would have engaged in these activities but for the organization's involvement.</i>		
3 Parent of Supported Organizations. Answer lines 3a and 3b below.		
a Did the organization have the power to regularly appoint or elect a majority of the officers, directors, or trustees of each of the supported organizations? <i>If "Yes" or "No" provide details in Part VI.</i>		
b Did the organization exercise a substantial degree of direction over the policies, programs, and activities of each of its supported organizations? <i>If "Yes," describe in Part VI the role played by the organization in this regard.</i>		

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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 Adjusted Net Income (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 Total (add lines 1a, 1b, and 1c)	1d	
e Discount 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 Minimum Asset Amount (add line 7 to line 6)	8	

Section C - Distributable Amount	(A) Prior Year	(B) Current Year (optional)
1 Adjusted net income for prior year (from Section A, line 8, column A)	1	Current Year
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 Distributable Amount. 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).		

**NATIONAL FOUNDATION FOR ECTODERMAL
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 - <i>provide details in Part VI</i>)	5
6 Other distributions (<i>describe in Part VI</i>). See instructions.	6
7 Total annual distributions. Add lines 1 through 6.	7
8 Distributions to attentive supported organizations to which the organization is responsive (<i>provide details in Part VI</i>). See instructions.	8
9 Distributable amount for 2022 from Section C, line 6	9
10 Line 8 amount divided by line 9 amount	10

Section E - Distribution Allocations (see instructions)	(i) Excess Distributions	(ii) Underdistributions Pre-2022	(iii) Distributable Amount for 2022
1 Distributable amount for 2022 from Section C, line 6			
2 Underdistributions, if any, for years prior to 2022 (reasonable cause required - <i>explain in Part VI</i>). See instructions.			
3 Excess distributions carryover, if any, to 2022			
a From 2017			
b From 2018			
c From 2019			
d From 2020			
e From 2021			
f Total of lines 3a through 3e			
g Applied to underdistributions of prior years			
h Applied to 2022 distributable amount			
i Carryover from 2017 not applied (see instructions)			
j Remainder. Subtract lines 3g, 3h, and 3i from line 3f.			
4 Distributions for 2022 from Section D, line 7: \$			
a Applied to underdistributions of prior years			
b Applied to 2022 distributable amount			
c Remainder. Subtract lines 4a and 4b from line 4.			
5 Remaining underdistributions for years prior to 2022, if any. Subtract lines 3g and 4a from line 2. For result greater than zero, <i>explain in Part VI</i> . See instructions.			
6 Remaining underdistributions for 2022. Subtract lines 3h and 4b from line 1. For result greater than zero, <i>explain in Part VI</i> . See instructions.			
7 Excess distributions carryover to 2023. Add lines 3j and 4c.			
8 Breakdown of line 7:			
a Excess from 2018			
b Excess from 2019			
c Excess from 2020			
d Excess from 2021			
e Excess from 2022			

NATIONAL FOUNDATION FOR ECTODERMAL
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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, and 3b; Part V, line 1; Part V, Section B, line 1e; Part V, Section D, lines 5, 6, and 8; 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

2018 AMOUNT: \$ 783.

2019 AMOUNT: \$ 3,652.

2020 AMOUNT: \$ 207.

2021 AMOUNT: \$ 803.

2022 AMOUNT: \$ 3,786.

Schedule B (Form 990)

Department of the Treasury Internal Revenue Service

Schedule of Contributors

Attach to Form 990 or Form 990-PF. Go to www.irs.gov/Form990 for the latest information.

OMB No. 1545-0047

2022

Table with 2 columns: Name of the organization (NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS) and Employer identification number (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 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

- [X] For an organization described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33 1/3% support test...
[] For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor...
[] For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor...

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 NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS	Employer identification number 37-1112496
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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	_____ _____ _____	\$ 51,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
2	_____ _____ _____	\$ 34,980.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
3	_____ _____ _____	\$ 40,626.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input checked="" type="checkbox"/> (Complete Part II for noncash contributions.)
4	_____ _____ _____	\$ 68,634.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input checked="" type="checkbox"/> (Complete Part II for noncash contributions.)
5	_____ _____ _____	\$ 65,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
6	_____ _____ _____	\$ 26,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)

Name of organization NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS	Employer identification number 37-1112496
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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	_____ _____ _____	\$ 27,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
8	_____ _____ _____	\$ 116,432.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
9	_____ _____ _____	\$ 50,000.	Person <input checked="" type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
_____	_____ _____ _____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
_____	_____ _____ _____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)
_____	_____ _____ _____	\$ _____	Person <input type="checkbox"/> Payroll <input type="checkbox"/> Noncash <input type="checkbox"/> (Complete Part II for noncash contributions.)

Name of organization NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS	Employer identification number 37-1112496
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Part II Noncash Property (see instructions). Use duplicate copies of Part II if additional space is needed.

(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions.)	(d) Date received
<u>3</u>	3,732 SHARES TEMPLETON DRAGON FUND _____ _____ _____	\$ <u>38,626.</u>	<u>09/02/22</u>
<u>4</u>	140 SHRES OF VGT STOCK _____ _____ _____	\$ <u>60,644.</u>	<u>08/15/22</u>
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____
_____	_____ _____ _____	\$ _____	_____

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

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.

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

OMB No. 1545-0047

2022

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.

Table with 3 columns: Question, (a) Donor advised funds, (b) Funds and other accounts. Rows include total number at end of year, aggregate value of contributions, grants, and end of year, and two Yes/No questions regarding donor property and grant fund usage.

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

Table with 3 columns: Question, (a) Donor advised funds, (b) Funds and other accounts. Rows include purpose(s) of conservation easements, a table for lines 2a-2d (Total number, acreage, certified historic structures, acquired after 2006), and questions about monitoring, expenses, and reporting requirements.

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.

Table with 3 columns: Question, (a) Donor advised funds, (b) Funds and other accounts. Rows include questions about reporting requirements for art and historical treasures, and a table for revenue and assets included.

**NATIONAL FOUNDATION FOR ECTODERMAL
DYSPLASIAS**

Schedule D (Form 990) 2022

37-1112496 Page **3**

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, col. (B) line 12.)		

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, col. (B) line 13.)		

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, col. (B) line 15.)	

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) LEASE LIABILITY	121,290.
(3)	
(4)	
(5)	
(6)	
(7)	
(8)	
(9)	
Total. (Column (b) must equal Form 990, Part X, col. (B) line 25.)	121,290.

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 ...

Schedule D (Form 990) 2022

NATIONAL FOUNDATION FOR ECTODERMAL
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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	673,323.
2	Amounts included on line 1 but not on Form 990, Part VIII, line 12:			
a	Net unrealized gains (losses) on investments	2a	-877,198.	
b	Donated services and use of facilities	2b	35,537.	
c	Recoveries of prior year grants	2c		
d	Other (Describe in Part XIII.)	2d	21,773.	
e	Add lines 2a through 2d	2e	-819,888.	
3	Subtract line 2e from line 1	3	1,493,211.	
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	1,493,211.	

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	1,145,569.
2	Amounts included on line 1 but not on Form 990, Part IX, line 25:			
a	Donated services and use of facilities	2a	39,926.	
b	Prior year adjustments	2b		
c	Other losses	2c		
d	Other (Describe in Part XIII.)	2d	21,773.	
e	Add lines 2a through 2d	2e	61,699.	
3	Subtract line 2e from line 1	3	1,083,870.	
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	1,083,870.	

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:

PER NOTE 1 OF THE AUDITED FINANCIAL STATEMENTS: TAX STATUS - THE FOUNDATION 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 21,773.

PART XII, LINE 2D - OTHER ADJUSTMENTS:

SPECIAL EVENT EXPENSE NETTED WITH REVENUE ON FORM 990 21,773.

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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
		HALLOWEEN BASH		5	(add col. (a) through col. (c))
		(event type)	(event type)	(total number)	
Revenue	1	Gross receipts	105,216.	250,117.	355,333.
	2	Less: Contributions	94,026.	199,870.	293,896.
	3	Gross income (line 1 minus line 2)	11,190.	50,247.	61,437.
Direct Expenses	4	Cash prizes			
	5	Noncash prizes			
	6	Rent/facility costs			
	7	Food and beverages			
	8	Entertainment			
	9	Other direct expenses	5,413.	16,360.	21,773.
	10	Direct expense summary. Add lines 4 through 9 in column (d)			21,773.
11	Net income summary. Subtract line 10 from line 3, column (d)			39,664.	

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			
Direct Expenses	2	Cash prizes			
	3	Noncash prizes			
	4	Rent/facility costs			
	5	Other direct expenses			
	6	Volunteer labor	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No	<input type="checkbox"/> Yes _____ % <input type="checkbox"/> No
	7	Direct expense summary. Add lines 2 through 5 in column (d)			
	8	Net gaming income summary. Subtract line 7 from line 1, column (d)			

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

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- 11 Does the organization conduct gaming activities with nonmembers? Yes No
- 12 Is the organization a grantor, beneficiary or trustee of a trust, or a member of a partnership or other entity formed to administer charitable gaming? Yes No
- 13 Indicate the percentage of gaming activity conducted in:
- | | | |
|-------------------------------|-----|---|
| a The organization's facility | 13a | % |
| b An outside facility | 13b | % |
- 14 Enter the name and address of the person who prepares the organization's gaming/special events books and records:

Name _____

Address _____

- 15a Does the organization have a contract with a third party from whom the organization receives gaming revenue? Yes No
- b If "Yes," enter the amount of gaming revenue received by the organization \$ _____ and the amount of gaming revenue retained by the third party \$ _____
- c If "Yes," enter name and address of the third party:

Name _____

Address _____

16 Gaming manager information:

Name _____

Gaming manager compensation \$ _____

Description of services provided _____

Director/officer Employee Independent contractor

17 Mandatory distributions:

- a Is the organization required under state law to make charitable distributions from the gaming proceeds to retain the state gaming license? Yes No
- b Enter the amount of distributions required under state law to be distributed to other exempt organizations or spent in the organization's own exempt activities during the tax year \$ _____

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

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Part IV Supplemental Information *(continued)*

**SCHEDULE I
(Form 990)**

Department of the Treasury
Internal Revenue Service

**Grants and Other Assistance to Organizations,
Governments, and Individuals in the United States**
Complete if the organization answered "Yes" on Form 990, Part IV, line 21 or 22.
Attach to Form 990.
Go to www.irs.gov/Form990 for the latest information.

OMB No. 1545-0047

2022

**Open to Public
Inspection**

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

Part I General Information on Grants and Assistance

- 1** Does the organization maintain records to substantiate the amount of the grants or assistance, the grantees' eligibility for the grants or assistance, and the selection criteria used to award the grants or assistance? **Yes** **No**
- 2** Describe in Part IV the organization's procedures for monitoring the use of grant funds in the United States.

Part II Grants and Other Assistance to Domestic Organizations and Domestic Governments. Complete if the organization answered "Yes" on Form 990, Part IV, line 21, for any recipient that received more than \$5,000. Part II can be duplicated if additional space is needed.

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

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

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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
TREATMENT FUNDING	2	8,409.	0.		
FAMILY CONFERENCE SCHOLARSHIPS	16	16,694.	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

2022

Open to Public Inspection

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

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

Department of the Treasury
Internal Revenue Service

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	3	114,300.	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 Acknowledgement **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.		

LHA For Paperwork Reduction Act Notice, see the Instructions for Form 990. Schedule M (Form 990) 2022

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

Multiple horizontal lines for supplemental information.

**SCHEDULE O
(Form 990)**

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 for the latest information.

OMB No. 1545-0047

2022

Open to Public
Inspection

Name of the organization NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS	Employer identification number 37-1112496
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FORM 990, PART III, LINE 4A, PROGRAM SERVICE ACCOMPLISHMENTS:

PROVIDES FINANCIAL ASSISTANCE TO INDIVIDUALS TO ATTEND THE FAMILY
CONFERENCE. NFED'S FAMILY TO FAMILY NETWORK CONNECTS FAMILIES WITH A
CARING LIAISON IN THEIR REGION WHO CAN PROVIDE MORAL SUPPORT,
INFORMATION AND PRACTICAL ADVICE, GUIDANCE AND RESOURCES.

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

THE ORGANIZATION PROVIDES A COPY OF FORM 990 TO EVERY BOARD MEMBER PRIOR TO
FILING. IT IS REVIEWED IN DETAIL BY THE ORGANIZATION'S EXECUTIVE DIRECTOR
AND BOARD.

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

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

Schedule O (Form 990) 2022

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